2012

Mapping a road to driving retirement with the driver who has a diagnosis of dementia: enhancing acceptance of the difficult decisions

Catherine Louise Andrew

University of Wollongong

Recommended Citation
UNIVERSITY OF WOLLONGONG

COPYRIGHT WARNING

You may print or download ONE copy of this document for the purpose of your own research or study. The University does not authorise you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site. You are reminded of the following:

Copyright owners are entitled to take legal action against persons who infringe their copyright. A reproduction of material that is protected by copyright may be a copyright infringement. A court may impose penalties and award damages in relation to offences and infringements relating to copyright material. Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.
Mapping a road to driving retirement with the driver who has a diagnosis of dementia:
Enhancing acceptance of the difficult decisions.

A thesis submitted in (partial) fulfilment of requirements for the award of the degree
Masters of Science – Research

from
University of Wollongong

by

Catherine Louise Andrew
Bachelor of Applied Science (Occupational Therapy)
Masters of Science – (Occupational Health and Rehabilitation)

Department of Nursing, Midwifery and Indigenous Health
Faculty of Health and Behavioural Science

2012
I, Catherine Louise Andrew, declare that this thesis, submitted in partial
fulfilment of the requirements for the award of the Degree of Masters of
Science – Research, the School of Nursing, Midwifery and Health in the
faculty of Health and Behavioural Sciences, University of Wollongong is
wholly my own work unless otherwise referenced or acknowledged. The
document has not been submitted for qualifications at any other academic
institution.

Catherine Louise Andrew
30/6/12
ABSTRACT

Background: Driving is a complex task demanding cognitive and physical skills that can be compromised by dementia. We know that some people are reluctant to accept decisions imposed upon them about the need to stop driving. This study sought to identify decisional support needs to inform strategies which may enhance acceptance of potential driving retirement for drivers with dementia.

Method: This is a qualitative study of current drivers over 55 and is one of a very few to include the views of people with dementia. Participants were recruited via public notices, a media release and clinical contacts to undertake a two phase unstructured interview process. Data collection consisted of one-to-one and group interviews. Thematic analysis was applied to generate themes and ‘NVivo9’ (2009) was used to manage the analysis.

Findings: A total of 15 drivers over 55 years (n=15) participated in 20 unstructured interviews (n=20). The participants were both male and female (40 % and 60% respectively) and included 2 people with dementia (n=2). The key themes identified in the findings were: (i) views of trusted people are important; (ii) on-road experiences are the most convincing; (iii) let’s discuss this before my judgement is compromised; (iv) knowing my alternatives would influence my decision; and (v) informative resources that include self-monitoring tools are useful.

Conclusion: This study contributes important empirical knowledge informed by consumers and potential consumers regarding decisional support for drivers with dementia facing decisions regarding the time to retire from driving. Further quantitative research is recommended to develop and evaluate the efficacy of decisional support strategies for drivers with dementia who may need to address decisional conflict regarding driving retirement.
ACKNOWLEDGEMENTS

I would like to thank the following people for the help support and encouragement in completing this thesis as part of my Degree of Masters of Science – Research:

Associate Professor Victoria Traynor
Professor Don Iverson (Pro Vice-Chancellor – Health)
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ABSTRACT</td>
<td>ii</td>
</tr>
<tr>
<td></td>
<td>ACKNOWLEDGEMENTS</td>
<td>iii</td>
</tr>
<tr>
<td></td>
<td>TABLE OF CONTENTS</td>
<td>iv</td>
</tr>
<tr>
<td></td>
<td>LIST OF FIGURES</td>
<td>vii</td>
</tr>
<tr>
<td></td>
<td>LIST OF TABLES</td>
<td>viii</td>
</tr>
<tr>
<td>1.</td>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>1.1</td>
<td>Overview of the thesis</td>
<td>1</td>
</tr>
<tr>
<td>1.2</td>
<td>Background</td>
<td>5</td>
</tr>
<tr>
<td>1.3</td>
<td>Summary</td>
<td>10</td>
</tr>
<tr>
<td>2.</td>
<td>Literature Review</td>
<td>12</td>
</tr>
<tr>
<td>2.1</td>
<td>Search Strategy</td>
<td>13</td>
</tr>
<tr>
<td>2.1.1</td>
<td>Search strategy 1: Database search</td>
<td>14</td>
</tr>
<tr>
<td>2.1.2</td>
<td>Search strategy 2: Incremental search</td>
<td>15</td>
</tr>
<tr>
<td>2.1.3</td>
<td>Search strategy 3: Delimiting inclusion and exclusion criteria</td>
<td>15</td>
</tr>
<tr>
<td>2.1.4</td>
<td>Search strategy 4: Critique of empirical evidence</td>
<td>16</td>
</tr>
<tr>
<td>2.2</td>
<td>Themes Identified</td>
<td>17</td>
</tr>
<tr>
<td>2.2.1</td>
<td>Theme 1: Driving is a complex task that can be compromised by dementia</td>
<td>18</td>
</tr>
<tr>
<td>2.2.2</td>
<td>Theme 2: Onset and severity of dementia are difficult to define</td>
<td>19</td>
</tr>
<tr>
<td>2.2.3</td>
<td>Theme 3: Dementia is progressive and impacts upon driving skills</td>
<td>21</td>
</tr>
<tr>
<td>2.2.4</td>
<td>Theme 4 Assessment of fitness to drive remains subjective</td>
<td>22</td>
</tr>
<tr>
<td>2.2.5</td>
<td>Theme 5 Some drivers with dementia are reluctant to accept negative driving assessment outcomes</td>
<td>24</td>
</tr>
<tr>
<td>2.2.6</td>
<td>Theme 6 The search continues for most effective means of preparing drivers with dementia to accept driver retirement</td>
<td>27</td>
</tr>
<tr>
<td>2.3</td>
<td>Summary</td>
<td>31</td>
</tr>
<tr>
<td>3.</td>
<td>Methods</td>
<td>33</td>
</tr>
<tr>
<td>3.1</td>
<td>Theoretical Framework</td>
<td>35</td>
</tr>
</tbody>
</table>
3.1.1 The model of consumer involvement in decision making..............36
3.1.2 The strategic process of creating an effective decisional support tool39
3.2 Research Design.................................................................41
3.2.1 Ethical Considerations ..................................................42
3.2.2 Setting and Sample .........................................................44
3.2.3 Recruitment .................................................................47
3.3 Data Collection..................................................................51
3.3.1 Conducting unstructured interviews with participants..........51
3.3.2 The interview format.......................................................53
   (i) Interview 1: Data collection..............................................54
   (ii) Interview 2: Data collection.............................................56
3.4 Data Analysis....................................................................58
3.5 Summary............................................................................59
4 Findings ..............................................................................61
4.1 Demographic Profile of Participants....................................62
4.2 Mapping a Road to Driving Retirement...............................66
   4.2.1 Theme 1: Whose opinion will I accept as trustworthy .........67
   4.2.2 Theme 2: Real on-road experiences are most convincing ....72
   4.2.3 Theme 3: Let’s discuss this before my judgement is compromised 78
   4.2.4 Theme 4: Would knowing my alternatives influence my decision to retire from driving?...........................................82
   4.2.5 Theme 5: Informative resources that include self-monitoring tools are useful.................................................................87
4.3 Summary............................................................................94
5 Discussion............................................................................96
5.1 Introduction.....................................................................96
5.2 Theoretical Framework....................................................98
   5.2.1 Mapping a decisional pathway ......................................99
   5.2.2 Addressing decisional conflict ........................................100
5.3 Making decisions during the window of opportunity .............104
LIST OF FIGURES

Figure 1: Distribution of Australian Population and Licence Holders by Age (per million) in 2005 (adapted from Australian Bureau of Statistics, 2008) ... 5

Figure 2: Projections of Dementia Incidence in the Australian Population 2008–2050 (adapted from Deloitte Access Economics (2011)) ..................... 6

Figure 3: Four Phase Search Strategy ................................................................. 13

Figure 4: Ottawa Decisions Support Framework (ODSF) Three Stage Decision making Process .................................................................................. 37

Figure 5: Content of Driving Decisions Resources Pack ............................................ 40

Figure 6: Research Activities .................................................................................. 41

Figure 7: Participant Information Pack ................................................................. 50

Figure 8: Outline of Facilitated Interviews 1 and 2 .................................................. 54

Figure 9: Participant Profile by Age Group and Gender .......................................... 64

Figure 10: Five Themes - Mapping a Road to Driving Retirement .......................... 67

Figure 11: Theme 1: - Whose Opinion Will I Accept as Trustworthy ................. 68

Figure 12: Theme 2 - Real On-Road Experiences Are Most Convincing ........... 73

Figure 13: Theme 3 - Let’s Discuss This Before My Judgement Is Compromised ......................................................................................... 79

Figure 14: Theme 4 - Would Knowing My Alternatives Influence My Decision To Retire From Driving ................................................................. 83

Figure 15: Theme 5 - Informative Resources That Include Self-monitoring Tools Are Useful ................................................................................. 88

Figure 16: Current Clinical Practice ........................................................................ 101

Figure 17: Strategies to Supplement the Journey to Driving Retirement .......... 103

Figure 18: Flow chart - Would Knowing my Alternative Influence my Decision ......................................................................................... 116
LIST OF TABLES

Table 1: Themes generated from the literature review ................................ 17
Table 2: Participant Interview Format by Data Collection Method .................
and Gender ................................................................................................. 63
Table 3: Driving Patterns of Participants by Driving Activity ....................... 65
Table 4: Themes Matrix ............................................................................... 97
1. INTRODUCTION

1.1 Overview of the thesis

The purpose of this chapter is to provide an overview of the thesis, beginning with a discussion of the issues prompting this study. We know that dementia is a chronic condition that progressively impacts upon cognitive function over time and that symptoms of dementia potentially impact on the ability to drive safely (Duchek et al., 2003, Carr, Shead and Storandt, 2005). Some individuals with dementia find the decision to retire from driving so confronting and difficult that they continue to drive despite evidence that their capacity to drive safely may be compromised. Other individuals appear to lack insight and do not recognise that their capacity to drive safely has been compromised by their dementia. A consequence for some can be a reluctance to accept the need to retire from driving, particularly when the decision is imposed upon them (Liddle et al., 2008). This thesis details the background, literature review, methods, findings, discussion and conclusions of a qualitative study conducted as a masters by research project.

It is predicted that the average age of the Australian population will increase over the next 50 years and the number of drivers presenting with dementia related impairment is therefore likely to increase (Deloitte Access Economics, 2011). The progressive nature of dementia means that cognitive skills needed to...
drive safely can gradually diminish (Carr et al., 2005). Current clinical practice acknowledges that: (i) a diagnosis of dementia is insufficient evidence for licence cancellation because the impact of dementia on driving varies between individuals (Molnar et al., 2006b); and (ii) an on-road assessment is the most accurate method for assessing fitness to drive (Fox et al., 1997, Dobbs, Carr and Morris, 2002, Lipski, 2002). The main focus of contemporary research into driving and dementia has been determining an accurate method of assessing fitness to drive (Molnar et al., 2006b). Another emerging research focus is the investigation of the efficacy of educational programs to promote greater awareness of alternative transport and lifestyle choices for older drivers facing driving retirement (Liddle, McKenna and Broome, 2005). The purpose of this study was not to identify an accurate assessment tool or investigate alternatives to community access in the absence of fitness to drive. Rather, this study addressed the decisional support needs of those people with dementia who wish to participate in the decision to retire from driving.

The purpose of this study was to identify decisional support needs to inform elements of a decisional support tool effective in enhancing acceptance of the potential need to consider driving retirement following recognition of dementia. The three primary objectives were to:

(i) undertake a review of existing educational literature on driving and dementia;
(ii) discover what drivers over 55 years would want in a new decisional support tool to enhance acceptance of the potential need to consider retirement from driving following the recognition of dementia; and

(iii) identify the type of evidence drivers who recognise they have dementia consider objective for justifying driving retirement.

The gap in the literature regarding the effectiveness of involving drivers with dementia in the decision making process will be addressed. The research design was informed by the protocol outlined in the ‘Ottawa Decision Support Framework’ (ODSF) for developing decisional support tools (O’Conner and Jacobsen, 2007). The ODSF was developed from the theory of decisional conflict (Janis and Mann, 1977). The theory of decisional conflict was selected as it refers to ‘uncertainty’ about which course of action to follow when a choice involving risk, loss, or regret needs to be made (Janis and Mann, 1977). The ODSF is an evidence-based framework used to develop and evaluate patient guides for making health decisions.

To examine the increasingly important and highly debated issue of when and how best to address driving retirement among drivers with dementia, a community based qualitative study was undertaken with current drivers aged 55 years and over. Participants were recruited as a convenience sample from consumer network groups and media articles. The sample consisted of 15 participants, including two drivers with dementia who volunteered to participate
in a two phase interview process. Phase 1 consisted of facilitated interviews regarding important criteria to include in a decisional support tool. Phase 2 interviews critiqued elements of existing publically available information that might be considered useful to include in the program. Interviews were conducted on either a one to one or small group basis depending on the participants’ geographical location and preference. Demographic and qualitative data were collected and ‘thematic analysis’ was applied to generate ‘patterns of meaning’ or themes. The emergent themes informed: (i) the most appropriate means, timing and delivery method for a decisional support tool; and (ii) inclusions that could provide the type of evidence required by those with dementia to inform their decision about the time to retire from driving.

It is anticipated that beyond this study, quantitative research will be undertaken to determine the effectiveness of a decisional support strategy for increasing acceptance of the potential need to consider driving retirement for the driver with dementia. Already this work has been shown to be useful in informing consumer driven research, and funding has been gained to develop and publish the decision tool both online and in hardcopy booklet format. Conclusions as to the content and structure of the proposed new decisional support tool and recommendations for proposed future research will be discussed later.
1.2 Background

The purpose of this section is to report on the key background issues pertaining to this study. Driving is an important activity of daily living for many people, particularly in Australia where distance and access to adequate public transport is a continuing challenge. This is demonstrated by the fact that the majority of Australians aged between 30 and 70 years have a driver’s licence (Austroads, 2012), (Figure 1).

![Distribution of Australian Population & License Holders by Age](image)

**Figure 1:** Distribution of Australian Population and Licence Holders by Age (per million) in 2005 (adapted from Australian Bureau of Statistics, 2008)

With the predicted increase in the average age of the Australian population over the next 50 years, road users, policymakers, and the wider community will be
debating issues about driving age and driver safety. The Australian Bureau of
Statistics (2008) projected one in four Australians will be aged 65 and over by
2056. However, the issues of social concern that need acknowledgment with
respect to driving should not be specifically limited to the age of the licence
holders. It is important that individual drivers are able to demonstrate those
physical and cognitive competencies essential for safe driving, regardless of age.
The complexity of driving has important implications for this driving oriented
society, given that it is estimate that 200,000 Australians have dementia. By 2050
the number is expected to rise to 730,000 (Deloitte Access Economics, 2011),
(Figure 2). The unspecified number of Australians driving with undiagnosed
symptoms of dementia only amplifies the concern.

![Projections of Dementia Incidence in the Australian Population 2008-2050](image)

**Figure 2:** Projections of Dementia Incidence in the Australian Population
2008–2050 (adapted from Deloitte Access Economics (2011))
Driving is a high level skill requiring selective attention to relevant cues, quick response to changing environments, and the ability to predict hazards (Adler et al., 2006). Safe driving relies on the ability to perform habitual motor functions such as operating gears and handling the car (long term memory), whilst simultaneously responding to changing environments of variable complexity (new learning). The ability to carry out these activities for those with a dementia may be compromised due to the associated decline in motor responsiveness and cognitive processing speed (Fox et al., 1997, Duchek et al., 2003, Brown et al., 2005a, Brown et al., 2005b, Perkinson et al., 2005). As a possible consequence, drivers with dementia who continue to drive may be at a higher risk of road accident rates when compared to their peers (Whelihan, DiCarlo and Paul, 2005).

In a review of motor vehicle crash risk, it was found that drivers with dementia were 2 to 2.5 times more likely to be involved in an accident when compared to age and sex matched controls (Hogan et al., 2008).

A diagnosis of dementia alone is not sufficient evidence to recommend driving retirement because the severity and impact of dementia varies between individuals (Perkinson et al., 2005, Brown et al., 2005b). For medical practitioners in Australia there is no legal obligation to report a patient’s diagnosis of dementia. Mandatory reporting obligations regarding impaired physical or cognitive fitness to drive are only legislated in South Australia and the Northern Territory (Brown et al., 2005b, Australian and New Zealand Society for Geriatric Medicine, 2009). When an individual is assessed by a clinician to be
demonstrating moderate to severe symptoms of dementia significantly impacting on their activities of daily living it is straightforward to determine that driving safety will be impaired. In contrast, when a person with dementia is experiencing only ‘mild’ effects on their daily life and cognitive function, fitness to drive is not clear cut and needs to be determined on a case by case basis (Carmody, Traynor and Iverson, 2012).

Clinic based assessment methods used to evaluate driving capacity among drivers with dementia include a combination of psychometric tests. These are not dementia specific assessments and practitioners consider these limited in their usefulness for assessing driving capacity among those with dementia (Fox et al., 1997, Molnar et al., 2006a). Currently, research claims that the most reliable method for assessing fitness to drive for people experiencing mild effects of dementia is an on-road driving assessment by a qualified assessor, with six monthly reviews to be conducted from the time of diagnosis until driving ceases (Molnar et al., 2006b). Practitioners, researchers and licensing authorities consider these on-road assessments reliable because they provide objective information about fitness to drive (Fox et al., 1997, Perkinson et al., 2005, Austroads National Road Transport Commission, 2012). In contrast, drivers with dementia, are often reluctant to accept the outcome of these on-road assessments, reporting that the assessment process is ‘not fair’ and does not accurately reflect actual capacity to drive (Perkinson et al., 2005, Byszewski,
Molnar and Aminzadeh, 2010). Alternative approaches to addressing decisional conflicts faced by drivers with dementia are explored in Chapter 5 of this study.

As stated previously, practitioners consider that an on-road assessment is a reliable predictor of driving ability; however, drivers with dementia can be reluctant to accept the validity of these assessments when retirement from driving is recommended (Freund et al., 2005). The purpose of this study was to identify decisional support needs to inform elements of a decisional support tool effective in enhancing the acceptance of the potential need to consider retirement from driving for people with dementia. An alternative consumer focused method for supporting those with dementia to consider driving retirement needs to be developed. One approach that has been implemented is the development of a range of educational materials to assist drivers and their care partners consider retirement from driving (Alzheimer’s Australia NSW, 2005, University of Michigan Transportation Research Institute, 2006, Hartford Financial Group and MIT AgeLab, 2007) However, the effectiveness of these resources on the decision making process for the driver with dementia is not yet known. The majority of previous studies involving driver perspectives regarding driving retirement decisions have purposely excluded the opinions of drivers with dementia. This study will provide an innovative contribution to current knowledge about people who are driving and have dementia by ensuring their participation (Shope and Eby, 1998, Charlton et al., 2003). It is considered essential that drivers with dementia be consulted about the type of information
they would consider useful and the type of evidence they would be accept as valid in relation to their driving safety.

In summary, this study investigates decisional support needs informed by and designed for drivers with dementia to enhance acceptance of the potential need to consider driving retirement. The background has provided an overview of the contemporary issues challenging individuals and the broader community with regard to the predicted increase in the population of older drivers, including those with dementia. Driving plays an important role for maintaining independence in activities of daily living for many people, and particularly in Australia where distance and access to adequate public transport is a continuing challenge.

1.3 Summary

This chapter began with an overview of the thesis, outlining the purpose and objectives of a study undertaken as part of the requirement for a degree of Master of Science - research. The context for the study was provided in the background section of this chapter with an overview of the importance of driving, and the implications of driving retirement for those with dementia. The next chapter reviews the literature and includes discussion of the themes generated from empirical research into dementia and driving. Gaps in the literature will also be addressed. The methods chapter (Chapter 3) provides a
description of the research design, detailing the theoretical framework, ethical considerations, setting and sample, recruitment, data collection and data analysis methods. The findings from participant interviews and emergent themes are examined in Chapter 4. The implications of research findings for clinical practice are reviewed in the discussion chapter (Chapter 5) where the strengths and limitations of this study are also discussed. The final chapter (Chapter 6) concludes with a discussion of the ability of the study design to address the research question: that is, ‘Can acceptance of driving retirement be enhanced by providing a decisional support tool informed by and for people with dementia?’

Already this work has been shown to be valuable for informing consumer driven research, and funding has been secured to develop the content and publish a new decision tool both online and in hardcopy booklet format. It is anticipated that beyond this study, further quantitative research will be undertaken to determine the decisional support tool’s effectiveness for increasing acceptance of the potential need to consider driving retirement for the driver with dementia.
2 LITERATURE REVIEW

The purpose of this chapter is to present a literature review of research investigating dementia and driving retirement generated over the past decade. The search strategy adopted will be described, and the following six (6) themes that emerged will be explained:

i) Driving is a complex task

ii) Onset and severity of dementia are difficult to define

iii) Dementia is progressive and impacts on driving skills

iv) Assessment of fitness to drive remains subjective

v) Some drivers with dementia are reluctant to accept negative assessment outcomes

vi) The search continues for the most effective means of preparing drivers with dementia for accepting driver retirement

The literature review uncovered a gap in our understanding of the most effective means of enabling drivers with dementia to make informed decisions and better accept evidence regarding the time to retire from driving. This finding informed the consumer based study presented in this thesis.
2.1 Search Strategy

A four phase search strategy was adopted to inform this review of the literature and explore the relationship between dementia and driving retirement: (i) database search; (ii) incremental search; (iii) delimiting inclusion and exclusion criteria; and (iv) critique of empirical research (Figure 3). These strategies and the number of articles identified in each phase are described below.

**Figure 3: Four Phase Search Strategy**
2.1.1 Search strategy 1: Database search

An initial database search was undertaken to identify contemporary opinion published in the literature between 1997 and 2010 regarding the relationship between dementia and the loss of ability to drive. The commencement date of the search was selected because the conclusions drawn by Fox et al. (1997) and Hunt et al. (1997) continue to be cited in the literature and used to inform clinical practice. To ensure access to a range of medical and allied health literature the following four (4) electronic databases were searched: (i) Medline; (ii) CINAHL; (iii) Web of Science; and (iv) Google Scholar.

The search terms applied to identify published empirical research and opinion based literature comprised the following:

- Truncations of ‘dementia OR Alzheimer’ combined with ‘drive’ (truncated) and ‘assess’ (truncated), using the Boolean operator ‘AND’.
- Published Australian and International English language articles including empirical studies, editorials, clinical based reports, consensus statements and guidelines that used all key words in both the title and topic.

Sources were excluded when the general topic of ‘Driving and Dementia’ was not addressed. These initial search results identified a total of 117 articles, all of which were then appraised using the following search strategy.
2.1.2 Search strategy 2: Incremental search

The reference lists of the 117 retained articles from the initial data base search were hand searched (Crookes and Davies, 2004) identifying ten (10) additional primary sources. Three experts in the field in Australia were contacted and a further two (2) studies were identified, which were subsequently published. All 129 articles were then critiqued using the third search strategy.

2.1.3 Search strategy 3: Delimiting inclusion and exclusion criteria

Subsequent to the initial search limits outlined in search strategy 1, additional criteria were applied to:

(i) Include empirical studies investigating the relationship between dementia and loss of ability to drive safely;

(ii) Exclude all opinion based publications, case studies and non-systematic reviews of the literature; and

(iii) Exclude studies investigating validity and reliability of tests of fitness to drive that did not assess drivers with dementia.

A total of 84 empirical studies were identified using these criteria including systematic literature reviews, quantitative, qualitative and mixed method
these studies were critiqued according to the fourth phase of the search strategy.

2.1.4 Search strategy 4: Critique of empirical evidence.

Review of the 84 articles retained after applying the limits outlined in strategy 3 revealed two distinct approaches in the literature investigating dementia and ability to drive safely:

- Qualitative (n=8), quantitative (n=15) and mixed methods studies (n=2) that investigated stakeholder attitudes and perspectives about older drivers’ (with or without a diagnosis of dementia) loss of ability to drive safely (n=25); and

- Quantitative studies examining reliability and validity of various tests for predicting fitness to drive (n=25).

All articles were critically reviewed for rigour using the Critical Appraisal Skills Programme (CASP) (Public Health Resource Unit, 2009) hierarchy of evidence and a total of 49 articles were retained to inform the literature review (Table 1). Inclusion criteria for this search phase consisted of: the level of evidence; quality of the study; and relevance to clinical practice (Appendices A and B).
Table 1: Themes generated from the literature review

<table>
<thead>
<tr>
<th>Theme</th>
<th>Title</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1.</strong></td>
<td>Driving is a complex task that can be compromised by dementia.</td>
<td>7</td>
</tr>
<tr>
<td><strong>Theme 2.</strong></td>
<td>Onset and severity of dementia are difficult to define.</td>
<td>12</td>
</tr>
<tr>
<td><strong>Theme 3.</strong></td>
<td>Dementia is progressive and impacts on driving skills.</td>
<td>7</td>
</tr>
<tr>
<td><strong>Theme 4.</strong></td>
<td>Assessment of fitness to drive remains subjective.</td>
<td>15</td>
</tr>
<tr>
<td><strong>Theme 5.</strong></td>
<td>Some drivers with dementia are reluctant to accept negative assessment outcomes.</td>
<td>12</td>
</tr>
<tr>
<td><strong>Theme 6.</strong></td>
<td>The search continues for the most effective means of preparing drivers with dementia for accepting driver retirement.</td>
<td>21</td>
</tr>
</tbody>
</table>

2.2 Themes Identified

The search strategy outlined above generated a total of 49 research articles investigating the relationship between dementia and ability to drive safely published between 1997 and 2010. The key findings were indexed and evaluated to identify commonalities and discrepancies in the literature. A matrix of themes was generated from the literature review to analyse patterns of meaning (Crookes and Davies, 2004, Hart, 2005) (Table 1). Each of the 6 themes generated from the analysis will be discussed in detail below.
2.2.1 Theme 1: Driving is a complex task that can be compromised by dementia

Driving is a high-level skill that requires selective attention to only relevant cues, quick response to changing environments, and the ability to predict hazards (Kay et al., 2008). Cognitive capacity to carry out habitual motor functions such as operating gears and handling the car (long-term memory) as well as ability to assess and respond to changing environments (new learning) is required (Adler and Kuskowski, 2003). An early prospective study by Hunt et al. (1997) evaluated the on-road driving performance of drivers with dementia and age matched controls. The authors concluded that high-level cognitive and physical driving skills required to negotiate dynamic traffic situations can become compromised for those with dementia. Findings of this study concur with later quantitative studies, including those conducted by Carr, Duchek and Morris (2000), Reger et al. (2004) and Valcour, Masaki and Blanchette (2002).

The potential safety implications for those with symptoms such as memory loss and inability to recognise familiar places have also been investigated. A retrospective study in the United States by Hunt, Brown and Gilman (2010) reviewed media reports of drivers with dementia becoming lost. Those who became lost or died were driving to or from familiar places, illustrating the potential impact of dementia on the complex tasks of route finding and
attention to relevant cues. The findings from the literature emphasised the complexity of driving, requiring high level cognitive and physical skills. These skills become compromised with the progression of dementia.

2.2.2 Theme 2: Onset and severity of dementia are difficult to define

Understanding the natural progression of dementia and the subsequent impact on fitness to drive remains incomplete (Hogan et al., 2008). Onset of initial symptoms and clinical diagnosis do not occur simultaneously. For example, an Australian study by Fox et al. (1997), undertaken with drivers with probable Alzheimer’s disease (n=19), concluded that the duration of symptoms was not a predictor of driving assessment results. A longitudinal study by Duchek et al. (2003) found evidence of decline in driving performance over time for drivers with early stage dementia. In addition, a quantitative study by Valcour, Masaki and Blanchette (2002) found that driving will eventually cease due to diagnosis. However, the continuum from onset of symptoms, time of diagnosis and then on to the eventual inability to drive safely cannot be clearly defined (Fox et al., 1997, Brown et al., 2005a, Perkinson et al., 2005).

Qualitative research carried out by Adler and Kuskowski (2003) investigated the process of driving cessation amongst male drivers with dementia and
concluded that driving continued long after onset of symptoms. Cessation was usually abrupt, unplanned and required input from family carers and physicians. This finding corroborates other studies including a systematic review by Man-Son-Hing et al. (2007). Whilst there are a range of clinical assessments used to determine fitness to drive for people with cognitive impairment, current research indicates that such tests are unable to accurately predict driver safety for drivers with very mild to mild dementia (Duchek et al., 2003, Molnar et al., 2006a). Reliance upon these assessments to screen for driving safety can lead to premature licence cancellation for some drivers with dementia whilst failing to identify those who are not safe to continue driving. Research by Abersman and Hunt (2008) found that some drivers with dementia can continue to drive safely after diagnosis with regular monitoring and evaluation of fitness to drive.

The difficulties associated with defining the time of onset and natural progression of symptoms highlight the implications of proposing decisional support interventions to promote driver participation in decisions regarding the time to retire from driving (Cotrell and Wild, 1999, Adler, Rottunda and Dysken, 2005). When the severity of symptoms call for practitioners and family carers to raise concerns about driving safety, the capacity of the person with dementia to participate in decision-making and understand the reasoning behind unfavourable assessment findings may be compromised.
2.2.3 Theme 3: Dementia is progressive and impacts upon driving skills

As discussed above, the potential need for drivers with dementia to cease driving is likely to occur due to the progressive nature of associated symptoms (Duchek et al., 2003, Carr et al., 2005). The gradual impact of dementia on driving skills has been a recurring focus for empirical research and public debate (Alzheimer’s Australia NSW, 2010). The balance between one’s right to prolong driving independence versus safety for all road users has implications for those with a dementia.

A case control study by Uc, et al. (2004) found that even though basic vehicle control abilities were considered normal, those drivers with mild dementia (n=32) made more frequent driving errors compared to asymptomatic controls (n=136) because driving imposes demands on memory, attention and perception. This relationship between driving competence, cognitive deficits and driving behaviour has also been identified in other case control studies, including those by de Simone et al. (2007) and Whelihan (2005). These studies substantiate claims in opinion based literature (Brown and Ott, 2004, Breen et al., 2007, Hogan et al., 2008) that:

(i) drivers diagnosed with dementia may need to retire from driving as their illness progresses; and
(ii) whilst six monthly reassessments are recommended, the timeline between onset of diagnosis and driving cessation is not clear-cut (Hogan et al., 2008, Adler, 2010).

Driving skills can progressively become compromised for those with symptoms of dementia; however, the impact of mild and very mild symptoms on driving capacity can vary between individuals.

2.2.4 Theme 4 Assessment of fitness to drive remains subjective

Contemporary evidence-based practice regarding assessment of fitness to drive for those with dementia is informed by the premise that: (i) there is no definitive clinic-based assessment that can accurately predict fitness to drive for those diagnosed with very mild to mild dementia; and (ii) on-road driving assessments are currently considered more accurate than the available clinical assessments (Dobbs, 1997, Fox et al., 1997, Hunt et al., 1997, Lipski, 2002, Duchek et al., 2003).

Research, including systematic reviews undertaken by Man-Son-Hing et al. (2007) and Molnar et al. (2006), concluded that on-road assessment of driving performance was the most accurate means of assessing fitness to drive. Accuracy of cognitive screening tools to detect those who were considered unsafe were inadequate whilst the on-road assessment was
referred to as ‘the gold standard’ (Fox et al., 1997, Dobbs et al., 2002, Lipski, 2002, Reger et al., 2004, Brown et al., 2005b, Lovell and Russell, 2005, Berndt, Clark and May, 2008). However, the systematic review by Molnar et al. (2006b) and other research raised questions about the validity and reliability of on-road assessments given the subjective methods of delivery and evaluation. For example, the outcome relies on assessor observation over a limited timeframe in a testing environment (Brown et al., 2005a). Furthermore, a Cochrane review by Martin, Marottoli and O’Neill (2009) found no randomised control evidence regarding clinic based, on-road or other assessments of safe driving ability for people with dementia. This paucity of rigorous research informing current clinical practice supports concerns raised by some drivers and family carers over the reliability and validity of assessments used to determine fitness to drive.

Meanwhile, development of accurate clinic based assessments to determine driver safety continues to be a primary focus of investigation exemplified in recent quantitative research by Kay, Bundy and Clemson (2009c) and Lincoln et al. (2010). Whilst results of both studies indicated a higher than previously obtained correlation between clinic based test scores and on-road assessments to accurately predict fitness to drive, further investigation to validate findings was recommended.
2.2.5 Theme 5 Some drivers with dementia are reluctant to accept negative driving assessment outcomes

Available research indicates the on-road assessment remains a more accurate predictor of driving safety compared to clinical tests (Lincoln et al., 2006); however, this on-road assessment generally relies on observation of driving skills over a relatively short period of time in an unfamiliar car and/or along unfamiliar driving routes. When drivers with dementia are presented with findings from an on-road assessment, some are reluctant to accept negative assessment outcomes (Jett, Tappen and Rosselli, 2005, Byszewski et al., 2010), with distraction by those present or anxiety in response to the test environment among the reasons cited for poor performance (Freund et al., 2005).

In a qualitative study by Perkinson et al. (2005) opinion was sought from a cohort (n=68) of consumers, family carers and practitioners as to the reasons why some drivers with dementia are resistant to relinquishing their licence. The current drivers with dementia (n=9) believed that their cognitive impairment did not affect their own driving safety. Approximately half of the former drivers with dementia (n=5) were of the view that they should have been allowed to continue driving. A more recent qualitative study by Byszewski, Molnar and Aminzadeh (2010) of drivers with dementia (n=15) who had been advised to cease driving by practitioners revealed
that 40% of the drivers (n=6) accepted the recommendation; 20% (n=3) did not agree but resigned themselves to the decision; and 40% (n=6) rejected the recommendation, insisting they remained fit to drive. Neither study reported reasons for the variation in level of acceptance between the participants.

Significant lifestyle and psychosocial implications that accompany licence cancellation have been reported in several studies. These included family conflict, loneliness, depression, social isolation and low self-esteem (Taylor and Tripodes, 2001, Perkinson et al., 2005, Rudman et al., 2006).

A quantitative study of stakeholder beliefs and cessation strategies by Perkinson et al. (2005) which included opinion of current drivers (n=9) and ex-drivers with dementia (n=5) reported risk of isolation and depression for both the driver with dementia and other family members as a consequence of driving cessation. This supports findings in an earlier study by Taylor and Tripodes (2001) surveying opinion of retired drivers with dementia (n=922) regarding the impact of driving cessation on lifestyle. Significant lifestyle changes reported by respondents included loss of ability to independently access transport to medical appointments, household shopping and social activities. There was an increased reliance on carers to provide transport to essential travel such as medical appointments and shopping. For discretionary travel including travel to recreational and social activities
there was a decrease in participation rather than an increased reliance on others transport. For example, those who reported ‘rarely’ participating in social activities increased from 5 % to 13 % with driving cessation.

In addition to social isolation and negative lifestyle changes reported in a qualitative study by Rudman et al. (2006) with ‘older drivers’ (n=79), participants also reported loss associated with the ‘symbolic’ meaning of driving to the individual facing driving retirement such has loss of sense of self, loss of spontaneity to engage in meaningful activities, and evidence of a decline in wellbeing.

Regardless of the reasons for the drivers’ reluctance to accept negative assessment outcomes, evidence demonstrates interventions that enhance acceptance of the possible need to consider driving retirement would be welcomed by drivers with dementia and their family carers (Taylor and Tripodes, 2001, Freund and Szinovacz, 2002, Freund et al., 2005, Rudman et al., 2006, Kostyniuk and Molnar, 2008, Adler, 2010, Byzewski et al., 2010).
2.2.6 Theme 6  The search continues for most effective means of preparing drivers with dementia to accept driver retirement

Review of the literature identified that the most effective way to prepare drivers with dementia for the potential loss of ability to drive has not yet been determined (Hogan et al., 2008, Adler, 2010). As stated previously, there have been two main topics in research concerned with driving and dementia: (i) assessment of fitness to drive; and (ii) lifestyle planning for the post-driving retirement phase. The main focus of research has been to identify fair, reliable and cost-effective assessment tools that can be used by practitioners to accurately predict and monitor fitness to drive (Brown et al., 2005a, Brown et al., 2005b, Molnar et al., 2006a, Kay et al., 2009c). The other primary focus of empirical investigation is the provision of educational support to assist consumers and their family carers with future lifestyle planning following driving retirement (Adler et al., 2005, Hunt and Arbesman, 2008). Research by Liddle, McKenna and Broome (2005) deemed that drivers can be categorised into 4 phases according to the decision process: (i) past (previous); (ii) pre-decision; (iii) decision; and (iv) post-decision phases. Whilst the research reports on tests for predicting fitness to drive in the decisional phase and lifestyle management for coping in the ‘post decision’ phase, the merit of including drivers with dementia in the decisional phase does not appear to be sufficiently investigated in empirical research (Dobbs et al. 2009). Research identified in the literature
as to the decisional conflicts faced by drivers with dementia and the efficacy of decisional support tools will be discussed below.

A study by Adler (2010) investigated attitudes about driving decision-making informed by drivers with dementia and their family carers. Drivers and their spouses were asked how people with dementia would know when it was time to retire from driving. Respondents reported several ‘flags’ to indicate the time to stop. A need for a shared approach inclusive of the driver with dementia in monitoring fitness to drive safely was advocated and respondents recommended further investigation into ways this should be achieved. Involving the driver in the decision making was also recommended by family carers in a qualitative study by Mizumo, Arai and Arai (2008); however, more often it was the family carers that were required to make the decision.

A study undertaken by Stern et al. (2008) investigated the usefulness of family carer educational support with particular focus on the information tool, ‘At the Crossroads’, developed by the Hartford Foundation (2007). The investigation found educational support was effective in preparing family carers of drivers with dementia to address issues of driving retirement. However, there remains a paucity of published literature to support the hypothesis that generated this study: that is, timely and appropriate consumer participation in self-assessment and monitoring of
driving safety using a decisional support tool may increase a person with dementia’s acceptance of the need to retire from driving (Snellgrove and Hecker, 2002, Perkinson et al., 2005, Adler, 2010).

Early qualitative research by Shope and Eby (1998) confirms opinion based literature (Pachana and Petriwski, 2006) that:

i) healthy older drivers are able to self-regulate their driving behaviours and make adjustments to increase their safety; whilst

ii) older drivers with impaired cognitive functioning fail to recognise the potential impact of their deficits and do not modify their driving habits to accommodate these.

Key findings were consistent with later studies, including a pilot study by Wild and Cotrell (2003) where a cohort of drivers with mild dementia (n=15) and age matched healthy controls (n=15) participated in a self-reported evaluation of driving skills and an on-road driving assessment. Whilst the drivers with dementia self-rated their driving ability as higher compared to the control group, actual driving performance was significantly worse.

Research into the value of using educational support to inform decisions about driving and driving cessation with older drivers has generated positive results. For example, findings by Baldock et al. (2006) investigating self-regulation habits and attitudes in a community based study in South
Australia with drivers aged 60 to 92 years concluded that provision of educational resources, self-assessment strategies and opportunity to obtain passenger feedback would assist drivers make decisions about their own driving ability. Also, a randomised control trial by Marottoli et al. (2007) found that provision of an education program enhanced on-road performance for older drivers. However, both of these participant samples purposely excluded drivers with impaired cognitive function.

The efficacy of educational programs to inform drivers with dementia about the potential impact of the disease on their ability to drive safely is supported by only a few studies. An early qualitative study by Cotrell and Wild (1999) found that when drivers with dementia (n=35) became aware of a ‘deficit’ they were able to modify driving patterns and consequently safely prolong their driving status. A qualitative study of practitioners and family carers of people with dementia (n=261) by Jett et al. (2005) advocated an ‘involved’ strategy of intervention inclusive of the driver with dementia facing decisions about when to retire from driving. This is supported in the qualitative findings by Byszewski et al. (2010). The authors concluded that timely access to information about the progressive impact of dementia on driving safety may enable people with dementia to participate in driving retirement decisions rather than facing sudden and externally imposed recommendations to cease driving.
Findings of this literature review recommend further research be undertaken to determine both the decisional support needs of drivers who recognise they have a dementia; and the effectiveness of a decisional support tool to facilitated acceptance that the ability to drive safely may become compromised to the point where driving retirement is required.

### 2.3 Summary

In summary the following six (6) themes that emerged from the literature review were discussed in detail in this chapter:

i) Driving is a complex task that can be compromised by dementia

ii) Onset and severity of dementia are difficult to define

iii) Dementia is progressive and impacts upon driving skills

iv) Assessment of fitness to drive remains subjective

v) Some drivers with dementia are reluctant to accept negative assessment outcomes

vi) The search continues for the most effective means of preparing drivers with dementia for accepting driver retirement.
This literature review acknowledges that driving is a complex task demanding cognitive and physical skills which can be compromised either as a natural process of aging or due to onset of ‘other’ dementias. Therefore, whilst the loss of licence may represent a loss of independence and control for the driver with dementia, there needs to be a balance between individual rights to independence and safety for all road users. This will remain an on-going social concern and a broadly debated community issue into the future.

For those with symptoms of dementia the most appropriate time to retire from driving needs to be assessed on a case-by-case basis. Whilst the on-road assessment is currently considered the most accurate predictor of driving ability for those with mild to very mild dementia, some drivers are reluctant to accept findings that their driving skills are impaired and that safety for themselves and others could be compromised. Therefore, research to determine the efficacy of decisional support tools for drivers facing potential, although gradual, loss of skills required to drive safely due to a recognised dementia is important. The research design undertaken to obtain consumer opinion to inform this research will be discussed in the next chapter.
3 METHODS

The purpose of this chapter is to explain the research design adopted to generate opinion regarding decisional support needs for people who become aware that they have dementia and may be faced with the decision to retire from driving. This community based study was approved by the University of Wollongong Human Research Ethics Committee (HREC). The theoretical framework was informed by the protocols from the ‘Ottawa Decision Support Framework’ (ODSF) (O’Conner and Jacobsen, 2007), an evidence-based framework for developing patient guides that address health decisions involving choice and uncertainty (Janis and Mann, 1977).

The importance of obtaining consumer opinion to inform research when findings impact on services provided to people with dementia is highlighted in the Alzheimer’s Australia research paper, ‘Consumer Involvement in Dementia Research: Consumer Dementia Research Network’ (2010). Consumers are defined as ‘people living with dementia and their family carers’. The report acknowledges that consumers understand dementia in ways that other people do not, consequently providing a unique and valuable contribution to research knowledge. The report also advocates that consumer involvement in research requires a framework that is systematic and empowering. In light of the recommendations of the report, the ODSF was selected as the most appropriate framework to inform the design of this study.
The technique of purposive sampling informed the recruitment strategies for this study (Silverman, 2011). All drivers over 55 years were considered relevant for this study because in the near future they could be required to consider driving retirement due to a dementia. The decision aid that could be developed from this study would be promoted to individuals who self-identify as having a dementia and those who self-identify as having no known cognitive impairment as preparation for managing decisions about future driving retirement prior to it being a requirement. Following the adoption of the recruitment technique of purposive sampling we sought potential participants from drivers over 55 years who would represent the target audience for a future decision aid. Drivers over 55 years who self-identified as having (i) a dementia and (ii) no known cognitive impairment were recruited to participate in this study.

Potential participants were recruited through consumer network groups and a local media release: (i) people who self-identified as having a dementia and (ii) others who self-identified as having no known cognitive impairment. Potential participants responded the recruitment notices and were provided with further information about the study before volunteering to participate. No assessment for the presence of a dementia or cognitive impairment was undertaken. All participants were asked to self-disclose whether they identified themselves as having ‘a dementia’ or ‘no known cognitive impairment’.
The technique of concurrent data collection and data analysis was applied to facilitate early exploration of emergent themes during subsequent interviews. Data generated were digitally recorded, transcribed, hand sorted and uploaded to ‘NVivo9’ (QSR International Pty Ltd, 2009) for data analysis. Transcripts were then coded and compared to identify ‘patterns of meaning’ or emergent themes (Corbin and Strauss, 2008). The themes generated were collated and appraised in relation to empirical literature. The findings, conclusions drawn and recommendations for proposed future research will be discussed in later chapters.

3.1 Theoretical Framework

The important and highly debated issue of retirement from driving for people diagnosed with dementia was explored using a community based study involving consumers and potential consumers. The ODSF was selected as the theoretical framework to inform the study because this approach promotes consumer involvement in decisions related to health concerns and refers to uncertainty about which course of action to follow when faced with choices involving risk, loss, or regret (Janis and Mann, 1977). Decisional conflict occurs due to intrinsic difficulties regarding choice; and factors such as lack of knowledge or lack of resources (O’Conner, Jacobsen and Stacey, 2002, O’Conner and Jacobsen, 2007). These are modifiable factors and therefore the decision making process can be
enhanced when access to effective decisional support tools is available. Two perspectives underpinning the research design are explored below: (i) the model of consumer involvement in decision making; and (ii) the strategic process of creating an effective decisional support tool.

3.1.1 The model of consumer involvement in decision making

Using the ODSF framework to inform this study fits well with the study’s purpose, that is, to investigate the decisional support needs of those people with dementia who may need to consider retirement from driving. The ODSF is described by O'Connor and Jacobsen (2007) as evidence-based, consumer driven and practical, drawing on the knowledge from areas of general and social psychology; and the theory of decisional conflict (Janis and Mann, 1977). This theoretical framework was identified during a search of grey literature and subsequently recommended during consultation with colleagues who are considered expert in conducting consumer focused research. The ODSF framework has been used as a guide to develop and evaluate programs that provide decisional support to consumers accessing a range of health services (Shorten et al., 2005, Stirling et al., 2012). Whilst decisional support tools have been developed for care partners of people with dementia and a generic decisional aid is currently available for older drivers, namely, ‘Healthy Aging: Is It Time to Stop Driving?’ (Healthwise, 2010), there was no evidence of the
existence of a decisional support tool specific to the topic of driving retirement for the person diagnosed with dementia.

Figure 4: Ottawa Decisions Support Framework (ODSF) Three Stage Decision making Process

The ODSF describes a three-stage process for guiding those who are confronted with health decisions and asserts that decision aids can address unresolved decisional needs (Figure 4) (Jacobsen and O'conner, 2006). Three stages of research are necessary to develop an ODSF (Figure 4). The three stages of research required to develop an ODSF driving decisional support tool are: The (i) Stage one: ‘assess and identify’ the type of information consumers want to be
included in a driving and dementia decisional support tool; (ii) Stage Two: develop a decision support tailored to the needs of Australian consumers and carers and (iii) Stage Three: evaluate the effectiveness of the decisional support tool for increasing acceptance of the potential need to consider driving retirement for people diagnosed with dementia. The aim of this study is to undertake Stage One in the development of an ODSF decisional support tool for driving and dementia. Future studies could undertake Stages Two and Three to finalise the development of an ODSF decisional support tool for driving and dementia.

There are differences between the aims of the ODSF and the objectives of this study pertaining to both ‘decision making influence’ and ‘choice’ that are worthy of discussion. The intended purpose of the ODSF is to assist individuals make informed choices about health concerns they are facing. Rather than influence consumer decisions in one direction or another, the objective is to provide the relevant information, without bias, for and against specific decisional choices, ensuring self-determination in the decision making process (O’Conner and Jacobsen, 2007). In contrast, the purpose of providing a decisional support tool is to influence consumer decisions toward ‘acceptance’ in the event that a driver with dementia is considered no longer safe to drive (Lovell and Russell, 2005, Austroads National Road Transport Commission, 2012). However, the use of the ODSF to inform the content of a decisional support tool remains relevant as the purpose is to inform those drivers who recognise that they have dementia.
regarding a potential decisional choice they may face as symptoms progress: that is, whether to cease driving voluntarily; or ‘be subjected to’ an assessment of fitness to drive that may lead to licence cancellation (Healthwise, 2010).

3.1.2 The strategic process of creating an effective decisional support tool

Based on recommendations by Jacobsen and O’Conner (2006) in ‘The Population Needs Assessment Workbook’, an extensive review of international databases was undertaken to identify grey literature that supported decisions about driving retirement. To reduce the risk of replication, the workbook outlines the procedure and rationale for reviewing the literature to identify existing resources prior to conducting the needs analysis. Approximately 15 easily accessible English language resources available to consumers facing decisions about driving retirement were located. These varied in length, complexity and specificity. These resources were critiqued by the researcher in relation to ease of accessibility, and generic or specific relevance to drivers with dementia.

The grey literature search revealed that an Australian working party funded by Department of Health and Ageing (DoHA) was compiling a ‘Dementia Resource Guide’ for people with dementia and their care partners. This was subsequently published in 2010. The draft listed five publicly available driving decision resources recommended for drivers with dementia, each of which had been identified during the grey literature search for this study. Whilst consultation had
been undertaken with practitioners, there was no evidence that a consumer informed needs analysis had been conducted to inform the choice of these resources as inclusions in the DoHA (2010) guide. Since the five resources recommended by DoHA met the 'population needs assessment' criteria outlined by Jacobsen and O’Connor (2006), it was deemed appropriate to include them as the resources to present to participants in this study and seek comment on their usefulness. The five resources listed in the DoHA guide and presented to participants for review are listed above (Figure 5).

<table>
<thead>
<tr>
<th>Consumer Driving Decision Resources Pack</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) <strong>About You: Information for People with Dementia: Driving Help Sheet</strong></td>
</tr>
<tr>
<td>(ii) <strong>At the Crossroads</strong></td>
</tr>
<tr>
<td>(iii) <strong>Driving Decisions Workbook</strong></td>
</tr>
<tr>
<td>(iv) <strong>Driving Safely while Ageing Gracefully</strong></td>
</tr>
<tr>
<td>(v) <strong>Over 55 Rating Scale</strong></td>
</tr>
</tbody>
</table>

**Figure 5:** Content of Driving Decisions Resources Pack
3.2 Research Design

The purpose of this section is to explain how this research was undertaken by way of strategic design to address key research activities. A total of 14 documents were collated to ensure relevant data were generated in line with each of the research activities. Each of the following key activities of the research
design will be discussed in detail below: (i) ethical considerations; (ii) setting and sample; (iii) recruitment; (iv) data collection; and (v) data analysis (Figure 6).

3.2.1 Ethical Considerations

This study was approved by the University of Wollongong Human Research and Ethics Committee (HREC). It is well known that gaining ethics approval can be challenging when involving individuals whose cognitive capacity may be considered compromised. However, lack of legal competence to give consent should not lead to exclusion from participation (Corner 2002). Whilst it is understood that symptoms of dementia are progressive and the capacity to provide informed consent can change over time (Pratt, 2002), it is reasonable to expect that those who are still driving have the cognitive capacity to provide informed consent (Alzheimer's Australia, 2010). Given the potential sensitivity of the topic of driving retirement reflecting both diminishing functional capacity and loss of independence (Byszewski et al., 2010), the researcher had an ethical responsibility to ensure ‘vulnerable’ people were protected from harm, and specifically the possibility of emotional distress. In order to address a range of ethical issues unique to this population, specific strategies were implemented (Bartlett and Martin, 2002, Pratt, 2002, Dewing, 2007, Kay et al., 2009c).
Studies successfully undertaken by researchers considered expert at including participants with dementia in research informed consent strategies and recruitment methods adopted in this study (Bamford C and Bruce, 2000b, Bartlett and Martin, 2002, Dewing, 2007, Kay, Bundy and Clemson, 2009a, Kay, Bundy and Clemson, 2009b). Ethics approval was previously gained for an Australian study involving drivers with dementia by obtaining written consent from each participant’s guardian in addition to the participant’s written consent (Kay et al., 2009c). Pratt (2002) addressed consent in her study by informing participants they could indicate their wish to withdraw from participation at any time. The method of ‘on-going process consent’ has been successfully adopted by Dewing (2007) for research involving participants with dementia. This approach requires the researcher to respond to any non-verbal or gestural indications of non-consent and acknowledge such responses as withdrawal from participation.

Whilst it is understood that dementia is progressive and one’s capacity to provide informed consent can consequently change over time, it was envisaged that eligible volunteers who self-identified as ‘current drivers with dementia’ would be in the early stages of disease progression, and thus have the cognitive capacity to provide informed consent. However, in order to satisfy requirements of the HREC, proven techniques of other researchers, including Kay et al (2009c), Pratt (2002), Bartlett and Martin (2002) and Dewing (2007), were embedded in the research approach. Rather than excluding individuals who might not have the
cognitive capacity to provide informed consent, the researcher sought and gained ethics approval by including the co-signing of the participant consent form by a person legally entitled to do so (as per Kay et al., (2009c)). To ensure participants with dementia were protected from harm, specifically potential harm from emotional distress, the researcher, (who has extensive clinical experience in undertaking assessments and outcomes counselling for drivers with dementia), was responsible for recognising signs and mitigating potential distress during the interview process; and terminating the interview if necessary (a practice observed by Pratt (2002) and Dewing (2007)). Since it was important to ensure that vulnerable participants had not been coerced into participation (Bartlett and Martin 2002), the process of self-referral rather than third party referral was adopted. The combination of these techniques enabled current drivers with dementia to participate in this research whilst specifically addressing the ethical considerations unique to this cohort.

3.2.2 Setting and Sample

This section describes the use of theoretical sampling to recruit participants from a community based setting and generate consumer opinion about decisional resource needs from a population of drivers living in Australia. The objective was to bring together a cohort of participants who could provide valuable insight and offer in-depth opinion to inform decisional support needs of Australian drivers with dementia facing driving retirement decisions. An outline of the setting and
the rationale for the sampling strategies applied to recruit eligible participants into this study is provided below.

The study was undertaken with volunteer drivers over 55 years recruited by way of public notices published in a New South Wales based consumer support magazine, a regional newspaper and contact with local practitioners. Participants were either drivers with dementia or people concerned about the impact of dementia on driving safety, drawn from a community based setting using a purposive sampling technique. The target population were drivers living in urban and regional New South Wales and specifically the Illawarra and surrounding regions.

Purposive sampling was applied to the recruitment strategy by way of public notices distributed to members of relevant consumer network groups and a local media release. Silverman (2011) states that purposive sampling in qualitative research permits construction of a meaningful sample by affording the researcher flexibility to select participants in terms of theory; and include those ‘deviant cases’ sought due to specific characteristics or life experiences that bring richness and depth to the study.

The research design was informed by the concept of theoretical sampling whereby the researcher concurrently collects and analyses the data. Whilst doing so, recruitment of participants who can provide opinion to further inform the
emerging concepts arising from early analysis of the data continues to be pursued (Glaser and Strauss, 1967). The recruitment and data collection process is completed when saturation occurs, that is, the data collection tools generate no new data and no further themes or concepts emerge. The rationale for applying theoretical sampling to inform the design of this qualitative study is outlined as follows:

(i) Only a few studies investigating opinion about driver safety include those with dementia as participants (Marottoli et al., 2007, Byszewski et al., 2010). As stated previously, the rationale for recruiting current drivers with dementia was based on the model of ‘consumer informed research’, (Alzheimer's Australia, 2010).

(ii) Drivers with a diagnosis of dementia were sought because they are likely to understand the impact of the disease in ways that other people do not; therefore their knowledge and experience offer a valuable perspective (Shope and Eby, 1998, Charlton et al., 2003).

(iii) Other drivers over 55 years were also recruited because prevalence of dementia increases with age (Deloitte Access Economics, 2011), hence current drivers from this population may face decisions regarding driving retirement at some future time. Their input as potential consumers was also considered important.
In summary, theoretical sampling was used to ensure participants who had experiences relevant to the topic were represented. Current drivers over 55 years representing people who self-identified as having a dementia as well as other drivers who self-identified as having no known cognitive impairment were recruited from a community based setting. A purposive sample was used to generate consumer informed opinion regarding the decisional support needs of people with dementia faced with decisions about the time to retire from driving.

3.2.3 Recruitment

The purpose of this section is to explain the strategies adopted to recruit current drivers over 55 years as a purposive sample from a community based setting to participate in a series of two unstructured interviews. As discussed in the section above, the technique of theoretical sampling was applied to recruit current drivers from NSW with dementia and generate consumer opinion regarding the decisional support needs of drivers with dementia facing the prospect of considering driving retirement. The recruitment strategies implemented will be outlined below.

Three strategies were applied consecutively to recruit participants: (i) public notices; (ii) media release; and (iii) contact with local practitioners.
Public notices: It was initially intended that recruitment and data collection occur over a three month period by way of a public notice disseminated within consumer organisations in NSW who agreed to distribute information to members. The target was to recruit 10 to 15 drivers with dementia to participate in one-to-one interviews, and 25 to 35 other drivers to participate in focus groups. The public notice sought expressions of interest from potential volunteers, outlining eligibility criteria and the purpose of the study. Alzheimer’s Australia, NSW agreed to publish the public notice in the autumn edition of its quarterly magazine ‘In Touch’ (2010). Interested readers were invited to contact the researcher to discuss details of the study and potential for participation. To ensure confidentiality was maintained and people with dementia were not coerced into participation, names and contact details were not accepted from a third party, including family carers, practitioners, or members of the community. Early in the recruitment phase it became apparent that this initial strategy would yield a sample of too few participants, so the proposed time line for recruitment and data collection was extended from three to five months. This enabled the researcher to introduce additional recruitment strategies and complete more interviews within the amended time line.

Media release: The second recruitment strategy implemented was a media release published in a regional newspaper (Illawarra Mercury)
coinciding with the launch of the Alzheimer’s Australia NSW ‘Discussion paper – Driving and dementia’ (2010) which was reported in state and national media. The article in the regional newspaper outlined local issues pertaining to the impact of dementia on driving and the research being undertaken. Readers interested in participating in the study were invited to contact the researcher for further information.

(iii) Contact with local practitioners: The third recruitment strategy was used specifically to increase the representation of drivers with dementia in the sample. Contact was made with local practitioners who agreed to display copies of the public notice and media release within a regional day centre for individuals with dementia and their family carers. Interested attendees were encouraged to contact the researcher for further information.

As each potential participant responded to the public notice and/or media release by contacting the researcher, eligibility screening was completed over the telephone using the following criteria: (i) licensed and currently driving; (ii) aged over 55 years; and (iii) self-identifying as either a person with dementia or with no known cognitive impairment. All eligible participants were provided with a detailed explanation of the research purpose and procedures. Any questions raised by respondents about the study were addressed. Those eligible volunteers who then agreed to participate were provided with the participant information
pack (Figure 7). Review of the information, return of the signed consent form and an appointment to conduct the first interview were then arranged.

Figure 7: Participant Information Pack

To summarise this section, a series of three strategies were applied consecutively to recruit a purposive sample of two types of current drivers over 55 years from a community based setting: those who self-identified as having dementia; and those who self-identified as having no known cognitive impairment. In accordance with the technique and rationale of theoretical sampling, recruitment continued over a five month period, concurrently with data
collection and data analysis, to identify participants who could contribute unique opinion regarding the decisional support needs of drivers with dementia. The next section explains the rationale for the data collection techniques applied as well as the variation to the original data collection plan to accommodate the lower than anticipated number of participants and their restricted availability.

3.3 Data Collection

The data collection strategy for this study consisted of two unstructured interviews with each participant. One-to-one or group interviews were conducted with participants either face-to-face or via telephone depending on geographical proximity to the research facility. Participants chose whether to participate in a face-to-face or telephone interview. No specific inclusion or exclusion criteria were set for the decision about whether participants were recruited to a face-to-face or telephone interview. The rationale for using the unstructured interview technique and an outline of the interview format are provided below.

3.3.1 Conducting unstructured interviews with participants

The unstructured interview technique was selected because it promotes exploratory discussion with participants (Corbin and Strauss, 2008), in this study, about the type of information drivers might consider appropriate for inclusion in
the decisional support tool. It was selected over semi-structured and structured interviews because the topic of dementia and driving retirement is one where the study is exploratory (DePoy and Gitlin, 2011). The conventional means of undertaking unstructured interviews, as described by Endacott (2005), relies on the delivery of pre-determined open questions to enable the participant and researcher to diverge from or pursue an idea in more detail. This interview technique can be applied to both one-to-one interview and group settings and thus provided the flexibility to accommodate preferences of participants as well as facilitate concurrent data collection and analysis as participants were recruited to the study.

To manage issues of consent and protection from potential harm one-to-one interviews were planned with participants recruited as drivers with dementia. It was anticipated that participants in the category of ‘Other drivers aged over 55 years’ would be recruited to participate in focus groups but due to the following reasons one-to-one and small group interviews were undertaken with this group of participants:

a) Fewer than anticipated respondents were recruited consecutively within the available time frame

b) Variation in geographical location of participants

c) Care partner responsibilities

d) Personal preference.
Details of the composition of the interviews conducted are provided in the findings chapter.

3.3.2 The interview format

The researcher employed a pre-planned interview format of provisional prompt questions for both interview 1 and interview 2 to facilitate discussion and further explore participant views in depth (Appendix C: Data collection tools). As described by Corbin and Strauss (2008), the researcher purposely entered a collaborative relationship with the participants to establish rapport and facilitate exploration of concepts rather than remaining detached. Prompt questions were used to facilitate discussion of the topics under investigation, encourage further exploration of concepts arising from the completed interviews, and enquire about respondent opinions in relation to emerging concepts. These questions were designed to promote relevant discussion but not to dictate the course of the interview (Corbin and Strauss, 2008). At the commencement of each interview informal conversation took place to set the participants at ease. In addition, participant consent, rules regarding confidentiality and the right to withdraw from participation were confirmed. The interviews concluded when participants confirmed they had no new information to provide. For practical purposes interviews with interstate participants were conducted via telephone and digitally recorded using a land line with a ‘speaker function’ in a confidential
setting. The specific format designed for interview 1 and interview 2 is outlined below (Figure 8).

<table>
<thead>
<tr>
<th>Interview 1</th>
<th>Investigation of decisional support needs of consumers and potential consumers regarding driving retirement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Gather participant opinion about information drivers with dementia require in order to increase their level of acceptance of the potential need to retire from driving.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interview 2</th>
<th>Critique of decisional support material publicly available</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Gather opinion from participants about five publically available resources to determine useful inclusions for the proposed decisional support tool.</td>
</tr>
</tbody>
</table>

**Figure 8:** Outline of Facilitated Interviews 1 and 2

(i) Interview 1: Data collection

The purpose of interview 1 was to investigate the decisional support needs of consumers and potential consumers regarding driving retirement. The data collection tools implemented to generate data during Interview 1 consisted of the following: a demographic data collection tool; and a series of prompt questions.

*The demographic data collection tool* was designed to generate a participant profile of age and gender, and identify both essential and discretionary travel patterns. Prior to finalisation of the demographic data
collection tool, drafts were tested and simplified to ensure ease of understanding. Only data relevant to the purpose of this study was generated (Appendix C: Data collection tools).

*Interview 1 prompt questions* were designed using recommendations from the ODSF to identify ‘what’ information would benefit consumers (Jacobsen and O’Conner, 2006). The purpose was to facilitate exploratory discussion about decisional conflict issues regarding the time to retire from driving and generate data to inform strategies to address decisional needs. The prompt questions were developed to explore the fundamental issue: ‘What factors would influence your decision to retire from driving if dementia was an issue for you?’

In summary participants provided demographic data and details of driving patterns at the commencement of Interview 1. Facilitated discussion was then conducted to generate consumer opinion of the decisional support needs of people with dementia facing potential decisions about the time to retire from driving (Figure 8). At the conclusion of the first interview a suitable time for the second interview was organised. Participants were provided with a resource pack to review prior to Interview 2 comprising of the five selected driving decisional support resources and a Likert satisfaction scale designed by the researcher to rate consumer opinion of each resource (Figure 5).
Interview 2 provided a consumer critique of five publically available resources with regard to their strengths and limitations for addressing decisional needs and informs key inclusions for a decisional tool (Figure 8). The section below describes the data collection tools and the format applied during Interview 2 to generate consumer opinion and inform potential inclusions for a decisional support tool specifically for Australian drivers with dementia.

The data collection tools for Interview 2 comprised of Interview 2 prompt questions and a Likert satisfaction scale (Appendix C: Data collection tools).

*Interview 2 prompt questions* were designed using recommendations from ‘Population Needs Assessment: A Workbook for assessing patients’ and practitioners’ decision making needs’ (Jacobsen and O’Conner, 2006). Attributes and deficits of the existing resources were identified. The authors recommended critiquing existing resources as per the needs assessment framework and to use the data to inform decisional support strategies that can be developed to address any gaps in the available material. To critique the content and design of the resources supplied to the participants, Interview 2 addressed the question: ‘Do you think you would be better prepared
to make decisions about driving retirement after reading the kind of educational material we have reviewed in this study?.

The Likert satisfaction scale was designed using the Likert approach (Trochim, 2006) to: (i) rate the five resource materials; and (ii) provide a starting point for the critical review of each of the resources during Interview 2 discussions. Prior to the interview participants were asked to rate each resource on an ordinal satisfaction scale of 1 to 5 (least to most satisfactory).

Further exploration of emergent themes identified from early data analysis also occurred during Interview 2. At the conclusion of the interview participants were thanked for their time and contribution. Those who wished to were encouraged to keep their copies of the resources. The timeline for completion of the study and method for obtaining information regarding results were also provided to participants.

In summary, specific data collection strategies were adopted to generate consumer opinion on a topic where there is a paucity of evidence as to the decisional needs of drivers with dementia facing decisions about the time to retire from driving. A series of two unstructured interviews were undertaken with participants via one-to-one or small group interviews to allow concurrent
data analysis and facilitate further exploration of emerging themes and concepts.
The data collection tools were designed to both identify the decisional needs of
drivers with dementia and critique existing tools, thus generating opinion from
consumers regarding decisional support needs of Australian drivers with
dementia facing retirement. The method of recording and analysing the data
generated is discussed in the next section of this chapter.

3.4 Data Analysis

In this study all data were subjected to the technique of thematic analysis using an
adapted grounded theory approach to identify emerging concepts and construct early
patterns of meaning (Endacott, 2005, Corbin and Strauss, 2008, DePoy and Gitlin,
2011). Data analysis commenced immediately following the completion of the first
interview. This technique is used by qualitative researchers to facilitate enquiry into
concepts identified, enabling the researcher to ‘follow up, validate and develop
concepts’ with respondents ‘whilst immersed in the data’ (Corbin and Strauss, 2008,
Silverman, 2011). Themes generated during the early stages were reviewed during
later interviews to refine and revise the thematic structure. Toward the later stages of
the analysis one core category emerged from theoretical integration of the identified
themes (Corbin and Strauss, 2008). This core category and its related themes were
used to structure the presentation of the findings.
As each interview was completed, the digitally-recorded data were transcribed verbatim into a Word document and reviewed against transcripts for accuracy. The transcripts were printed and hand sorted to commence the coding process. Data were analysed line by line and organised into categories. As categories and concepts began to emerge, each Word document was uploaded to ‘NVivo9’ (QSR International Pty Ltd, 2009) to manage thematic analysis of the data. Initially data from Interviews 1 and 2 were coded, categorised and analysed as separate sets of data. Later the data sets were combined and further analysis was undertaken to identify and extract concepts common to both sets of data. The coded data were then compared and interpreted to conceptually order ‘patterns of meaning’ and emergent themes (Corbin and Strauss, 2008). The concepts were grouped into themes and subthemes were identified.

3.5 Summary

The research design adopted in this study was based on stage 1 the ODSF and the theory of decisional conflict. The design sought to apply an evidence-based, practical framework and actively involve consumers in research to identify appropriate elements of a decisional support tool for drivers with dementia who may be faced with making decisions regarding the time to retire from driving. Stage 1 in the development of an ODSF decisional support tool makes an important contribution to ensuring the content of a decisional support tool for
driving and dementia is generated from the information needs of consumers. Future research to develop the tool will rely on the findings from this study.

Ethical considerations relevant to all participants in this study, including those who were considered vulnerable, were addressed in the ethics proposal approved by the HREC, University of Wollongong. Once approval was gained, data collection commenced with participants via a series of two unstructured interviews. Data analysis occurred concurrently during Interview 1 data collection and continued beyond Interview 2 data collection. The data were managed using ‘NVivo9’ (QSR International Pty Ltd, 2009) to assemble coded and categorised participant responses. Thematic analysis was applied to the data to generate themes to inform the content of a decision tool specific to the decisional needs of drivers with dementia. The findings generated from thematic analysis of the data are discussed in detail in the following chapter.
The purpose of this chapter is to report the findings of this study on driving and dementia. The study consisted of a series of interviews with consumers undertaken over five months. Demographic and qualitative data were generated from a purposive sample of 15 current drivers over 55 years, including two people who self-identified as having a dementia and 13 people who self-identified as having no known cognitive impairment. Recruitment activities actively sought the participation of drivers over 55 years who self-identified as having a dementia. These activities yielded only a small sub-set of participants (n=2) who self-identified as having a dementia and the larger group of participants (n=13) who self-identified as having no known cognitive impairment.

As participants were recruited, concurrent data collection and thematic analysis commenced. Face-to-face interviews were undertaken with the participants residing in NSW whilst those living interstate participated in telephone interviews. All interviews were digitally recorded, transcribed verbatim into Word documents, hand sorted, coded and uploaded to ‘NVivo9’ (QSR International Pty Ltd, 2009) for further analysis. The data were then categorised to identify patterns of meaning or themes. In this chapter an overview of the participant profile is described and details of each of the following key themes generated are provided:
(i) Whose opinion will I accept as trustworthy;
(ii) On-road experiences are the most convincing;
(iii) Let’s discuss this before my judgement is compromised;
(iv) Would knowing my alternatives influence my decision; and
(v) Informative resources that include self-monitoring tools are useful.

4.1 Demographic Profile of Participants

A total of 15 participants completed the first interview and 14 completed the second interview (Table 2). Demographic details were obtained from all 15 drivers aged 55 and over, including two male drivers with dementia who participated in this study. Male and female drivers were almost equally represented in the sample (Figure 9). Of the 15 volunteer drivers, seven males and eight females completed Interview 1; and six males and eight females completed Interview 2. One male participant elected to participate in Interview 1 only and withdrew from the study prior to Interview 2. One male participant completed a one-to-one interview for Interview 1 and elected to join a group for Interview 2.
Table 2: Participant Interview Format by Data Collection Method and Gender

| Profile of Participant Interviews | Interview 1 | | | Interview 2 | |
|---|---|---|---|---|
| | Male | Female | Total | Male | Female | Total |
| One-to-one | 5 | 1 | 6 | 3 | 1 | 4 |
| Telephone | 1 | 1 | 2 | 1 | 1 | 2 |
| Small groups | 1 | 6 | 7 | 2 | 6 | 8 |
| Total | 7 | 8 | 15 | 6 | 8 | 14 |

All participants were licensed to drive a car and of these, two females and two males were also licensed to ride a motorcycle. One male was licensed to drive a truck in addition to a car and motorcycle. Initially it was envisaged that the participant sample would be drawn from a population of drivers residing in urban and regional communities in New South Wales. However, the distribution of the community based magazine published by Alzheimer’s Australia NSW (In Touch) included interstate readers who expressed interest in the study. The sample of 15 participants consisted of: 11 drivers from the Illawarra; two drivers from the south coast region of NSW; and two drivers residing interstate.
Essential and discretionary driving patterns were reviewed in terms of the purpose and choices drivers made about driving to undertake their routine daily activities (Table 3). For example, daily driving was undertaken by 14 participants, including one driver with dementia, whilst one driver with dementia drove three to four times per week. Those who maintained employment used their car to travel to and from work. A total of 12 participants reported driving the car for holidays. However, where travel involved complex or long distance driving, self-restricted limitations and alternatives such as public transport were preferred. All participants used their car for grocery shopping.
### Table 3: Driving Patterns of Participants by Driving Activity

<table>
<thead>
<tr>
<th>DRIVER Code</th>
<th>Purpose for Driving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code</td>
<td>Groceries</td>
</tr>
<tr>
<td>1*</td>
<td>✓</td>
</tr>
<tr>
<td>2*</td>
<td>✓</td>
</tr>
<tr>
<td>3</td>
<td>✓</td>
</tr>
<tr>
<td>4</td>
<td>✓</td>
</tr>
<tr>
<td>5</td>
<td>✓</td>
</tr>
<tr>
<td>6</td>
<td>✓</td>
</tr>
<tr>
<td>7</td>
<td>✓</td>
</tr>
<tr>
<td>8</td>
<td>✓</td>
</tr>
<tr>
<td>9</td>
<td>✓</td>
</tr>
<tr>
<td>10</td>
<td>✓</td>
</tr>
<tr>
<td>11</td>
<td>✓</td>
</tr>
<tr>
<td>12</td>
<td>✓</td>
</tr>
<tr>
<td>13</td>
<td>✓</td>
</tr>
<tr>
<td>14</td>
<td>✓</td>
</tr>
<tr>
<td>15</td>
<td>✓</td>
</tr>
</tbody>
</table>

* denotes those current drivers who self-identify as having dementia.

The overview of the demographic data provided a profile of gender, age and driving patterns of those participants who volunteered for this study. Although the sample size was limited to 15 participants, a wide age range and a diversity of driving patterns was represented.
4.2 Mapping a Road to Driving Retirement

The purpose of this section is to present the themes generated from 20 unstructured interviews with 15 participants over 55 years, comprising two drivers with dementia and 13 drivers with no known cognitive impairment. Qualitative data from Interview 1 and Interview 2 were coded separately, and thematic analysis was undertaken to identify patterns of meaning. Five major themes were generated from analysis of participant data. Further analysis generated sets of subthemes which provided in-depth understanding about the significance of each theme (Figure 10). Responses also revealed the types of evidence considered meaningful to consumers and potential consumers, including ability to self-assess one’s fitness to drive. The characteristics of credible informants who would be trusted to provide reliable evidence regarding changes in safe driving behaviour were identified. These findings will be used to explain the views of consumers about dementia and decisions about the time to retire from driving.
4.2.1 Theme 1: Whose opinion will I accept as trustworthy

This theme explains whose opinion participants would accept as trustworthy if faced with making decisions about the time to retire from driving due to a dementia. Those informants the driver would consider trusted and the importance of the driver/informant relationship were identified. Participants acknowledged they would rely on feedback from those people who knew them and their situation, and who were in a position to observe changes in situational judgement in relation to driving and as well as other matters. The characteristics of key informants, including family carers, doctors and other practitioners whose views would be considered trustworthy, are discussed below (Figure 11).
It was clear from the findings that the quality of the driver/informant relationship was more important than the designated role of the informant. A person who would be considered a reliable source of feedback was defined as someone for whom the driver had respect, who knew the driver well, and had an appreciation of the negative impact driving retirement would have on the driver. Feedback from family members or practitioners whose opinion was trusted by the participant would be valued in contrast to an opinion provided by a doctor who was not respected or a one-off assessment with an unfamiliar assessor. The following extract exemplifies these findings:

*I do rely, and would rely on information from my wife ... as well as my doctor [who is] very intimately involved with my case ... to say, “You no longer have the ability to make*
the determination of when you should or should not drive and therefore you shouldn’t drive any more”. I think the key is that it needs to be somebody that knows me well and somebody that I respect.

(Int1, P001, p. 2)

The ‘trustworthiness’ of the care partner/family, doctor or other practitioners as sources of informant opinion regarding changes in driving safety are explored in more detail below:

(i) Care partner/family: Participants advised that the relationship between the person with dementia and members of their family impacts the driver’s ‘believability’ of feedback given about ability to drive safely. The driver would trust a respected family member, such as a spouse or care partner, because they would understand how important driving is. They would also have the opportunity to provide honest feedback and observe ‘changes’ in driving performance over time. Whilst the advice of adult children may be respected by some participants, others believed this source would not be considered reliable as ‘families get a bit emotionally involved’ (Int2, P012, p. 9). This could impact on the informant’s objectivity and thus their ability to be trusted to provide credible feedback. One participant explained that they would not readily accept feedback from a person their own age or a sibling therefore any feedback from these sources would be taken as criticism. There was consensus among participants
that when embarking on any conversation regarding fitness to drive initiated by the family ‘be prepared for the storm’ (Int2, P007, p.9) and therefore such discussion should be facilitated by a professional. As exemplified in the following extract, this becomes important when looking at roles and making assumptions that the driver with dementia would take notice of family or care partner feedback.

The relationship between the person who’s trying to convince the person is a very important factor in whether that person’s going to decide to forego their licence or not. And I guess that gets down to trust ... that’s the key word.

(Int2, P13, p. 12)

(ii) The Doctor: The majority of participants identified the respected doctor who has been involved in the journey of the person with dementia as a trusted informant. The doctor was considered the first point of contact for a driver concerned about impaired memory or driving safety. The majority of participants determined that it was the doctor’s duty of care to monitor, discuss and determine their ‘patient’s’ ability to drive safely, based on their knowledge of the disease process; their qualifications; and their status as a doctor. Participants reported that whilst they may not take the advice of family members seriously, they would pay attention to the treating doctor’s opinion, including
recommendations regarding the need for further investigation. Some participants even considered that fitness to drive informed by a pen and paper test undertaken in a doctor’s clinic rather than a practical driving environment would be acceptable if the driver considered the doctor conducting the assessment to be a trusted informant and appropriately qualified. This is exemplified in the following extract:

*I’d ask the doctors. I believe in the doctors. The doctors, I think, should know. I think it’s better for the doctors to ... come out and tell you that it’s time.*

(Int1, P009, p. 7)

(iii) *Other practitioners:* It was clear from the analysis that the quality of the relationship between the driver and the practitioner was a determining factor in accepting recommendations from this source. A practitioner assisting a driver with dementia to make decisions about retirement would either need to be considered trustworthy and in a position to know the driver’s capabilities or alternatively involve the opinions of the driver’s ‘trusted’ informants. The opinion of a practitioner who knew the individual well, had developed rapport, and had displayed sensitivity to the importance of driving for the individual would be credible. In contrast, a ‘one-off’ driving assessment by an unknown occupational therapist or the licensing authority did not provide this level of trust. For example:
[F]rom time to time I see a ... counselling psychologist ...

[who is] very intimately involved with my case and I would certainly rely a lot on what they believed, given my situation....

(Int1, P001, p. 1)

The theme ‘whose opinion will I accept as trustworthy’ explored the importance of trustworthiness as the primary quality of the driver/informer relationship when addressing issues about fitness to drive and the time for driving retirement. Involving those people whom the driver considers ‘trusted’ and in a position to know their capabilities was identified as essential for decision making. Participants suggested that those practitioners whose role involves supporting people with dementia and their care partners need to learn how to initiate discussion regarding the potential impact dementia may have on future driving safety by fostering trust and acknowledging the importance of driving to the individual.

4.2.2 Theme 2: Real on-road experiences are most convincing

The second theme generated from data analysis indicated that a driver would be more readily influenced about driving retirement when the driver’s opinions are included in decisions and such decisions are derived from evidence obtained
from real on-road experiences (Figure 12). In contrast, clinic based assessments or one-off driving tests can be unconvincing. Participant opinion about the value of self-assessment, real on-road experiences, feedback from trusted sources, and the usefulness of formal assessment to monitor changes in driving safety are discussed below.

**Figure 12: Theme 2 - Real On-Road Experiences Are Most Convincing**

Participants indicated that a driver is more likely to accept recommendations about driving retirement when gradual limit-setting of driving tasks has already occurred. This can involve avoiding night driving, ceasing to drive to appointments in a major capital city, or foregoing interstate travel. Drivers reported that they would continue to base their opinion of current driving abilities on their self-assessment of those behaviours they considered critical indicators of safe driving. As exemplified in the extracts below, participants believed they would be able to identify generalised and more specific warning
signs or clues indicative of changes in their own driving safety, including lack of confidence in traffic, memory problems, and loss of ability to predict traffic situations.

... if I was too hesitant and couldn’t make decisions about where to merge with traffic or such like ... if I didn’t feel confident, I would stop driving.

(Int1, P009 p. 1)

and

I think the clues might be when you’re driving in the garage and maybe you hit the door or you hit the front of the garage or you run over the flower pot or you get in the car park and maybe lose the car.

(Int1, P004, p. 5)

Whilst participants were able to clearly identify a range of warning signs they would use to gauge their own ability to drive safely, it was also acknowledged that gradual onset of symptoms associated with a dementia could compromise one’s capacity to accurately monitor such changes. Hence participants indicated they might need to rely on feedback from others at some point. The importance of feedback obtained from trusted sources that addressed warning signs from observation of real on-road performance is exemplified in the following extracts.
If I had input from other people that were in the car with me that were very concerned about my driving skills. I would probably feel that I’d need to really probably think about it seriously.

(Int1, P012, p. 3)

and

Say to your son, “I want to drive around this route because I’m going for this driving test”, and I think my son would be saying, “Mum, you know, maybe don’t bother”, or, “Yeah, you’re all right”, “Mum, you can do this.” …

And … I don’t think [my son and daughter] would let me go if they thought I was going to fail because they would know I’d fail on the day.

(Int1, P004, p. 8)

The findings clearly indicated that the relationship between the driver and the observer is an important factor in determining whether or not the driver will be convinced to ‘forego’ their licence. However, there was consensus that ‘fronting up’ to the licensing authority venue for a test or undertaking an on-road assessment with an occupational therapist is a stressful experience, potentially impacting on a driver’s performance. Those interviewed considered that the brevity of the test does not provide a realistic review of actual driving
capabilities, given that dementia symptoms manifest as having ‘good days’ and ‘bad days’. Participants agreed that whilst they would be obliged to legally accept the outcome of the licensing authority’s opinion, they would not trust these findings for several reasons. For example, participants believed that the age test and the disability test are not standardised, thus a driver could attend one location for a test and fail, and then go to another location and pass. These on-road experiences would not provide convincing evidence that the driver’s safety was so compromised as to warrant licence cancellation.

_It would not be a situation where I was given a paper and pencil test or even a one-time assessment because my ability to drive varies day by day; and so, if I took that test and it happened to be a bad day for me, well, that’s a day I wouldn’t have been driving anyway, and other days I know I can._

(Int1, P001, p. 2)

and

...'I would much more rely on professionals who know me and know my situation well, rather than any test administered at any single point of time.'

(Int1, P001, p. 3)
The majority of participants indicated that whilst they may need to accept the decision of a formal assessment, they would not consider the source trustworthy. The few participants who did say they would accept the decision acknowledged they would trust the opinion of the licensing authority for two reasons: because they must; and because assessors should be qualified to determine dementia or age related driver safety. However, they were concerned that the assessor may not have the ability to distinguish between one-off errors caused by anxiety as opposed to unsafe behaviours related to symptoms of dementia. Consequently participants identified strategies for enhancing acceptance of a negative outcome from a formal assessment. These included opportunity to prepare for the assessment; receive feedback from the assessor; and have the option of re-assessment.

*I’d believe the RTA [Roads and Traffic Authority NSW], like driving assessors, I would believe them because they’re the ones that give you your license to start with. So I guess, yeah, I would believe them. But I don’t know, it’s really hard because I think until someone else assesses then you’re not really going to know yourself.*

(Int2, P012, p. 19)

This theme identified that the need to retire from driving may be more convincing where people with dementia are provided with tools to monitor
changes that may impact on their own driving safety over time and seek feedback from people they trust. Participants considered that the honest feedback from a trusted passenger or observer who is regularly in a position to comment on changes in driving performance may have greater impact on a person’s level of acceptance compared to formal assessments. These assessments can be considered subjective in that they are carried out at one point in time, within an unfamiliar, test oriented context. Any considerations given by the assessor for day-to-day variability or the impact of anxiety on performance are not made explicit to the driver. Early identification of deterioration in driving abilities and acceptance of the need to consider driving retirement could therefore be facilitated by providing risk identification tools to be used by driver and those whom the driver trusts.

4.2.3 Theme 3: Let’s discuss this before my judgement is compromised

The theme ‘Let’s discuss this before my judgement is compromised’ explores participant opinion regarding strategies to empower driver participation in decisional choices about the time to retire. Whilst participants indicated that they would stop driving if they noticed important clues or signs that were evident of changes in driving safety, concerns were raised about a driver with dementia’s ability to self-monitor these changes if judgement became compromised due to disease progression. The need to discuss issues around future loss of driving skills
with trusted sources and plan for when ability to self-determine the time to retire from driving may be compromised is discussed. The strategies reported by participants, including promoting awareness, initiating discussion and seeking feedback about actual driving performance are also discussed (Figure 13).

Figure 13: Theme 3 - Let's Discuss This Before My Judgement Is Compromised

Findings revealed consensus in opinion that the timeliness for conversations regarding fitness to drive is important, ideally occurring as early as possible after diagnosis with those informants the driver identifies as trustworthy. It was clear from analysis that facilitating early discussion between the person with dementia and their trusted sources enables the driver to participate in decisions about their driving retirement while they have the capacity to do so. Participants highlighted three key issues related to being prepared for the time when judgement becomes compromised: loss of fitness to drive; loss of ability to judge one’s own safety; and acknowledgement that judgement may be lost as the
disease progresses. Participants wanted to be advised when judgement was deteriorating to the point where it impacted on driving safety and ability to self-monitor, even though they acknowledged this news would be unpleasant. Participants with and without dementia raised the concern that whilst they currently believed they were able to judge their fitness to drive, this may change in the future. Therefore initiating discussion in the early phases of the disease regarding the timing of driving retirement, safety and implications for engaging in activities of daily living was preferred.

Where I sit now..... I would be quite happy to say to all of my family, “If you see the signs that we saw in Nan or Mum, then I would want you to say to me, 'You’re not safe to drive’.”... It might not make it any easier. It might not make me any less angry when the time comes if I’m in that state of mind, but at least it’s something that’s been discussed and talked about.’

(Int1, P005, p. 4)

The importance of promoting a gradual transition from driving to driving retirement was raised by all participants. The majority believed this could be achieved by encouraging people with dementia to modify driving patterns and gradually self-limit more complex driving activities over time, in line with changes in functional capabilities. Drivers reported basing their current decisions about...
whether to drive or seek alternatives on how comfortable they felt with the level of driving complexity in each situation, and they intended to use this strategy to inform future decisions. However, whether someone could honestly say ‘I am not driving as well as I used to’ was frequently discussed during the interviews and participants differed in opinion. Some participants, including the two drivers with dementia agreed that if involved in the decision making they would be able to judge that they were less capable and honestly admit they were. Those participants who believed a driver with dementia would not acknowledge a problem with their own driving safety derived this belief from either their personal experience of observing progressive symptoms of memory loss in a relative or acquaintance with dementia or from their general understanding of dementia and its symptoms. Regardless of the difference in opinion regarding the ability to recognise the need to limit or retire from driving, there was consensus that the timing of conversations is important, ideally occurring as early as possible after diagnosis and including feedback about actual driving performance.

*So unless someone intervenes, that to me is the crux of the matter. I think it’s observation by other people ... I’d like to think I knew I was losing it, but having seen dementia and Alzheimer’s I know that it doesn’t really work that way.... You think you’re 100 per cent and you’re not.*

(Int1, P004, p. 4)
This theme explored the importance of early discussion between drivers and their trusted informants to prepare for issues regarding the potential need to retire from driving while capacity to be involved in the decision making process is still present. There is potential for decisional conflict with regard to the driver’s perception of safety and other conflicting priorities influencing driving retirement decisions. Participants identified strategies that provided the driver with opportunities to both discuss the need to consider driving retirement with trusted sources early in the disease process and be involved in gradually self-limiting complex driving tasks before judgement is compromised.

4.2.4 Theme 4: Would knowing my alternatives influence my decision to retire from driving?

The purpose of this section is to report on the theme ‘Would knowing my alternatives influence my decision to retire from driving?’ Participants clearly identified that knowing about alternatives for maintaining independence and lifestyle choices would influence their decision to retire from driving. However, they acknowledged other factors that influence a driver’s level of acceptance including the importance of driving to the individual and the implicit barriers to accessing alternatives. The relationship between the perceived significance of the loss of ability to drive safely and the willingness to consider alternatives reported by participants are described below (Figure 14).
Figure 14: Theme 4 - Would Knowing My Alternatives Influence My Decision To Retire From Driving

Whilst drivers expressed a variety of reasons as to why they would prefer to continue driving, there was consensus among participants that driving played a key role in maintaining current lifestyle choices. The personal circumstances of the driver can impact on their willingness to accept alternatives to driving. Participants acknowledged that if they had someone else in the family who could drive them where they needed to go, their decision to retire from driving may be slightly easier. Furthermore, it was reported that if the person with dementia is the only driver or they are the carer for another person who doesn’t drive, then the ramifications for ceasing are far-reaching. This population of drivers would have ‘more to lose’ by relinquishing their licence. These issues are exemplified in the following extract:
[O]ne of the guys [in the support group] just gave up his ability to drive and he did so, based largely on his wife and his daughter who both live around here. And he did it, accepting it, but he sure hates it, that’s all I can say, you know, it’s been a big loss for him. One of the other guys who drives [is] starting to make plans as to when he won’t be able to drive. His situation’s different than mine because his wife can’t drive, my wife can. And so for me, it would be [more] of a psychological loss than a real loss of ability to go places.

(Int1, P001, p. 2)

It was clear from the analysis that the availability of perceived alternatives can impact on a driver’s decision about readiness to retire from driving. Participants considered drivers with access to public transport would be less disadvantaged compared to those who live in more isolated communities. However, drivers facing decisions about driving retirement needed to acknowledge on a deeper level ‘why driving is important’ and what the loss of driving will represent. The majority of participants agreed that the loss of licence would represent a great loss of freedom. Consequently participants acknowledged that when thinking rationally, it made sense to cease driving and adopt the alternatives; however, when the time comes, it may not be easy to give up on an emotional level.
It’d be a very hard thing. I was just over 17 when I got my licence, so I’ve been driving for a long bloody time; and I don’t mind driving, you know…. so to have to give it away it would be a very hard thing, and I think, if it did come, I’d be trying [my] hardest to get out of having to do it or having to put it in..... they would have to turn around almost and take it off me.’

(Int1, P010, p. 2)

Participants also acknowledged that beyond practical discussion to address the physical barriers associated with a loss of the ‘independence’ that driving afforded, an exploration of the psychological and emotional barriers was also required. Some participants reported that they had always loved to drive anywhere, any distance, whilst others preferred to avoid driving in situations that could be stressful. Those drivers who reported that they ‘loved to drive’ reported that they were never ‘fazed’ by complex traffic situations and any modification to their driving behaviours had occurred only to appease family concerns for safety. In contrast, those drivers who reported reluctance to drive had developed strategies that they intended to use in the future by self-limiting exposure to stressful driving situations. These included travelling on public transport, combining local driving with train travel, making lifestyle choices around geographical access to alternative transport.
But, really, the alternatives for driving are an influence but not the prime influence. The loss of the independent mobility of driving then triggers [the question of] what are you going to do if you haven’t got that independence.

(Int2, P013, p. 4)

and

Then you’d probably think, “If I stop driving, then that’s a lot of your freedom gone”. You’ve got to try and get a bus or the train. I don’t travel well on either, and I get travel sickness if someone else is driving. I’m pretty good on trains but there’s not always a train available; and buses, they really knock me around, so hopefully I would stop driving and get some help from somewhere, but there’d be a temptation not to, I know that, but hopefully I would.

(Int1, P015, p. 1)

The theme ‘Would knowing my alternatives influence my decision to retire from driving?’ discussed the potential to positively influence decisions about retirement by employing alternate strategies to maintain engagement in activities of daily living. The findings indicated that having the alternatives in place may address some of the physical barriers that concern drivers. However, the emotional and psychological issues of loss that accompany the need to
identify alternatives remained an issue for those drivers who loved to drive and enjoyed the freedom that driving offered.

4.2.5 Theme 5: Informative resources that include self-monitoring tools are useful

The purpose of this section is to report on the theme, ‘Informative resources that include self-monitoring tools are useful’. Participants clearly identified useful resources for self-monitoring driving behaviours and enhancing acceptance of the need to retire from driving. In addition, resources had the capacity to facilitate the difficult conversation between the driver with dementia and their trusted informant, for example, in regard to planning for and implementing driving retirement strategies. Participant opinion regarding key features and delivery style of suitable resources are discussed below, along with the strengths and limitations of existing resources and suggestions for aligning resource content to the needs of Australian drivers with dementia (Figure 15).

When asked to critique the resources presented for review, participants agreed that the key features were those that promoted self-monitoring of driving behaviours, as these raised awareness of the changes to which drivers needed to pay attention, and re-affirmed current competencies. Information that was sensitive, relevant and concise was important for understanding implications of driving safety and the potential need to consider driving retirement. General
Figure 15: **Theme 5 - Informative Resources That Include Self-monitoring Tools Are Useful**

Comments made about the style of the material indicated that checklists were more useful than information in narrative form only, and a resource that includes a combination of both narrative and checklist formats was preferred. It was suggested that the checklists could be completed independently by the driver, followed by discussion and review of the results with a trusted informant. The information, including the checklists, validated the participants’ opinion about their own driving, that is, that they were still currently safe to drive. Participants intended to re-visit the information at intervals in the future to self-assess for any deterioration in driving safety.
With the Driving Decision Workbook ... I thought that was excellent and I actually learnt things about myself; and it’s something that you would do again, maybe in 2 years or something, and just see if your answers were the same.

(Int2, P007, p. 1)

and

About Your Driving, maybe that was a good one because that’s got information in it, and if you read that, well then you might pursue it further. “When driving do you need directions? Do you drive on the wrong side of the road? Do you violate the traffic laws?”

(Int2, P004 p3)

It was clear that there were two distinct areas where participant opinion contrasted: length and level of complexity appropriate for a decisional support tool. The opportunity to review a range of resource formats was considered valuable as readers would find a medium that resonated well with them. Some participants expressed preference for lengthy documents that provided checklists, feedback, comprehensive explanations and reasoning. In contrast, others believed that the shorter resources were more suitable. ‘At the Crossroads’ (Hartford Financial Group and MIT AgeLab, 2007) was a 28 page colour brochure designed for facilitating discussion between people diagnosed with dementia and their families. It was considered ‘very useful’ by some
participants whilst others considered it to be too complex and too detailed for a person with dementia. One common perception expressed by drivers over 55 years with no known cognitive impairment was that a driver with dementia could not maintain concentration long enough to read such a comprehensive document. This opinion is exemplified in the quotes below. The two drivers with dementia did not agree with this perception, indicating that a resource needed to be empathic, sensitive and comprehensive, providing insight into the potential impact of dementia on the capacity to drive in a manner that addresses the psychological impact of loss of the ability to drive safely.

Yeah. Well, because in dot form, people who were developing dementia might be able to relate to it [Driving Safely While Aging Gracefully] a lot easier than the “At the Crossroads” one which was more verbose.

(Int2, P005, p. 1)

The same participant on another occasion expanded on this.

A lot of the information is the same and certainly for a younger person or a more able person, the “Driving Decisions Workbook” would be the best, but for someone that’s perhaps older, perhaps [with] a bit of confusion this [About You: Driving Help Sheet] would have to be better
because you’re not confronting them with a lot of words
and the information really that comes out of it would be
arriving at the same conclusion.

(Int2, P005, p. 1)

and

So I think it’s not just one thing, its multiple things and
multiple things at different stages and for different types
of people that you might be dealing with. So it might have
a core element but there might be different parts of it.

(Int2, P005, p. 13)

Participants also identified potential limitations for accessing resources designed for people with dementia. For example, those resources that were dementia specific reflected a style that could not be easily applied to care partner discussions about driving safety with those drivers who had not been given a diagnosis of dementia. The reference to ‘dementia’ within the resource material would hamper discussion with family or care partners due to the stigma associated with the wording in the information. Those resources that did not address dementia specifically could be used. These comments helped identify the need for separate formats to cater for both the driver with a diagnosed dementia seeking monitoring tools; and the driver identified as having unsafe behaviours as an indicator of potential dementia diagnosis.
But I think we might need two pamphlets. There’s nothing wrong with this if you’ve been diagnosed because the person’s been told and it’s not news to them, but you’re not going to get anyone to read this, I think, if like, they’ll put it in their bag and go, “[this is] for people with dementia. I haven’t got dementia”.

(Int2, P004, p. 22)

Another important opinion raised by participants provided insight into the potential use of the currently available consumer information with the Australian audience. For example, the information was considered useful because:

(i) a description of what can happen to driving skills from the early stages of dementia is provided;
(ii) safe and unsafe behaviours are defined;
(iii) where the driver is on the continuum of driving changes can be identified; and
(iv) advice for improving driver safety is provided.

The information can be used as a tool to facilitate informed discussion between the driver and their trusted sources. However, tailoring a resource to the specific needs of Australian drivers facing decisions about timing for retirement due to a dementia was recommended. For example, participants raised concerns about references to driving on the right hand side of the road and the lack of reference
to roundabouts, an increasingly important feature in the Australian driving context.

_The only confusion ... [for me was] where they talked about turning left and it should have been right, and I thought, oh yes, OK, we’re talking America here.... And there wasn’t much in here about roundabouts and I think roundabouts are the one thing that really confuse the elderly because they can confuse me._

(Int2, P007, p. 2)

This theme explored the value of drawing upon publically available resources to facilitate consumer involvement in decision making about the time to retire from driving for those drivers diagnosed with dementia. Those resources that address the complexity of the driving task and the impact of changes in health upon driving safety allow the driver to be involved in making decisions whilst they have the capacity to do so. There was consensus of opinion that having access to this type of information would be useful for enhancing the acceptance of the need to consider driving retirement. Resources facilitated self-monitoring of one’s own capacity to drive and supported those difficult conversations between the driver and those concerned about their on-going fitness to drive. There were variations in preferences for length, complexity and format of resources. There was,
however, consensus recommending the combination of checklists with exemplary narratives and modifying resources to suit the Australian setting.

4.3 Summary

The purpose of this section was to report on the five main themes that emerged from the analysis of qualitative data generated from a series of interviews with consumers:

(i) Whose opinion will I accept as trustworthy;
(ii) On-road experiences are the most convincing;
(iii) Let’s discuss this before my judgement is compromised;
(iv) Would knowing my alternatives influence my decision; and
(v) Informative resources that include self-monitoring tools are useful.

The findings generated useful information regarding trusted sources of feedback, evidence that would be considered credible and the key features of a resource tool that would be effective in enhancing the decision about when to retire from driving. One overarching concept from themes identified in the findings was the emergence of a potential driving retirement decisional pathway to support the decisional needs of drivers with dementia and their care partners.

This chapter reported on the findings generated from a series of unstructured interviews with 15 current drivers, including two people with dementia and 13
people with no known cognitive impairment. An overview of the demographic profile was provided, including age, gender and driving patterns of participants. The qualitative data generated from the participant interviews were coded and categorised and uploaded to ‘NVivo9’ (QSR International Pty Ltd, 2009) for further analysis. This analytic technique enabled the identification of key themes and subthemes from consumer informed opinion as to the most effective means of enhancing driving retirement decision making for the person diagnosed with dementia. The findings will inform discussion regarding the implications for enhancing consumer care via clinical practice which will be undertaken in the next chapter (Chapter 5). The emergence of a prospective ‘driving retirement decisional pathway’ will be explored.


5 DISCUSSION

5.1 Introduction

The purpose of this chapter is to position the findings with what we already know from current evidence and clinical practice; what adds to the existing body of literature; and what will be useful in the future. The literature review highlighted the complexity of driving and the challenges of determining fitness to drive for those with dementia, concluding that the most effective means for supporting drivers facing decisions about the time to retire from driving were not yet clear (Hogan et al., 2008, Adler, 2010). The finding’s chapter explored the five key themes generated from the analyses: (i) whose opinion will I accept as trustworthy; (ii) real on-road experiences are most convincing; (iii) let’s discuss this before my judgement is compromised; (iv) would knowing my alternatives influence my decision; and (v) informative resources that include self-monitoring tools are useful. In this chapter implications of these findings are explored. The potential to augment the current driving retirement process for drivers with dementia is discussed, specifically comparing the findings of this study with evidence from the literature, decisional conflict theory and cognitive self-efficacy theory (Table 4). The strengths and limitations of the study are also presented in this chapter, followed by the implications for practice and recommendations for future research.
### Table 4: Themes Matrix

<table>
<thead>
<tr>
<th>Themes from the literature</th>
<th>Themes from the finding</th>
<th>Theoretical Framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>Driving is a complex task</td>
<td>Onset and severity of dementia are difficult to define</td>
<td>Decisional conflict</td>
</tr>
<tr>
<td>Dementia is progressive and impacts on driving skills</td>
<td>Assessment of fitness to drive remains subjective</td>
<td>Cognitive self-efficacy</td>
</tr>
<tr>
<td>Some drivers with dementia are reluctant to accept negative assessment outcomes</td>
<td>The search continues for the most effective means of preparing drivers with dementia for accepting driver retirement</td>
<td>Mastery</td>
</tr>
<tr>
<td>On-road experiences are the most convincing</td>
<td>Let's discuss this before my judgement is compromised</td>
<td>Social Persuasion</td>
</tr>
<tr>
<td>Would knowing my alternatives influence my decision</td>
<td>Informative resources that include self-monitoring tools are useful</td>
<td>✓</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Themes from the literature</th>
<th>Themes from the finding</th>
<th>Theoretical Framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whose opinion will I accept as trustworthy</td>
<td>✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓</td>
<td></td>
</tr>
<tr>
<td>On-road experiences are the most convincing</td>
<td>✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓</td>
<td></td>
</tr>
<tr>
<td>Let's discuss this before my judgement is compromised</td>
<td>✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓</td>
<td></td>
</tr>
<tr>
<td>Would knowing my alternatives influence my decision</td>
<td>✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓</td>
<td></td>
</tr>
<tr>
<td>Informative resources that include self-monitoring tools are useful</td>
<td>✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓ ✓</td>
<td></td>
</tr>
</tbody>
</table>
5.2 Theoretical Framework

Decisional conflict theory (Janis and Mann, 1977) and the ‘Ottawa Decision Support Framework’ (ODSF) (O’Conner and Jacobsen, 2007) informed the methodology of this study into the decisional support needs of the Australian population of drivers with dementia and their care partners. A second framework is also used to examine and explain the findings, the cognitive self-efficacy theory (Bandura, 1986). This framework explains the impact of perceived capabilities or ‘mastery’, thought patterns and emotional reactions on an individual’s decision to execute tasks requiring new or established skills. It also describes the impact of ‘social persuaders’ to influence or modify one’s own, but sometimes inaccurate perception, of their capacity to execute a task. The ‘mastery’ concept fits well with the driver with dementia’s need for convincing evidence, including opportunity for self-assessment of on-road performance to inform decisions about impaired capacity to execute the previously ‘mastered’ task of driving. The concept of social persuasion fits well with the identified themes: ‘whose opinion will I accept as trustworthy’; ‘let’s discuss this before my judgement is compromised’; and ‘would knowing my alternatives influence my decision’. Involving the driver and their trusted informants in early discussion reflects ‘social persuasion’ to influence acceptance of the time to retire from driving (Table 4).
5.2.1 Mapping a decisional pathway

This study addresses a gap in our understanding of the most effective means of enhancing acceptance regarding the time to retire from driving for people with dementia. Findings indicate that involving the driver in the decision making process is an important strategy for facilitating a positive impact on health outcomes. Early preparation involving self-assessment, review of evidence the driver considers valid, and obtaining feedback from trusted sources may pave the way for increased acceptance in the event that negative on-road assessment outcomes occur (O’Conner and Jacobsen, 2007). Participants reported an inclusive approach would enhance the journey to driving retirement. Evidence of changes in fitness to drive that were derived from real on-road driving experiences were considered important to the driver, in contrast to the current clinical practice of undertaking a one-off assessment in an unfamiliar test environment.

There was consensus between these findings and those in the literature that the ability of the driver with dementia to be involved in decisions may be compromised at some point due to symptoms associated with disease progression (Perkinson et al., 2005). However, when safety becomes a concern the driver would have been involved in an on-going decision making process with forewarning about the impact of dementia on capacity to drive rather than experiencing abrupt licence cancellation (Adler, 2010, Byszewski et al., 2010).
The potential to redefine the pathway to driving retirement by addressing decisional conflict will be explored with respect to empirical evidence, current clinical practice, and the theories of decisional conflict and cognitive self-efficacy.

5.2.2 Addressing decisional conflict

Participants agreed that capacity to retain a driver’s licence represents an implied degree of physical and cognitive competence (Adler and Kuskowski, 2003). The need to retire from driving due to a dementia or another health related issue often represents a confronting loss for the individual on a number of levels, including physical, psychological and emotional wellbeing. (Hunt et al., 1997, Carr et al., 2000, Valcour et al., 2002, Reger et al., 2004, Adler et al., 2005, Byszewski et al., 2010). Concerns regarding an individual’s fitness to drive can be the catalyst for seeking a medical explanation as to the underlying cause of a cluster of otherwise non-specific symptoms one might associate with factors such as ageing, stress, and depression (Bamford and Bruce, 2000, Freund and Szinovacz, 2002) As a consequence, the driver may then be referred for an on-road assessment to: (i) determine fitness to drive; (ii) quantify any restrictions; or (iii) recommend licence cancellation, (Austroads National Road Transport Commission, 2012, Carmody et al., 2012), (Figure 16).
Figure 16: Current Clinical Practice

For those with very mild to mild dementia the on-road assessment is considered the ‘gold standard’ in both the empirical literature and current clinical practice (Dobbs, 1997, Hunt et al., 1997, Lipski, 2002, Perkinson et al., 2005, Molnar et al., 2006a, Australian and New Zealand Society for Geriatric Medicine, 2009, Byszewski et al., 2010), (Figure 16). However, evidence indicates negative results from such assessments do not provide convincing evidence for the driver with dementia (Brown et al., 2005a). The method seemed unfair to participants. Reluctance to accept negative feedback was attributed to the brevity and subjectivity of one-off driving assessments (Freund et al., 2005, Brown et al., 2005a, Martin et al., 2009).
The core category generated from theoretical integration (Corbin and Strauss, 2008) of participant data challenged current clinical practice. A decisional pathway for drivers who recognise they have dementia, incorporating relevant decisional tools is recommended to enhance acceptance of the need to consider driving retirement (Figure 17). Participants acknowledged the value of conducting on-road driving assessments to monitor capacity to drive within the context of a consumer involved approach (Jett et al., 2005, Byszewski et al., 2010, Alzheimer's Australia NSW, 2010). This ‘road to retirement’ creates a window of opportunity for those with dementia who elect to be involved in the decision making process (O’Conner and Jacobsen, 2007). The driver is able to consider options and alternatives at critical points along the continuum from time of diagnosis, which can be a trigger for dementia assessment, to the inevitable need for licence review. There would be opportunity to: (i) seek input regarding fitness to drive from trusted sources; (ii) self-monitor driving performance against a series of key warning signs; and (iii) prepare for any formal assessments recommended by practitioners. For example, prior to undergoing the on-road assessment, the driver can decide whether to relinquish their licence, undertake the formal assessment or even request to be re-assessed if having ‘a bad day’ (Figure 17).
Figure 17: Strategies to Supplement the Journey to Driving Retirement.

- Risks identified
  - triggers for investigating dementia diagnosis; or
  - triggers for discussion regarding fitness to drive

- Early discussion
  - Identify the trusted informants
  - Initiate the difficult conversation
  - make plans about when to retire
  - Decisional conflict theory

- Objective evidence
  - self monitor using checklists and warning signs
  - identify sources of evidence valid to the driver
  - seek driving performance feedback from trusted sources
  - Cognitive Self efficacy Theory (Mastery)

- Choose to be assessed or retire
  - formal assessment to determine fitness to drive; or
  - elect driving retirement

- Accept Cancellation or Challenge decision
  - review assessment recommendations with trusted doctor
  - explore opportunity to modify behaviours and undertake further assessment
  - consider retirement, remediation and /or re-assessment
  - Cognitive Self efficacy Theory (Social Persuasion)

- Retirement or cancellation
  - driving is deemed unsafe
  - driving retirement occurs or cancellation is imposed
5.3 Making decisions during the window of opportunity

Findings from this study revealed that involving the driver with dementia in the decision making process was important for enhancing acceptance of the need to consider driving retirement. Two key themes provided strategic recommendations as to who should be discussing the issues of driver safety and when the discussion should take place: (i) ‘whose opinion will I accept as trustworthy’; and (ii) ‘let’s discuss this before my judgement is compromised’. These themes are discussed in the context of what we know, what we have discovered and implications for future practice.

5.3.1 Whose opinion will I accept as trustworthy

Participants identified that facilitated discussion between the driver and those they consider trusted informants can enhance the journey to driving retirement. The findings provides a valuable contribution to the existing body of knowledge (Fox et al., 1997, Duchek et al., 2003, Brown et al., 2005a, Perkinson et al., 2005). Consumer opinions about key informants such as family carers, doctors and other practitioners challenge as well as confirm findings in the literature (Marieke et al., 2006, Mizuno et al., 2008, Carmody et al., 2012). Participants indicated that informant credibility was the crucial factor, influenced by the quality of the relationship between the driver and the person providing the
feedback. The most reliable informant would be someone who the driver trusts and respects, and who is in the position to observe warning signs that reflect a change in capacity to drive safely. This informant would be considered capable of monitoring changes in fitness to drive as well as cognitive capacity for other routine activities of daily living. For example, participants emphasised the trusted doctor’s role in monitoring capacity to drive. Recommendations made by the trusted doctor about the time to retire from driving would more likely be respected due to their social status associated with their medical role, whilst it is more often the family who is required to intervene (Mizuno et al., 2008).

5.3.2 Let’s discuss this before my judgement is compromised

In addition to identifying ‘who’ should be included in decision making conversations, the results of this study highlighted the need to consider ‘when’ the discussion about driving retirement should occur. There was consensus that conversations may be difficult for both the driver and the informant; however, timing is important. Since the ability to be involved in making decisions about driver safety may be compromised at some point due to symptoms associated with disease progression, the discussion should not be delayed and strategies to support gradual transition from driver to non-driver should be implemented early (Carr et al., 2005). Participants acknowledged interventions that promoted initiation of early discussion between drivers diagnosed with dementia, or those
drivers who may be exhibiting ‘at risk’ behaviours, and their trusted sources are essential. The empirical evidence demonstrated that discussion should occur in the first year of diagnosis (Hogan et al., 2008, Adler, 2010). However, due to the potential time delay between onset and formal diagnosis it is recommended that leaving the discussion for a later date is not ideal.

5.4 Weighing up the evidence.

Whilst the impact of dementia and aging can sometimes compromise driving safety (Kay et al., 2008), participants agreed that a diagnosis of dementia alone is insufficient evidence to determine fitness to drive (Hunt and Arbesman, 2008). The results challenged current clinical practice and raised important issues regarding the type of evidence drivers consider relevant for determining their fitness to drive (Australian and New Zealand Society for Geriatric Medicine, 2009), (Figure 16). Potential to supplement the current process of assessing fitness to drive using consumer informed strategies are derived from the following two themes: (i) on-road experiences are the most convincing; and (ii) Informative resources that include self-monitoring tools are useful. These themes are discussed below in relation to enhancing the decisional pathway to driving retirement, current evidence in the literature and cognitive self-efficacy theory.
5.4.1 On-road experiences are the most convincing

It is commonly found that drivers prefer to keep driving for as long as possible (Perkinson et al., 2005). Findings supported existing empirical evidence that when the time comes to retire some drivers will accept, possibly reluctantly, and some will resist the decision no matter who gives the news (Perkinson et al., 2005, Byszewski et al., 2007). Participants discussed the issues faced by families and practitioners should those with dementia over-rate their ability and deny impairment of capacity to drive safely (Freund et al., 2005, Jett et al., 2005, Adler et al., 2006, Liddle et al., 2008). For example, the driver with dementia may not retain the skills or insight needed to accurately measure their own capacity to drive safely (Shope and Eby, 1998, Perkinson et al., 2005). However, participants also indicated that the individual driver would be able to identify critical warning signs reflecting changes in their own ability to drive safely during the early phases of disease progression.

This contradiction can be explained with reference to cognitive self-efficacy theory. This theory has primarily been used to describe formal and informal educational experiences across the lifespan. A scan of the literature (CHINAL and Web of Science) found that this theory has been rarely, if ever used to explain the relationship between dementia and the reluctance of drivers with dementia to accept negative evidence regarding the time to retire from driving. Stern et al (2008) used this approach to enhance care partner knowledge and ability to cope
with a driver with dementia’s reluctance to consider driving retirement. Care partners participated in a group program: ‘At the crossroads: development and evaluation of a dementia caregiver group intervention to assist in driving cessation’. The group intervention was designed to support care partners as they are the ones most often required to address the difficult issues of driving retirement with their loved one. Positive changes in feelings of self-efficacy regarding the ability to address driving related issues with their loved one were reported for those who participated in the group intervention. Cognitive self-efficacy theory has also been used in other consumer education programs designed to support those with dementia facing lifestyle choices (Fitzsimmons and Buettner, 2003, Richeson, Boyne and Brady, 2007). The relevance of this theory to inform the understanding of, and thus address the variation in drivers’ perceived and actual driving ability is discussed below.

This study determined that observation of early warning signs and symptoms would enable consumer participation in monitoring driver safety and facilitate discussion between the driver and their trusted informants (Liddle et al., 2008). We know from previous research that addressing deficit awareness can allow drivers to modify their behaviours and prolong their capacity to drive (Cotrell and Wild, 1999, Ackerman et al., 2011). The decisions about driving retirement are not easy for the driver, the family or practitioners to address (Cotrell and Wild, 1999, Adler et al., 2005). However, our findings indicated that providing credible and timely feedback from trusted informants regarding the
capacity to continue driving would be beneficial, given that other alternatives such as an on-road assessment are often considered less convincing (Freund et al., 2005, Jett et al., 2005, Adler et al., 2006, Liddle et al., 2008).

One aspect of cognitive self-efficacy theory, specifically the driver’s perceived ‘mastery’, was reflected in participant responses raising concerns about their capacity to self-monitor fitness to drive. It was proposed this concern could be addressed by incorporating feedback from trusted sources regarding the observation of critical driving behaviours in the context of real on-road experiences. This strategy, combined with self-monitoring, becomes an integral part of the retirement process not an alternative to current clinical practice. In doing so, the focus on consumer involvement becomes a reality (Alzheimer’s Australia, 2010). Early discussion, before cognitive capacity is compromised further, enables the driver to articulate whose opinion they would listen to and the type evidence they would accept, including warning signs they would heed (Snellgrove and Hecker, 2002, Perkinson et al., 2005, Adler, 2010). This study revealed that before accepting that fitness to drive is sufficiently compromised to warrant driving retirement, some drivers wish to seek a clinic based opinion from their doctor; some would prefer to obtain feedback from family travelling in the car with them; and others want evidence from a number of sources. This highlights the importance of identifying the evidence that is important to each driver facing decisions about driving retirement (Mizuno et al., 2008).
Participant opinion that drivers provided with the opportunity to self-modulate driving behaviours and assess their own driving abilities against critical indicators is supported by Adler (2010) who has stated that several ‘flags’ would indicate driver safety for people with dementia and their care partners. These findings, parallel with other studies, acknowledged that warning signs and triggers for intervention would be identifiable for the care partner and driver in the early stages of the disease (Adler, 2010). For example, participants reported that drivers with early dementia would be able to monitor changes in driving safety using those indicators they identified as critical including near misses, dents on the car and getting lost. In addition, if it became clear to trusted informants that participants were no longer safe to drive then ‘imposed’ driving retirement was preferred over being a risk to themselves or more importantly others, regardless of their personal attitude to retiring at the time.

5.4.2 Informative resources that include self-monitoring tools are useful.

As discussed above, negative outcomes of on-road assessments are not readily accepted by the driver (Perkinson et al., 2005, Byszewski et al., 2010). The findings support supplementing current clinical practice by (i) including early preparation; and (ii) review of the evidence the driver considers valid with their trusted informant. This has potential to facilitate acceptance in the event that negative findings of the on-road assessment occur (Figure 17). The driver with
dementia would be involved in addressing decisional conflicts and making decisions that impact on their health and wellbeing (Stern et al., 2008, Alzheimer's Australia, 2010). For example, those participants who had been exposed to educational resources reported an appreciation of the future need to consider driving retirement as a natural consequence of aging. They reported having an awareness of community resources available for supporting the non-driver when the time to retire occurred (Baldock et al., 2006, Marottoli et al., 2007).

(i) The importance of generating strategic interventions that acknowledge implications of impaired driving safety and issues of driving retirement in a manner that is sensitive, relevant and concise were highlighted by the findings. Each resource needs to have a clear aim for the target audience (Perkinson et al., 2005, Byszewski et al., 2010). Providing a generic resource for those with driving safety concerns would not be considered appropriate due to the unique issues confronting drivers in different circumstances, for example, the undiagnosed driver exhibiting risky driving behaviours versus the driver with a diagnosis of dementia.

(ii) Resources that included checklists were recommended by participants as these could be used to validate opinion of the driver’s
current competencies. In addition, these resources have the capacity to raise awareness about potential future changes in competencies and facilitate the difficult conversations between the driver with dementia and their trusted informants (Byszewski et al., 2010). This corroborates the literature review findings: drivers and their family care partners would welcome interventions that enhance acceptance of driving retirement (Taylor and Tripodes, 2001, Freund and Szinovacz, 2002, Freund et al., 2005, Adler, 2010).

5. 5 The impact of alternatives on the road to driving retirement

It was clear from the findings that the availability of perceived alternatives has implications for addressing barriers for drivers making decisions about driving retirement due to a diagnosis of dementia (Liddle et al., 2008). Participants acknowledged the potential to positively influence decisions about driving retirement by adopting transport alternatives to maintain lifestyle choices (Cotrell and Wild, 1999, Snellgrove and Hecker, 2002, Adler et al., 2005, Perkinson et al., 2005, Hunt and Arbesman, 2008, Liddle et al., 2008). For example, those drivers with access to alternatives may be in a more favourable position to accept driving retirement. Thus, having a spouse that can drive, or living within easy access to public transport, would make the decision easier (Liddle et al., 2005). However, the findings also indicated that the availability of
alternatives may not sufficiently address issues of decisional conflict faced by drivers with dementia (Bamford and Bruce, 2000a, Adler, 2010). There was a relationship between the perceived significance of the loss of ability to drive safely and the willingness to consider alternatives.

The most important reason for wanting to drive identified by the participants is that ‘driving allows flexibility’ and therefore offers a level of convenience other options may not (Hunt et al., 1997, Carr et al., 2000, Valcour et al., 2002, Reger et al., 2004, Adler et al., 2005, Byszewski et al., 2010). Whilst access to alternatives may address some of the physical barriers retired drivers face, the emotional and psychological issues of loss that go hand in hand with the need to identify alternatives may not. Participants acknowledged that when thinking objectively, it made sense to cease driving and take up the alternatives. However, when the time comes, it may not be easy to accept driving retirement. The intrinsic personal benefits driving provide and the barriers retirement from driving represents needs to be addressed when providing access and information. Less tangible implications can also impact on a person’s attitude toward driving retirement such as: the love of driving; convenience; perceived level of capacity to drive safely; and belief in the inherent right to drive (Byszewski et al., 2010).

The need to retire from driving therefore needs to focus those social persuaders considered important to the individual to enhance acceptance of the time to
retire from driving, and consequently more readily accept alternatives (Figure 18). As noted in the literature review (Chapter 2), Adler et al. (2006) conducted a qualitative investigation with 12 volunteers who had ceased driving within two years to identify potential driving retirement strategies. Three categories of retirees were identified: (i) proactive; (ii) reluctant acceptors and (iii) resistors. Figure 18 outlines the implications and opportunities available to influence those who ‘reluctantly accept’ and those who ‘resist’ driving retirement. For example, those who accept the decision can adopt practical alternatives to maintain lifestyle choices; those who reluctantly accept can be persuaded to adopt the alternatives by embracing personal reasons for driving versus retiring; and those who initially ‘resist’ recommendations to retire may be able to reach a level of acceptance otherwise not available to them.

The differences in level of acceptance can be explained in part by cognitive self-efficacy theory, and specifically the concept of social persuasion (Figure 17). A practitioner could adopt this process to structure a discussion with the driver who is ‘reluctant’ or ‘resistant’ to accept the need to retire from driving by providing feedback and addressing those less tangible key barriers to accepting driving retirement. The flowchart below acknowledges the three categories of drivers and the potential to use cognitive self-efficacy theory to modify perceptions and thus address decisional conflict (Figure 18). For example, the ‘acceptors’, are those who indicate ‘Yes’ to adopting alternatives; ‘reluctant acceptors’ are represented by those who indicate ‘No’ and then ‘Yes’; and
‘resisters’ are represented as those that indicate ‘No and then ‘Maybe’. Cognitive self-efficacy theory has informed issues related to change in ‘mastery’, and the type of evidence relevant to drivers with dementia.

The concept of ‘social persuasion’ also has relevance by identifying those key factors important to the driver such as their personal safety or that of their loved ones. Rather than clinical interventions that only focus on implementing transporting options and community access solutions, acknowledgement about ‘why driving is important’ and what the loss of driving will represent to the individual is recommended (Hartford Financial Group and MIT AgeLab, 2007). It is also recommended that this aspect of cognitive self-efficacy theory be incorporated in the development of tools designed to address decisional conflict for those who are facing decisions about the time to retire from driving. These will potentially facilitate a shift from non-acceptance to acceptance for some drivers (resisters and reluctant acceptors).
Figure 18: Flow chart - Would Knowing my Alternative Influence my Decision

- Would knowing my alternatives influence my decision?
  - Yes
  - No
    - Perceived barriers are explicit and can be resolved with practical solutions
  - Maybe
    - Explore self efficacy theory
      - I have always been a good driver.
      - I love to drive.
      - I don’t like buses, and I need to be independent……..
    - Perceived barriers are less tangible and potential solutions are not considered
5.6 Strengths and limitations

The strengths of this study lie in the method applied to obtain data from consumers and potential consumers about the issues faced by those drivers who have dementia and who need or will need to consider the impact of their disease on the change in capacity to drive. Consumer informed research has been identified as a critical focus for implementing clinical intervention strategies appropriate to the needs of this group of consumers (Alzheimer's Australia, 2010). This is one of a very few studies where the end user and potential end user evaluated consumer driving assessment tools for drivers over 55 years, inclusive of those who self-identified as having dementia.

The challenges of obtaining ethics approval for research involving vulnerable populations such as those with dementia can lead to exclusion from participation. A strength of this study was that ethics approval was granted thereby allowing opinions of individuals with dementia to be heard. Consumer and potential consumer views and experiences generated valuable information to ensure future interventions for driving and dementia can be relevant and useful for people with dementia.

The sample size was impacted by access to potential volunteers and the time available to complete the Master of Science Degree. The number of participants is small with only 13% of drivers with dementia (n=2) represented. However, the
technique of concurrent data collection and data analysis enabled the researcher to explore emergent themes and clarify concepts raised by participants. There was evidence from the data analysis that saturation had been achieved. The data were read and re-read several times and the line-by-line constant comparative data analysis technique was adopted to generate codes and categories (Corbin and Strauss, 2008) to create the themes which explained the experience of decision making for driving and dementia by the participants. The data were entered into NVivo9 (2009) and codes checked to ensure ‘nothing new was found’ in the data. Data analysis was concluded when repetition of concepts derived from participant responses that informed the themes occurred (Corbin and Strauss, 2008).

Another strength of this study was the deductive approach taken to develop a decision aid for drivers with dementia. A quantitative study can use these findings to develop and test a driving and dementia decisional aid (DDDA) for people living with dementia to supplement the current clinical practices for assessing capacity to drive. An important consideration was that this study, though small in participant numbers, became a catalyst for greater interest in listening to the needs of consumers and potential consumers, that is, drivers with dementia facing decisions about the time to retire from driving (Alzheimer’s Australia, 2010). This will enable further research to address the limitations of this qualitative study.
5.6.1 Limitations

Although this study was able to instigate discussion about enhancing acceptance of driving retirement and provide recommendations relevant to clinical practice there were limitations associated with the sample recruited and thus the ability to generalise the findings across the broader population.

The initial target for this study was for 45 consumers (drivers over 55 years identifying as having a dementia) and potential consumers (drivers over 55 years identifying as having no known cognitive impairment) (n=45). The actual sample size was small (n=15) and included only two drivers who self-identified as living with a dementia (n=2). The number of participants is therefore a limitation. The barriers to involving greater numbers of participants related to: (i) difficulties in recruiting participants; and (ii) time constraints to recruit and conduct the study as part of a Masters project. In a future study

5.7 Implications for future practice and further research

This study has important implications for clinical practice and further research, informed by consumers and potential consumers. Findings identified that retirement from driving can be a supportive and effective journey for people with dementia. Strategies have been identified to supplement current clinical
practice for those practitioners assisting drivers with dementia who are facing decisions about the time to retire from driving. Providing access to sensitive, concise and relevant decisional support resources may enhance the quality of decision making for drivers with a dementia and their trusted care partners. Including views of trusted sources, feedback from real on-road experiences, early discussion and identification of suitable alternatives is also recommended. These strategies could be adopted by practitioners to ameliorate the decision making process for people with dementia who are facing driving retirement. Early after a diagnosis, practitioners can facilitate the often difficult discussion about the likely impact of dementia on safe capacity to drive over time, provide advice on up-skilling driving techniques to extend driver safety, and encourage self-monitoring of the signs that indicate the need to consider driving retirement.

5.8 Summary

The need to retire from driving is confronting because it represents evidence of loss of cognitive and physical capacity and as a consequence may compromise lifestyle choices. This chapter focused on the implications of the findings on clinical practice. Combining views of trusted sources, early discussion about driving retirement, feedback from real on-road experiences, and identifying suitable alternatives can moderate the negative impact of driving retirement and ensure a supportive and effective process for people with dementia. Findings
challenge current clinical practice for addressing the need to retire from driving by recommending consumer involvement in the decision making process. Providing interventions that supplement the current clinical practice is recommended to facilitate acceptance of the need to retire from driving.
CONCLUSIONS AND RECOMMENDATIONS

In Australia, driving is considered a rite of passage into adulthood and as a consequence the lifestyle choices made about how individuals spend time at home, work and leisure are integrated with the opportunity to drive. The need to retire from driving due to a dementia is confronting because it represents loss of cognitive and physical capacity to undertake usual activities of daily living. As a consequence, driving cessation potentially compromises lifestyle choices. Research into driving and dementia has primarily focused on identifying and designing robust clinical assessments to accurately determine fitness to drive safely (Marottoli et al., 2007, Australian and New Zealand Society for Geriatric Medicine, 2009, Austroads National Road Transport Commission, 2012). However, this does not address the decisional conflict faced by drivers who are assessed as unfit to drive but do not agree that the decision represents a fair or accurate reflection of their actual capacity to drive (Adler et al., 2006). This study sought opinion from consumers and potential consumers regarding means to enhance acceptance of the need to retire from driving and inform ways to augment current clinical practice (Mizuno et al., 2008, Adler, 2010).

The research question underpinning this study was ‘Can acceptance of driving retirement be enhanced by providing a decisional support tool informed by and for people with dementia?’ Drivers with dementia face decisions about loss in
many aspects of their lifestyle including independence and access to usual lifestyle choices due to the progressive nature of the disease. As expected, when licence cancellation is imposed and capacity to continue driving is considered unsafe by family, practitioners or concerned others, the driver with dementia may not agree with the recommendations, nor accept that potential alternatives are satisfactory.

The study was informed by the protocols developed in the ‘Ottawa Decision Support Framework’ (ODSF) (O’Conner and Jacobsen, 2007) informed by the theory of decisional conflict (Janis and Mann, 1977), a process of identifying and addressing decisional needs of consumers facing health related uncertainties. Consumers and potential consumers were recruited as a convenience sample to undertake a series of unstructured interviews. Data analysis was carried out using an adapted form of grounded theory (Corbin and Strauss, 2008). Five themes were generated from analysis of data: (i) whose opinion will I accept as trustworthy; (ii) real on-road experiences are most convincing; (iii) let’s discuss this before my judgement is compromised; (iv) would knowing my alternatives influence my decision; and (v) informative resources that include self-monitoring tools useful. Further analysis identified an over-arching theme or core category that informed a decisional pathway enabling those with dementia to engage in decisions about time to retire from driving. Participation in the decision making process and discussing the actual or perceived barriers to retirement with trusted informants was recommended. Cognitive self-efficacy theory provided a
framework to explore the findings and inform strategies identified to supplement current clinical practice.

This qualitative study suggests that providing appropriate decisional tools, specific to the needs of the Australian population of drivers with dementia can enhance acceptance of the need to consider driving retirement (Traynor, Andrew and Iverson, under review). Further, intervention tools would be most effective when combined with other factors, specifically, timely intervention that: (i) encourages early discussion with trusted informants; (ii) provides the type of evidence about fitness to drive the driver considers valid; and (iii) involves the driver with dementia in the decision making journey along the continuum from driver to non-driver (Andrew, Traynor and Iverson, under review).

There are varied reasons to explain why drivers are reluctant to agree with clinical opinion or other evidence about their loss of ability to drive safely. However, early discussion about realistic expectations for ongoing fitness to drive and why driving retirement is so confronting allows the driver and their trusted informants to investigate ‘social persuaders’ important to the driver when addressing barriers to acceptance. An important consideration for both the driver and the informant is that the discussion occurs whilst the driver still has the capacity to do so. As recommended by participants, this enables the care partner to implement the necessary steps when the time comes for driving retirement even though the person with dementia may later challenge decisions.
they were initially involved in making. The unique contribution of this study is the development of a decisional pathway supplementing current clinical practice that researchers can use to further explore the challenging topic of dementia and driving retirement (Figure 17).

The findings from this study generated consumer views about driving and dementia could be used in future research as Stage One in the development of an ODSF decisional support tool for driving and dementia. Stage Two would consist of a research study which developed a driving decisional tool specific to the needs of drivers with dementia and Stage Three would be a randomised control trial evaluating the effectiveness of a decisional aid for enhancing the journey from driver to driving retirement for drivers with dementia.


Andrew, C, Traynor, V & Iverson, DJ (submitted 2012), ‘Mapping a decisional road to driving retirement – what are the issues?’, *International Psychogeriatrics*, (under review).


Depoy, E & Gitlin, L 2011, Introduction to research : Understanding and applying multiple strategies, St Louis, Mosby.

Dobbs, AR 1997, ‘Evaluating the driving competence of dementia patients’, *Alzheimer Disease and Associated Disorders*, vol. 11, supplement 1, pp. 8-12.


Freund, B, Colgrove, LA, Burke, BL & Mcleod, R 2005, ‘Self-rated driving performance among elderly drivers referred for driving evaluation’, *Accident Analysis & Prevention*, vol. 37, no.4, pp. 613-618.


Kay, L, Bundy, A & Clemson, L 2009c, ‘Predicting fitness to drive in people with cognitive impairments by using Drivesafe and Driveaware’, *Archives of Physical Medicine and Rehabilitation*, vol. 90, no.9, pp. 1514-1522.


Taylor, BD & Tripodes, S 2001, ‘The effects of driving cessation on the elderly with dementia and their caregivers’, *Accident Analysis & Prevention*, vol. 33, no.4, pp. 519-528.


APPENDICES
8.1 **APPENDIX A: EMPIRICAL CITATIONS BY THEME**

<table>
<thead>
<tr>
<th>Theme</th>
<th>References Cited</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Driving is a complex task</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2 Onset and severity of dementia are difficult to define</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3 Dementia is progressive and impacts on driving skills</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. de Simone et al. (2007)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>4 Assessment of fitness to drive remains subjective</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Kay et al. (2009b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>5 Drivers with dementia are reluctant to accept negative assessment outcomes</strong></td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>1. Adler et al. (2006)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Freund et al. (2005)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Freund and Szinovacz (2002)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Liddle et al. (2005)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Lincoln et al. (2006)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Perkinson et al. (2005)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Rudman et al. (2006)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Taylor and Tripodes (2001)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>6 The search continues for the most effective means of preparing drivers with dementia for accepting driver retirement</strong></td>
<td></td>
<td>21</td>
</tr>
<tr>
<td>1. Abersman and Hunt (2008)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Adler et al. (2005)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Adler (2010)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Brown et al. (2005a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Brown et al. (2005b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Kay et al. (2009c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Hogan et al. (2008)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Liddle et al. (2005)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Marottoli et al. (2007)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Mizuno et al. (2008)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Molnar et al. (2006b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Perkinson et al. (2005)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Stern et al. (2008)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8. 2  APPENDIX B:

OVERVIEW OF ARTICLES RETAINED FROM SEARCH OF THE LITERATURE
APPENDIX B: OVERVIEW OF 49 ARTICLES RETAINED FROM SEARCH OF EMPIRICAL LITERATURE

<table>
<thead>
<tr>
<th>Author</th>
<th>Locale</th>
<th>Design</th>
<th>Setting</th>
<th>Sample</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abersman and Hunt (2008)</td>
<td>USA</td>
<td>Quantitative Interventions</td>
<td>Systematic literature</td>
<td>Evidence-based literature review</td>
<td>Articles that met the inclusion criteria i.e. reporting the impact of person related interventions on older adult driving participation (n=19)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>to improve drivers’</td>
<td></td>
<td></td>
<td>Impaired driver skills including vision, cognition and motor function may be addressed with specific intervention programs, thereby extending safe driving and maintaining independence.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>performance 65+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Male drivers with dementia</td>
<td>Direct assessment of driving knowledge is a better predictor of fitness to drive compared to the MMSE.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(n=75); aged matched controls</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(n=80)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Community</td>
<td>Three categories of retired drivers identified:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Drivers who had ceased driving within the past 2 years (n=12)</td>
<td>(i) proactive; (ii) reluctant acceptors; and (iii) Resistors. Recommended:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(i) developing a self-evaluation to assist with driver decision making; (ii) Include driving cessation as a topic in retirement planning education.</td>
</tr>
</tbody>
</table>

1. Adler, Rottunda, Christensen, Kuskowski and Thuras (2006)
<table>
<thead>
<tr>
<th>Author</th>
<th>Locale</th>
<th>Design</th>
<th>Setting</th>
<th>Sample</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Adler and Kuskowski (2003)</td>
<td>USA</td>
<td>Quantitative</td>
<td>Cohort</td>
<td>Male drivers and their informants (n=53)</td>
<td>Over 25 to 39 months, 53% had ceased driving (n=23); and unexpectedly, 47% continued driving (n=20) for several years after diagnosis.</td>
</tr>
<tr>
<td>5. Baldock, Mathias, McLean and Berndt (2006)</td>
<td>Australia</td>
<td>Quantitative Self-regulation and driving ability</td>
<td>Cohort</td>
<td>Drivers 60 + (n=104):including those referred for assessment (n=11); and community volunteers (n=93)</td>
<td>(i) assessed on-road driving ability did not correlate with driving avoidance; and (ii) Drivers may not appropriately self-regulate in the presence of factors impacting driving ability.</td>
</tr>
<tr>
<td>6. Berndt, Clark and May (2008)</td>
<td>Australia</td>
<td>Quantitative</td>
<td>Cohort</td>
<td>Drivers with dementia (n=115) participated in standardised on-road assessments; performance was compared with CDR scores</td>
<td>Findings support previous studies recommending: (i) CDR rated drivers with moderate to severe dementia should not drive; (ii) assessment is recommended for drivers with mild to very mild dementia; and (iii) 6 monthly evaluations due to progressive nature of dementia.</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>--------</td>
<td>---------</td>
<td>--------</td>
<td>--------------</td>
</tr>
<tr>
<td>Brown, Stern, Cahn-Weiner, Rogers, Messer, Lannon, Maxwell, Souza, White and Ott (2005)</td>
<td>USA</td>
<td>Quantitative Test of fitness to drive</td>
<td>Case Control</td>
<td>Drivers with dementia (n=31); healthy controls (n=24)</td>
<td>New Neuropsychological Assessment Battery (NAB) appears to have good validity predicting on-road driving abilities. Recommended replication with a larger sample.</td>
</tr>
<tr>
<td>Brown, Ott, Papandonatos, Sui, Ready and Morris (2005)</td>
<td>USA</td>
<td>Quantitative Test of fitness to drive</td>
<td>Cross sectional: case control</td>
<td>Total drivers (n=75): Mild dementia (n=17); Very Mild dementia (n=33); elderly controls (n=25)</td>
<td>Assessment by an experienced neurologist may be a valid predictor of fitness to drive for patients with early dementia.</td>
</tr>
<tr>
<td>Byszewski, Molnar and Aminzadeh (2010)</td>
<td>Canada</td>
<td>Qualitative Driver perspectives of the impact of being told to stop driving</td>
<td>Cohort</td>
<td>Drivers with dementia (n=15) who were assessed and told to stop driving as a result of their initial dementia evaluation; and their family carers</td>
<td>3 reactions identified when drivers were advised they were unable to continue driving: (i) acceptance (n=6); (ii) resignation (n=3); (iii) disagreement (n=6) Recommended practitioners be sensitised to and prepared for the emotional reactions of drivers.</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>--------</td>
<td>---------</td>
<td>--------</td>
<td>--------------</td>
</tr>
<tr>
<td>10. Carr, Shead and Storandt (2005)</td>
<td>USA</td>
<td>Quantitative</td>
<td>Case-control</td>
<td>Archival database</td>
<td>Collateral reporting of cases aged 51 + (n=143) who ceased driving between initial and subsequent assessments including those initially assessed as non-demented (n=8)</td>
</tr>
<tr>
<td>11. Carr, Duchek and Morris (2000)</td>
<td>USA</td>
<td>Quantitative</td>
<td>Retrospective case control pilot study</td>
<td>Crash data</td>
<td>Total (n=121) drivers: dementia (n=63); controls (n=58)</td>
</tr>
<tr>
<td>12. Cotrell and Wild (1999)</td>
<td>USA</td>
<td>Quantitative</td>
<td>Cohort</td>
<td>Outpatient clinic</td>
<td>Drivers with dementia: current drivers (n=19); retired drivers (n=16)</td>
</tr>
<tr>
<td>13. de Simone, Kaplan, Patronas, Wassermann and Grafman (2007)</td>
<td>USA</td>
<td>Quantitative</td>
<td>Case control</td>
<td>Outpatient clinic and community</td>
<td>Total participants (n=30): patients with dementia (n=15), male (n=10) and female (n=5); Healthy age matched controls (n=15)</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------</td>
<td>-----------------------</td>
<td>--------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| 14. Dobbs (1997)              | Canada | Quantitative         | Case Control                   | Drivers (n=115) with cognitive impairment early stage dementia and aged matched unimpaired drivers (n=58) | (i) Errors made by drivers with cognitive impairment in the on-road assessments were different compared to controls;  
(ii) A specific on-road assessment course for drivers with dementia is recommended.                                                   |
| 15. Dobbs, Harper and Wood (2009) | Canada | Mixed methods        | Cohort                         | People with dementia (n=44) and careers (n=30) attending either: traditional support groups; or driving specific support groups | Support groups that focused on driving retirement were effective in ameliorating the negative consequences of driving retirement.                              |
Mild dementia (n=29)  
Very mild dementia (n=21) | Driving performance declined over time, supporting need for driving assessment and re-assessment for those drivers with dementia.  |
<p>| 17. Freund, Colgrove, Burke and McLeod (2005) | USA    | Quantitative         | Cohort                         | Drivers 65 + referred to a clinic for driving assessment Drivers (n=152) | Drivers were asked to self-rate their driving ability compared to their peers and undertake a cognitive assessment and/or a simulated driving evaluation. All unsafe drivers rated their expected driving performance as the same or better than their peers. |</p>
<table>
<thead>
<tr>
<th>Author</th>
<th>Locale</th>
<th>Design</th>
<th>Setting</th>
<th>Sample</th>
<th>Key findings</th>
</tr>
</thead>
</table>
| 18. Freund and Szinovacz (2002)             | USA        | Quantitative Impact of gender and transport alternative on driving cessation | Cohort Survey data | Total drivers aged 70+ (n=5460): male (n=2261); female (n=3199)       | (i) 37% of people with poor cognitive function continued to drive.  
(ii) Women with poor cognitive function tended to cease driving whilst men continued to drive.                                                                                                             |
| 19. Fox, Bowden, Bashford and Smith (1997)  | Australia  | Quantitative Test of fitness to drive       | Cohort Outpatient clinic | Drivers with probable dementia (n=19)                                 | On-road assessments were more accurate than clinic based assessments for drivers with mild to very mild dementia.                                                                                               |
| 20. Hogan, Bailey, Black, Carswell, Chertkow, Clarke, Cohen, Fisk, Forbes, Man-Son-Hing, Lanctot, Morgan and Thorpe (2008) | Canada       | Quantitative Management approaches for driving and dementia Systematic literature review | Articles published between 1996 and 2005 | Articles meeting selection criteria (n=954): i.e. recommendations for management of mild to moderate dementia | Recommendations in relation to driving:  
(i) pro-active planning required for driver retirement since dementia is progressive;  
(ii) An individual capacity to drive should be determined by functional abilities.                                                                                                                                 |
<table>
<thead>
<tr>
<th>Author</th>
<th>Locale</th>
<th>Design</th>
<th>Setting</th>
<th>Sample</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>21.</td>
<td>Hunt, Brown and Gilman (2010)</td>
<td>USA</td>
<td>Quantitative Media reports of lost driver</td>
<td>Media and newspaper reports of lost drivers with dementia (n=207): (i) not found (n=70); (ii) found dead (n=32); (iii) found alive (n=116)</td>
<td>(i) Drivers became lost either driving to or from familiar places; (ii) Failure to address risks of becoming lost has serious consequences.</td>
</tr>
<tr>
<td>22.</td>
<td>Hunt, Murphy, Carr, Duchek, Buckles and Morris (1997)</td>
<td>USA</td>
<td>Quantitative Test fitness to drive</td>
<td>On-road assessment of aged matched healthy controls (n=58) with drivers with very mild dementia (n=36), and drivers with mild dementia (n=29)</td>
<td>(i) Significant correlation between on-road performance and assessed level of dementia; (ii) On-road assessment of cognitive behaviours is accurate and reliable.</td>
</tr>
<tr>
<td>23.</td>
<td>Jett, Tappen and Rosselli (2005)</td>
<td>USA</td>
<td>Qualitative Factors that influence driving cessation for older drivers</td>
<td>Practitioners, drivers with cognitive impairment and family carers (n=216)</td>
<td>Driving cessation can occur voluntarily, however for those that do not wish to cease driving, the decision should be imposed.</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>--------</td>
<td>---------</td>
<td>--------</td>
<td>--------------</td>
</tr>
<tr>
<td>Kay, Bundy, Clemson and Jolly (2008)</td>
<td>Australia</td>
<td>Quantitative Test of validity and reliability of the on-road assessment</td>
<td>Prospective Case control study</td>
<td>Drivers with visual deficits (n=20); Healthy drivers (n=80)</td>
<td>Strong evidence of construct validity between the on-road driving assessment and driving errors, indicative of driving safety.</td>
</tr>
<tr>
<td>Kay, Bundy and Clemson (2009a)</td>
<td>Australia</td>
<td>Quantitative Determine validity and reliability of “Drive Aware” psychometric test.</td>
<td>Cohort</td>
<td>Adults 16 to 86 years with varying cognitive and/or physical diagnoses (n=91)</td>
<td>Strong evidence that the Drive Aware measured awareness of driving ability and could be a useful tool to assess awareness of driving ability for drivers with medical conditions.</td>
</tr>
<tr>
<td>Kay, Bundy and Clemson (2009b),</td>
<td>Australia</td>
<td>Quantitative Predicting fitness to drive</td>
<td>Cohort</td>
<td>Drivers with functional impairment (n=115) including a subgroup of drivers with cognitive impairment (n=96)</td>
<td>Clinical tests predicted those who needed to undergo on-road assessments; however findings should be replicated before clinical practice is changed.</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>----------------</td>
<td>-------------------------------</td>
<td>------------------</td>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| 27. Kostynuik and Molnar (2008) | USA            | Quantitative                 | Community        | Drivers and recently retired drivers 65+ with no cognitive impairment (n=961) | (i) Women are more likely to self-regulate compared to men;  
(ii) Those with visual impairment were more likely to self-limit driving  
(iii) Those with reduced tolerances for walking were less likely to drive in adverse weather. |
| 28. Liddle, Turpin, Carlson and McKenna (2008) | Australia | Mixed method:  
Driving cessation implications | Community        | Convenience sample of 65+ (n=234) consisting of current drivers (n=137), retired drivers (n=56) and non-drivers (n=41) excluding those with cognitive impairment | (i) Driving cessation has implications for safety and wellbeing;  
(ii) Resources that provide information and skill development regarding access to alternatives to driving are recommended. |
| 29. Liddle, McKenna and Broome (2005) | Australia | Qualitative  
The process of driving cessation | Community        | Participants (n=18): retired drivers (n=9); family members (n=3); practitioners (n=6) | A driver education program that addresses issues related to preparation for driving retirement empowers older people to self-manage the lifestyle issues associated with driving retirement. |
Fitness to drive screening | Community        | General Practitioners (n=173) | GPs are not routinely screening patients with dementia for fitness to drive. |
<table>
<thead>
<tr>
<th>Author</th>
<th>Locale</th>
<th>Design</th>
<th>Setting</th>
<th>Sample</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. Lincoln, Taylor, Vella, Bouman and Radford (2010)</td>
<td>UK</td>
<td>Quantitative Test of fitness to drive</td>
<td>Cohort</td>
<td>Practitioner referral</td>
<td>Drivers aged 58 + with dementia (n=75) were assessed on-road, and with cognitive tests (i) Clinical test battery predicted safety to drive in 76% of drivers; (ii) Test battery useful for identifying those who would benefit from on-road assessment.</td>
</tr>
<tr>
<td>32. Lincoln, Radford, Lee and Reay (2006)</td>
<td>UK</td>
<td>Quantitative Test of fitness to drive</td>
<td>Case control</td>
<td>Practitioner referral and Community</td>
<td>Drivers with dementia (42) and healthy aged matched drivers (n=33) Safety of drivers with dementia could be predicted to 67% using the battery of 6 tests and this could be used to identify those who need an on-road assessment.</td>
</tr>
<tr>
<td>33. Lovell and Russell (2005)</td>
<td>Australia</td>
<td>Quantitative Test of fitness to drive</td>
<td>Cohort</td>
<td>Memory clinic</td>
<td>Drivers with dementia (n=20) (i) Recommended Routine referral for driving assessment after diagnosis; and; (ii) 6 monthly reviews</td>
</tr>
<tr>
<td>34. Man-Son-Hing, Marshall, Molnar and Wilson (2007)</td>
<td>Canada</td>
<td>Quantitative Test of fitness to drive</td>
<td>Systematic review</td>
<td>Case control studies</td>
<td>Studies (n=23) that included drivers with dementia; and reported on state or career reported crash rates; performance based road tests or simulator evaluations Drivers with dementia were considered less competent than cognitively normal drivers but there was no difference in crash rates.</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>---------------------------------------</td>
<td>----------</td>
<td>-------------------</td>
<td>-----------------------</td>
<td>-------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Marottoli, Van Ness, Araujo, Iannone, Acampora, Charpentier and Peduzzi (2007)</td>
<td>USA</td>
<td>Quantitative</td>
<td>Randomised control study</td>
<td>Clinic and community</td>
<td>Drivers 70 + (n=126)</td>
</tr>
<tr>
<td>Martin, Marottoli and O'Neill (2009)</td>
<td>UK</td>
<td>Cochrane review</td>
<td>Cochrane Collaboration</td>
<td>Data sources:</td>
<td>There were no studies identified that met the inclusion criteria i.e. randomised control trials (n=0) Health and social inclusion are issues for people with dementia who cease driving and lack of alternatives may be reasons why assessing driver safety is a greater issue rather than investigating mobility alternatives.</td>
</tr>
<tr>
<td>Mizuno, Arai and Arai (2008)</td>
<td>Japan</td>
<td>Qualitative</td>
<td>Cohort</td>
<td>Outpatient s clinic</td>
<td>Pairs of drivers and ex-drivers with dementia and their family carer informant (n=79) Drivers should participate however placing full responsibility for the decision making on the driver or family carer should be avoided; policy is required to meet needs for alternative transport and sustainable urban planning.</td>
</tr>
<tr>
<td>Molnar, Patel, Marshall, Manson-Hing and Wilson (2006 )</td>
<td>Canada</td>
<td>Quantitative</td>
<td>Systematic review</td>
<td>Primary evidence 1984 to 2005</td>
<td>Review of studies (n=164) investigating specific period of follow up for driving assessments Only three studies met the search criteria (n=3). Further research into period of reviews for fitness to drive recommended.</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>--------</td>
<td>---------</td>
<td>--------</td>
<td>--------------</td>
</tr>
<tr>
<td>Perkinson, Berg-Weger, Carr, Meuser, Palmer, Buckles, Powlishta, Foley and Morris (2005)</td>
<td>USA</td>
<td>Quantitative Beliefs and cessation strategies among stakeholders</td>
<td>Cohort</td>
<td>Community</td>
<td>Focus groups (n=10) with key stakeholders (n=68) including current drivers (n=9) and ex-drivers with dementia (n=5) (i) Education for the stakeholders was recommended; (ii) families play a role in decisions regarding driver cessation and would like the doctor to be more involved; and (iii) Drivers believed they remained fit to drive.</td>
</tr>
<tr>
<td>Reger, Welsh, Watson, Cholerton, Baker and Craft (2004)</td>
<td>USA</td>
<td>Quantitative Test of fitness to drive</td>
<td>Meta-analysis</td>
<td>Published literature - Primary studies</td>
<td>Published studies which met inclusion criteria (n=27) on the relationship between driving and dementia (i) As cognitive function declines, driving abilities decline; and (ii) neurological results could predict need to undertake a driving assessment</td>
</tr>
<tr>
<td>Rudman, Friedland, Chipman and Sciortino (2006)</td>
<td>Canada</td>
<td>Qualitative Self-regulation of driving amongst older adults</td>
<td>Focus groups – semi structured interviews</td>
<td>Community</td>
<td>People without a medical condition that requires driving cessation (n=79) including drivers 55-64 years (n=29); drivers 65 + over (n=24); ex drivers (n=26) Public awareness and interventions to facilitate transition to ex driver in a timely and personally acceptable manner was recommended.</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------</td>
<td>-----------------</td>
<td>--------------------</td>
<td>----------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Shope and Eby (1998)</td>
<td>USA</td>
<td>Qualitative</td>
<td>Focus groups</td>
<td>Focus groups (n=16) representing drivers aged 65+ including: solo drivers; couples; former drivers (n=97); and concerned adult children of current drivers (n=37)</td>
<td>Use of a self-evaluation instrument may be one useful strategy for some older drivers facing decisions about driving retirement.</td>
</tr>
<tr>
<td>(Snellgrove and Hecker, 2002)</td>
<td>Australia</td>
<td>Quantitative</td>
<td>Postal survey</td>
<td>GPs responded to a 12 item questionnaire (n=485)</td>
<td>(i) Role of the GP is to offer information and advice about driving (93%); but reluctant to be responsible for assessing fitness to drive. (ii) A multi-disciplinary team making the determination of unfit (83%). (iii) 21% of GP’s did not assess for cognitive capacity when completing licence renewal forms.</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Stern, D’Ambrosio, Mohyde, Carruth, Tracton-Bishop, Hunter, Daneshvar and Coughlin (2008)</td>
<td>USA</td>
<td>Quantitative Usefulness of driving retirement education</td>
<td>Test, retest</td>
<td>Outpatient clinics and Community</td>
<td>Family carers of drivers with dementia (n=66) randomly assigned to one of 3 groups: active intervention (n=31); written intervention (n=23); no intervention controls (n=12)</td>
</tr>
<tr>
<td>Taylor and Tripodes (2001)</td>
<td>USA</td>
<td>Quantitative Impact of driving cessation on lifestyle</td>
<td>Survey</td>
<td>Residential care facilities.</td>
<td>Survey mailed to residents whose licences had been revoked or suspended (n=922)</td>
</tr>
<tr>
<td>Uc, Rizzo, Anderson, Shi and Dawson (2004)</td>
<td>USA</td>
<td>Quantitative Test of fitness to drive</td>
<td>Case control</td>
<td>Existing database</td>
<td>Licensed drivers with mild dementia (n=32) and unimpaired controls (n=136)</td>
</tr>
<tr>
<td>Author</td>
<td>Locale</td>
<td>Design</td>
<td>Setting</td>
<td>Sample</td>
<td>Key findings</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------</td>
<td>--------------------------------------</td>
<td>-----------------------</td>
<td>------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>47. Valcour, Masaki and Blanchette (2002)</td>
<td>USA</td>
<td>Quantitative &lt;br&gt;Self-reported and physician reported fitness to drive</td>
<td>Cross-sectional study</td>
<td>Drivers aged 65 + assessed to determine cognitive status (n=202): drivers without impaired cognitive function (n=148); drivers with moderately impaired cognitive function (n=21); drivers with severe cognitive impairment (n=9)</td>
<td>Recognition rates of cognitively impaired drivers who were still driving could affect interventions regarding driving cessation. Driving rates decreased. For example only 4.8% (n=1) of drivers with moderate and 11% (n=1) with severe cognitive function impairment had been recognised by their doctor as having cognitive problems.</td>
</tr>
<tr>
<td>48. Whelihan, DiCarlo and Paul (2005)</td>
<td>USA</td>
<td>Quantitative Test of fitness to drive</td>
<td>Case control Memory clinic and community</td>
<td>Drivers with dementia (n=23) and healthy aged matched controls (n=23)</td>
<td>Significant relationship between cognitive tests used and on-road assessment results.</td>
</tr>
<tr>
<td>49. Wild and Cottrell (2003)</td>
<td>USA</td>
<td>Quantitative Ability to self-rate driving performance</td>
<td>Case Control Memory clinic and community</td>
<td>Drivers with dementia living with a family carer (informant) (n=15); healthy drivers each with an informant (n=15)</td>
<td>(i) Healthy driver self-rating scores were similar to on-road assessment ratings; and (ii) Self-rating scores were higher than the on-road assessment ratings for drivers’ with dementia.</td>
</tr>
</tbody>
</table>
8.3 APPENDIX C: DATA COLLECTION TOOLS

8.3.1 Interview Schedule

Format: Unstructured Interviews

Setting: One-to-one and small group interviews

<table>
<thead>
<tr>
<th>Interview 1</th>
<th>Interview 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Main concept:</strong></td>
<td><strong>Main Concept:</strong></td>
</tr>
<tr>
<td>What factors would influence your decision to retire from driving?</td>
<td>Do you think you would be better prepared to make decisions about driving retirement after reviewing the 5 resources provided?</td>
</tr>
<tr>
<td>Prompt questions</td>
<td>Prompt questions</td>
</tr>
<tr>
<td>(i) Do you think someone would be able to tell if they need to retire from driving?</td>
<td>(i) What did you like/dislike about each resource</td>
</tr>
<tr>
<td>(ii) How would you decide when to retire from driving?</td>
<td>(ii) What should stay?</td>
</tr>
<tr>
<td>(iii) What information would help someone decide about retiring from driving?</td>
<td>(iii) What should go?</td>
</tr>
<tr>
<td>(iv) Whose advice would you listen to about your ability to keep driving safely?</td>
<td>(iv) What else do you think should be included?</td>
</tr>
<tr>
<td>(v) What kind of evidence would you accept that you are not safe to drive?</td>
<td></td>
</tr>
<tr>
<td>(vi) Would you like to know if you were unsafe to drive?</td>
<td></td>
</tr>
<tr>
<td>(vii) Would you like someone to tell you if you were not driving safely?</td>
<td></td>
</tr>
<tr>
<td>(viii) Who would you like that person to be?</td>
<td></td>
</tr>
</tbody>
</table>
### 8.3.2 Demographic data collection schedule

<table>
<thead>
<tr>
<th>1</th>
<th>Age Range/years</th>
<th>55 to 59</th>
<th>60 to 64</th>
<th>65 to 69</th>
<th>70 to 74</th>
<th>75 to 79</th>
<th>80 plus</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Gender</td>
<td>Male</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Female</td>
</tr>
<tr>
<td>3</td>
<td>How old were you when you obtained your licence?</td>
<td>1990</td>
<td>1991</td>
<td>1992</td>
<td>1993</td>
<td>1994</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>What type of licence do you have?</td>
<td>Truck</td>
<td>Car</td>
<td>Motorcycle</td>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Are there any conditions on your licence?</td>
<td>None</td>
<td>Spectacles</td>
<td>Daylight driving only</td>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Do you drive a car with manual or automatic transmission of both?</td>
<td>Manual</td>
<td>Automatic</td>
<td>Both</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>When do you drive? : Choose one or more of the following</td>
<td>Groceries, shopping, bill paying</td>
<td>Transport to work</td>
<td>Transport to leisure and social activities</td>
<td>Voluntary work</td>
<td>Holidays</td>
<td>Only in emergencies</td>
</tr>
<tr>
<td>8</td>
<td>Approximately how far do you drive?</td>
<td>Just around my local neighbourhood, i.e. less than 5km</td>
<td>To places within 20km from home</td>
<td>To places about 50km from home</td>
<td>To places about 100km from home</td>
<td>To places more than 100km from home</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Approximately how often do you drive?</td>
<td>In an emergency only</td>
<td>About once to twice per month</td>
<td>About once per week</td>
<td>Just about every day</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>If you had to attend an appointment in the CBD of Sydney how would you prefer to travel there?</td>
<td>I would drive</td>
<td>I would have someone drive me</td>
<td>I would catch public transport</td>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>If you wanted to travel interstate, how would you travel there?</td>
<td>I would drive</td>
<td>I would have someone drive me</td>
<td>I would go by coach or bus</td>
<td>I would catch a train</td>
<td>I would take a plane</td>
<td>Other</td>
</tr>
</tbody>
</table>

### 8.3.3 Likert satisfaction scale for rating 5 existing educational resources

<table>
<thead>
<tr>
<th>In your opinion how useful are each of the following resources</th>
<th>I think this is extremely useful</th>
<th>I think this might be useful</th>
<th>I think it might not be useful</th>
<th>I don't think it is useful at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>About You: Driving Help Sheet</td>
<td>😊😊</td>
<td>😊</td>
<td>😜</td>
<td>😜😊</td>
</tr>
<tr>
<td>At the Crossroads</td>
<td>😊😊</td>
<td>😊</td>
<td>😜</td>
<td>😜😊</td>
</tr>
<tr>
<td>Driving Decisions Workbook</td>
<td>😊😊</td>
<td>😊</td>
<td>😜</td>
<td>😜😊</td>
</tr>
<tr>
<td>Driving Safely while Ageing Gracefully</td>
<td>😊😊</td>
<td>😊</td>
<td>😜</td>
<td>😜😊</td>
</tr>
<tr>
<td>Over 55 Rating Scale</td>
<td>😊😊</td>
<td>😊</td>
<td>😜</td>
<td>😜😊</td>
</tr>
</tbody>
</table>