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Economic Analyses of Dementia Care in Ireland and Europe – Perception of Services and Care, the Market Value of Informal Care and Changes in Service Utilisation Attributed to Comorbid Depression

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Abstract

Dementia is a progressive syndrome causing cognitive decline and functional impairment. The economic burden of dementia is greater than that of stroke, heart disease and cancer combined; however, resources allocated to dementia care continue to be substantially lower than each of these individual disease groups. The World Health Organisation observes a growing gap between budget allocation and associated burden of mental health disorders, particularly in higher income countries. Ireland is currently estimated to provide half the OECD average level of dementia care.

The aim of this thesis is to investigate the determinants of dementia care as they pertain to perception of care, value of informal care and the level of formal service utilisation. Through analysis of two datasets, the following three pieces of new evidence are obtained:

1. Perceptions of care in Ireland are determined by externalities such as socioeconomic status, and evidence suggests that access is unequal. This presents the risk of worsening symptoms and the transference of the burden of care to informal carers (e.g. friends or family).

2. Informal carers in Ireland report providing greater than 10 hours of care in 85% of cases, and this analysis finds daily care increases further with dementia progression. Estimated daily per day spend on informal dementia care is valued at the market rates and costs are found to range from €240 in early stage dementia to €570 in late stages.

3. Depression occurring in dementia substantially influences health services utilisation. Specifically, depression reduces the likelihood of accessing appropriate services but once services are accessed, increases the quantity of services required by 39%.

In light of the evidence presented, this thesis draws the conclusion that greater policy focus is required to ensure ‘equal access for equal needs’, to ensure adequate community support services are available and that complicated psychiatric symptoms of dementia are appropriately detected and managed.
### Table of Contents

Abstract ........................................................................................................................... vi
Table of Contents ........................................................................................................ viii
Declaration ................................................................................................................... x
Acknowledgements ...................................................................................................... xi
Table of Notation .......................................................................................................... xiv
Table of Abbreviations ............................................................................................... xvi
Thesis Summary ........................................................................................................... xx
PART I INTRODUCTION ............................................................................................... 1
   Chapter 1. Motivation, the Information Gap and the Research Questions .......... 5
PART II LITERATURE REVIEW .................................................................................... 38
   Chapter 2. Ageing Policy in Ireland ........................................................................ 42
   Chapter 3. Review of Cost of Illness Studies ......................................................... 47
   Chapter 4. Depression in Dementia ....................................................................... 59
PART III METHODS ....................................................................................................... 65
   Chapter 5. Datasets for a Study of Dementia (ASI 2007 & SHARE) ................. 68
   Chapter 6. Analysis of Perceptions of Dementia Care ........................................ 87
   Chapter 7. Proxy-Good Valuation for Informal Care .......................................... 95
   Chapter 8. Propensity Score Matching and Two-Stage Regression .................... 101
   Chapter 9. Limitations in the Data and Findings ................................................. 118
PART IV RESULTS ......................................................................................................... 132
   Chapter 10. Descriptive Statistics of Dementia (ASI 2007) ............................... 136
   Chapter 11. What Determines Perceptions of Care in Ireland .......................... 178
   Chapter 12. Informal Care by Stage and Task: Time and Value ...................... 187
   Chapter 13. Dementia in Europe: Summary Statistics from SHARE .......... 202
   Chapter 14. Comorbid Depression and Impacts on Dementia Health Care Utilisation 213
PART V DISCUSSIONS ................................................................................................. 227
   Chapter 15. What Determines Individuals’ Perceptions of Care ....................... 231
   Chapter 16. Dementia Stage and Informal Costs of Care ................................. 239
   Chapter 17. Demand Associated With Depression in Dementia ...................... 245
   Chapter 18. Conclusions: Informing Future Dementia Care ............................ 251
Bibliography ................................................................................................................ 261
Appendices

Appendix 1: A Carer’s Survey – The Questionnaire
Appendix 2: Calculation of the Proxy Market Value
Appendix 3: Analysis of the Opportunity Cost of Informal Care
Appendix 4: Table of Health Expenditure (OECD 2008)
Declaration

I, Dominic Trépel, declare that this thesis and the work presented in it are my own, and it has been generated by me as a result of my own original research. This thesis is solely the work of the author and it is submitted in partial fulfilment of the requirements of the Doctor of Philosophy in Economics at the University of Limerick. I confirm that any material that has been used for the completion of this thesis is accurately presented in the reference section, including work that has been presented to conferences and published by the author of this thesis.

Signed ………………………………………………………………………………………………………………………………

Date: 2 August, 2011
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Finally, I thank the Irish Research Council for Humanities and Social Sciences for awarding me the Government of Ireland Scholarship for this Ph.D. in health economics; I will ensure that your funding has meaningful impacts on dementia care.
**Table of Notation**

<table>
<thead>
<tr>
<th>Notation</th>
<th>Description</th>
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<tbody>
<tr>
<td>H</td>
<td>Health</td>
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<tr>
<td>i</td>
<td>Individual</td>
</tr>
<tr>
<td>y</td>
<td>Outcome /Dependent Variable</td>
</tr>
<tr>
<td>Q</td>
<td>Quality/Level of Activity</td>
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<tr>
<td>b</td>
<td>Scaling Factor</td>
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<tr>
<td>r</td>
<td>Risk Preference</td>
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<td>C</td>
<td>Cost</td>
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<tr>
<td>Z</td>
<td>Exogenous Constraint</td>
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<tr>
<td>e</td>
<td>Effort</td>
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<td>ε</td>
<td>Measurement Error</td>
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<tr>
<td>U</td>
<td>Utility</td>
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<tr>
<td>R</td>
<td>Revenue</td>
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<td>D</td>
<td>Observed</td>
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<td>E</td>
<td>Expected</td>
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<tr>
<td>η</td>
<td>Selection Bias</td>
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<tr>
<td>x</td>
<td>Random Variable</td>
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<tr>
<td>k</td>
<td>Constant</td>
</tr>
<tr>
<td>θ</td>
<td>Unknown Parameter</td>
</tr>
<tr>
<td>P</td>
<td>Probability</td>
</tr>
<tr>
<td>X</td>
<td>Vector of Covariates</td>
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<tr>
<td>β</td>
<td>Coefficient</td>
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<tr>
<td>L</td>
<td>Likelihood Function</td>
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</tbody>
</table>
\( \ln L \)  Log Likelihood Function
\( u \)  Censoring Threshold
\( \alpha \)  Model Intercept
\( s \)  Dementia Stage
\( O \)  Observed
\( \pi \)  Predicted Probability
\( N \)  Number of Independence Observations
\( n \)  Sample Number
\( \phi \)  Normal Density Function
\( \perp \)  Independence
\( \Delta \)  Difference Between Outcomes
\( f(.) \)  Function
\( g(.) \)  Conditional Function
## Table of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>AChI</td>
<td>Acholinesterase Inhibitors</td>
</tr>
<tr>
<td>ADL</td>
<td>Activity of Daily Living</td>
</tr>
<tr>
<td>AIC</td>
<td>Akaike Information Criterion</td>
</tr>
<tr>
<td>ASI</td>
<td>Alzheimer Society of Ireland</td>
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<td>ASI 2007</td>
<td>Survey by Alzheimer Society of Ireland in 2007</td>
</tr>
<tr>
<td>ATE</td>
<td>Average Treatment Effect</td>
</tr>
<tr>
<td>ATET</td>
<td>Average Treatment Effect on the Treated</td>
</tr>
<tr>
<td>BIC</td>
<td>Bayesian Information Criterion</td>
</tr>
<tr>
<td>BUPA</td>
<td>British United Provident Association</td>
</tr>
<tr>
<td>CBA</td>
<td>Cost Benefit Analysis</td>
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<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>CEA</td>
<td>Cost Effectiveness Analysis</td>
</tr>
<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
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<tr>
<td>CSDD</td>
<td>Cornell Scale for Depression in Dementia</td>
</tr>
<tr>
<td>CSO</td>
<td>Central Statistics Office</td>
</tr>
<tr>
<td>CV</td>
<td>Compensation Variation</td>
</tr>
<tr>
<td>DEMQOL</td>
<td>Dementia Specific Measure of Health-Related Quality of Life</td>
</tr>
<tr>
<td>DOHC</td>
<td>Department of Health and Child</td>
</tr>
<tr>
<td>DRG</td>
<td>Diagnostic Related Groups</td>
</tr>
<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders (4th Edition)</td>
</tr>
<tr>
<td>EBM</td>
<td>Evidence Based Medicine</td>
</tr>
<tr>
<td>ESRI</td>
<td>Economic and Social Research Institute</td>
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<tr>
<td>EU</td>
<td>European Union</td>
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<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>EV</td>
<td>Equivalent Variation</td>
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<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
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<tr>
<td>GLM</td>
<td>Generalised Linear Model</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HAM-D</td>
<td>Hamilton Depression Scale</td>
</tr>
<tr>
<td>HIA</td>
<td>Health Insurance Authority</td>
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<tr>
<td>HIPE</td>
<td>Hospital In-Patient Enquiry Scheme</td>
</tr>
<tr>
<td>HIQA</td>
<td>Health Information and Quality Authority</td>
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<tr>
<td>HPV</td>
<td>Human Papilloma Virus</td>
</tr>
<tr>
<td>HSE</td>
<td>Health Service Executive</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental Activity of Daily Living</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Classification of Diseases</td>
</tr>
<tr>
<td>ISCED</td>
<td>International Standard Classification of Education</td>
</tr>
<tr>
<td>LYG</td>
<td>Life Years Gained</td>
</tr>
<tr>
<td>MCI</td>
<td>Mild Cognitive Impairment</td>
</tr>
<tr>
<td>mle</td>
<td>Maximum Likelihood Estimator</td>
</tr>
<tr>
<td>MRS</td>
<td>Marginal Rate of Substitution</td>
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<tr>
<td>MRT</td>
<td>Marginal Rate of Transformation</td>
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<tr>
<td>MSB</td>
<td>Marginal Social Benefit</td>
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<tr>
<td>MSC</td>
<td>Marginal Social Cost</td>
</tr>
<tr>
<td>NB</td>
<td>Net Benefit</td>
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<tr>
<td>NCAOP</td>
<td>National Council on Ageing and Older People</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>NICE</td>
<td>National Institute of Health and Clinical Excellence</td>
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<tr>
<td>NMDAR</td>
<td>N-methyl-D-aspartate receptor</td>
</tr>
<tr>
<td>NPI</td>
<td>Neuropsychiatric Inventory</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>NPV</td>
<td>Net Present Value</td>
</tr>
<tr>
<td>OCED</td>
<td>Organisation for Economic Co-operation and Development</td>
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<tr>
<td>OLS</td>
<td>Ordinary Least Squares</td>
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<tr>
<td>PS</td>
<td>Producer Surplus</td>
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<tr>
<td>PSSRU</td>
<td>Personal Social Services Research Unit.</td>
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<tr>
<td>QALY</td>
<td>Quality-Adjusted Life Year</td>
</tr>
<tr>
<td>RAND</td>
<td>Research ANd Development (non-profit policy group)</td>
</tr>
<tr>
<td>RTS</td>
<td>Return to Scale</td>
</tr>
<tr>
<td>SHARE</td>
<td>Survey of Health, Ageing and Retirement in Europe</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
</tr>
<tr>
<td>SWB</td>
<td>Subjective Well-Being</td>
</tr>
<tr>
<td>SWF</td>
<td>Social Welfare Function</td>
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<tr>
<td>UHI</td>
<td>Universal Health Insurance</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>US$</td>
<td>United State Dollar</td>
</tr>
<tr>
<td>VHI</td>
<td>Voluntary Health Insurance Board <em>(An Bord Árachais Sláinte Shaorálaigh)</em></td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>WTP</td>
<td>Willingness to Pay</td>
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Thesis Summary

Dementia is a progressive syndrome causing cognitive decline and functional impairment, and this thesis presents economic analyses which aim to investigate the determinants of dementia care as they pertain to perception of care, value of informal care and the level of formal service utilisation.

To achieve these aims, the thesis is presented in five parts:

**Part I. Introduction:** This first part aims to highlight the importance of considering the economics of dementia and provides a motivation for this research thesis. Dementia is an economic priority which has a global economic impact, is endemic in Irish society and requires alignment with agreed international standards. The various strategies available are scrutinised and placed in the context of various national dementia strategies and the potential future of dementia in Ireland is outlined. This review identifies three important gaps in the information available for policy decisions and three specific research questions are formulated.

**Part II. Literature Review:** To position the three research questions in the context of relevant background literature, each question is assigned a specific chapter which reviews related literature. The first question asks: what factors determine the Irish dementia population’s perceptions of care? Chapter 2 examines Irish ageing policy to provide a backdrop for current perceptions of care. The second question asks: how much informal care is provided in Ireland at the progressive stages of dementia and what is the value of this care? Chapter 3 presents previous research into the cost of illness, explaining what new information is provided through applying a proxy-good valuation to this question. Chapter 4 examines clinical and economic literature on depression in dementia and motivates the final research question asks: how is formal service utilisation influenced by depression in dementia?

**Part III. Method:** To provide findings related to the three specific research questions, observations data is analysed using various econometric methods. Chapter 5 presents two datasets obtained for analysis, firstly introducing a dataset which is new to Ireland (ASI 2007) and explaining how an on-going European survey (SHARE) provides a further dementia population for analysis. Chapter 6 illustrates methods applied to examine the determinants of perceptions of care in
Ireland, reviewing how data was prepared to form binary variables of perceptions of care and what explanatory variables specify the logit model. Chapter 7 presents methods used in the proxy-good valuation, explaining how a censored daily informal-care-dependent variable is estimated using a Tobit model. The explanatory variables are used to estimate informal care time at progressive stages and how proxy-good values are assigned. Chapter 8 presents a series of three methods used to estimate the incremental effect of comorbid depression on health care utilisation in dementia. Firstly the methods of how the extent that depression predict dementia is specified. Next how quasi-experimental conditions are formed using propensity score matching. The final part specifies a two stage regression of health care utilisation. Before proceeding to the results, Chapter 9 presents potential limitations of the data that may affect the findings.

Part IV. Results: Summary statistics and regression outputs related to the three research questions are presented. Chapter 10 portrays individuals with dementia and their informal carers from ASI 2007 summary statistics. Chapter 11 presents the outputs of six logistic regressions, interpreting regression coefficients to indicate the determinants of perceptions of care. Chapter 12 explains the outputs of the Tobit regression used to explain informal care time, draws inferences on regression coefficients and assigns market values to specific components of dementia care. Chapter 13 describes the dementia population found in SHARE using summary statistics and then summarises the relationships between depression and dementia. Chapter 14 presents the three sequential results required to isolate the incremental effect of depression on health care use in dementia.

Part V. Discussion: For each specific research question, all new information is discussed highlighting what determines dementia care. Chapter 15 contends that diagnosis, disclosure, types of interactions with service and finances determine perceptions of care. Chapter 16 illustrates that requirements for informal care increase with dementia stages and symptoms may often require high levels of professional competency not generally available in informal carers. The valuation presented argues that the shadow price of informal care illustrates the intensity of care provided indicating the need for policy intervention. Chapter 17 deliberates on the role of depression in dementia and the implication of findings for health care
utilisation. **Chapter 18** presents conclusions and recommendations on how the new findings should inform future dementia care.
PART I
INTRODUCTION
Part I – Overview

The aim of this thesis is to investigate the determinants of dementia care as they pertain to perception of care, value of informal care and the level of formal service utilisation.

Chapter 1 introduces the investigation into dementia care, explaining the motivation behind the three specific research questions asked, highlighting gaps in the current knowledge base and positioning the aim of this thesis.
Chapter 1. Motivation, the Information Gap and the Research Questions

Dementia is a progressive syndrome causing cognitive decline and functional impairment. Chapter 1 introduces the economic issues related to dementia over three sections. Section 1.1 examines the economic motivation to research dementia, specifically reviewing the expected impact of dementia on the global economy, the demographic profile of dementia in Ireland and positioning the objectives in the international context. Section 1.2 examines potential approaches to managing dementia, exploring the options to prevent, provide care for or cure dementia and then consolidates this evidence base by reviewing three national dementia strategies adopted in countries with comparable implementation capacity to Ireland. Having positioned the need for enhanced strategies and better knowledge, the Chapter concludes by setting the aims and highlighting the three specific research questions of this thesis.

1.1. Dementia: An Economic Priority

Why dementia is considered an economic priority forms the aim of this section. Evidence is presented to indicate dementia as a global priority requiring further research. Prevalence figures, health expenditure and service output for dementia services in Ireland are then assessed. Objectives are then positioned in the context in an international context.

1.1.i Dementia and the global economy

Dementia is a major health issue and a global condition. Increasing prevalence and the costs and burden of the disease produce significant pressures on economic and social systems in many countries.

Globally costs for people with dementia are estimated to amount to more than 1% of world gross domestic product (GDP) (Wimo and Prince 2010). Concurrently, the World Health Organisation (Saxena et al. 2007) observes a growing gap between
budget allocation and the associated burden of mental health disorders, particularly in higher income countries. The economic burden of dementia is greater than that of stroke, heart disease and cancer combined (Lowin et al. 2001); however, resources allocated to dementia care continue to be substantially lower than each of these individual disease groups.

All signs point to a major economic issue requiring an enhanced knowledge base to provide the correct level of service and meet current and future demand.

1.1.ii Dementia in Ireland: Prevalence, expenditure and service outputs

Current estimates suggest that the number of people with dementia in Ireland lies somewhere in the range of 42,441 (O'Shea and O'Reilly 1999) to 47,893 (Cahill 2011), and forecasts project the dementia population to grow to 103,998 by 2036. Comparing these projections internationally, Ireland is expected to see higher than average levels of growth in the over 65s and over 80s (Knapp and Prince 2007).

Financing of the growing elderly population will become increasingly difficult as the ratio of people in Ireland’s labour force to the growing elderly population dwindles; this dynamic is captured in the dependency ratio. Ireland currently has a relatively young population with a favourable dependency ratio, but in comparisons of the growth in the older population of all European countries in the coming decades, Ireland’s growth rate is predicted to be the largest (National Audit Office 2007). In real terms, the population is predicted to increase threefold, but with the largest increase in the oldest old (i.e. those over 90), which should result in a large growth in demand for dementia-specific services.

Decision makers must aim to efficiently allocate resources to dementia in a way that maximises total social welfare with respect to competing treatment groups such as cancer, heart disease and stroke. To achieve this, national accounts on health expenditure need to be reassessed, apportioning the correct level to match the needs of each disease related group. In the absence of a national accounts system in Ireland, this thesis provides insights into perceptions of services and the level of informal care, and indicates the demand for formal services in dementia. Knowing dementia’s
effect on the formal and informal sectors is becoming increasingly important, particularly as the availability of care becomes increasingly scarce.

During the recent economic boom in Ireland (often referred to as the ‘Celtic Tiger’), health expenditure has grown substantially from 6.1% of GDP in 1999 to 9.5% in 2008 (see Figure 1).

![Total Health Care Expenditure in Ireland (% GDP)](image)

**Figure 1:** Total health care expenditure in Ireland (% GDP) [Source: OECD 2008].

A Cross-comparison of countries in the OECD, shows Ireland’s rise in expenditure has brought the country’s health budget up to equal the average contribution to health found in OECD countries (see Figure 2).
Figure 2: Health expenditure as a share of GDP [Source: OECD 2008].
OECD figures on health expenditure in 2008 show that Ireland’s input into the health care system is just below the OECD average (9%), but equal to the United Kingdom input (8.7%) and marginally higher than Australia and Norway.

At face value, this level of input into the health system in Ireland would suggest that the system is sufficiently well resourced to be as productive as the OECD average. This comparison provides a crude measure of productivity between countries on how efficient the health financing system is with respect to care outputs. For an indication of the productivity level of the health system (without controlling for efficiency), it is also important to have some comparative measure of output; one measure is the level of services available to individuals with dementia. Dementia may not be as readily distinguishable as some other disease groups and when it is, multiple agencies (e.g. health and social services) are involved in dementia care, so ascertaining expenditure has inherent difficulties (Knapp et al. 2007). A viable indicator is investment in long-term care, which is a composite of institutional and community-based home care (see Figure 3).
Figure 3: Adapted from the 'International comparison of service availability for dementia care' by Knapp et al, 2007. [Original Source of Data Analysed: OECD 2008.]
In Figure 3, data cited by Knapp et al. (2007) from the OECD compares public and private sector spend (as a percentage of GDP) on long-term care. This international comparison would suggest that Ireland has approximately half the OECD average level of resources available for individuals with dementia. More importantly, the UK, Canada and Australia, where dementia-specific strategies have been implemented, show sizable differences\(^1\) (later this Chapter presents dementia strategies and their construct in greater detail). Ireland has a relatively low level of service output for dementia, which can be partly explained by the absence of an implemented dementia-specific policy.

Taking a degree of inefficiency across the health system as a constant, dementia sufferers face further disadvantages in competing for scarce health care resources because of a low levels of awareness and understanding, inherent discrimination against the elderly (ageism), stigmatisation (Alzheimer's Society of Ireland and Trinity College Dublin 2006) and a feeling that nothing can be done to help.

Given the prognosis of dementia combined with its predicted economic impact, the economics of dementia care becomes a central research question for Ireland.

Next, the research objective is discussed within the backdrop of international recommendations and a plethora of innovative solutions to better manage the projected growth in expenditure. Within the international context, the motivation underlying the objective of this thesis is presented.

\(^1\) The comparison of GDP expenditure by country does not indicate how efficient this expenditure is, nor does the associable measure of services available for dementia. Understanding efficiency can be achieved through examining productivity in relation to a possibility frontier. By taking single points, all the possible productivity levels over a range of expenditure cannot be controlled. Given this fact combined with the heterogeneity of individual countries, inferences on cost from these citations on efficiency should be treated with caution.
1.1.iii Objective in an international context

Great uncertainty still exists as to how health services will meet increases in demand for dementia care projected to occur during the twenty-first century. This thesis applies econometric techniques to appropriate survey data in an attempt to better understand economic determinants in dementia in Ireland and Europe.

The central aim of this thesis is: to investigate determinants of dementia care as they pertain to perception of care, value of informal care and the level of formal service utilisation. This aim raises three specific research questions. The first two investigate society’s viewpoint by analysing community-based survey data from Ireland of individuals with dementia and their carers. The third research question examines formal services for dementia through analysis of service utilisation across Europe and specifically asks what impact depression in dementia has on formal services.

Dividing the analysis in this manner presents bottom-up analysis specifically relevant to Ireland and a top-down analysis of dementia comparing services across Europe, against which Ireland’s service can be benchmarked.

To position these analyses within a currently available array of management strategies, the next section presents the current evidence on prevention, provision of care or cure of dementia, highlighting that it is dementia care that merits the focus of this research.

1.2. Current Dementia Strategies and Knowledge Gaps

This section examines current management options to prevent, provide care for or cure dementia. Following this, three national dementia strategies will be reviewed to ascertain key actions required and to indicate potential gaps in the current knowledge base which will be addressed in this thesis. This section concludes by reviewing recent agreements to implement an Irish dementia strategy.

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2 The European analysis examines the Survey of Health, Ageing and Retirement in Europe (SHARE), which will be introduced and presented in greater detail later in this thesis.

3 Benchmarking of Ireland’s service utilisation related to dementia in the currently available releases of SHARE has certain limitations (discussed further in Chapter 9).
1.2.i  Current management strategies for dementia

As in many countries, Ireland faces challenges and choices in relation to investment in dementia care. International evidence can aid prioritisation on spending in a manner which will maximise benefits to society whilst maintaining optimal cost efficiency. This section examines three dementia strategies, presenting evidence on the role of prevention, care and a cure.

**Prevention** asks the question to what extent are measures to prevent dementia effective and is applying effort before a diagnosis a realistic option to reduce the impacts of dementia.

**Care** presents the construct of dementia management in Ireland, proposing an international benchmark which reveals how most of the burden is placed on the informal sector in Ireland. Evidence suggests that overburdening of informal care is associated with an increased risk of carer burnout and further evidence indicates that targeting interventions towards informal carers is therefore an efficient use of resources. This section underpins important issues studied in this thesis and serves to indicate the need to enhance the knowledge base.

**Cure** examines whether the prognosis for dementia can be altered, presenting the currently available “positive outcomes of treatment” and examines the general consensus of international expert opinion, which indicates the need to prioritise care.

(1)  **Prevention: Can Dementia Be Averted?**

The detection of dementia in community settings can be challenging (Cahill et al. 2006). In a survey of Irish GPs, the most commonly reported barriers to diagnosis were differentiation from the normal ageing process (31%), lack of confidence (30%) and fear of diagnosis (29%). As such only 19% stated they often or always disclosed a diagnosis. Common instruments used to facilitate diagnosis of dementia have come under question (Mitchell 2009), affirming health-care practitioner reluctance to diagnose and disclose. Counteracting this requires expert guidelines based on diagnostic accuracy research (Holsinger et al. 2007) implemented through a dementia strategy (discussed later).
Current thinking is that prevention may be one step before early diagnosis, through targeting those with mild cognitive impairments (MCI). Risk factors would suggest that 12–15% of people with MCI progress to Alzheimer’s disease or at least to a non-specific dementia (Kinsella et al. 2009), compared with a rate of 1–2% in healthy adults. The viability of self-referral memory clinics are being piloted for their role in detecting MCI.

Following detection of MCIs, a wealth of research suggests potential interventions may be available. Systematic reviews have examined the potential of cognitive interventions (Jean et al. 2010), alternative approaches such as Chinese medicines (May et al. 2008), gingko (Kaschel 2009), physical activity (Coelho et al. 2009), pharmaceutical treatments like cholinesterase inhibitors (Sobów and Kłoszewska 2007) and the role of vitamins such as B6 (Malouf and Grimley Evans 2003), B12 (Malouf and Areosa Sastre 2003) or E (Isaac et al. 2008).

The Canadian Alzheimer Society simulated scenarios for prevention by targeting risk factors (Alzheimer's Society Canada 2010). The ensuing report finds that the number of diagnoses could be significantly reduced by increasing exercise rates by 50% (Laurin et al. 2001). The economic outcome of delaying onset of dementia by two years was found to be the reduction of the number of people with dementia by up to 36.4% with potential savings of $218 billion (Brookmeyer et al. 2007).

Whilst the evidence for the clinical and economic potential of dementia prevention is compelling, findings on outcomes of interventions remain weak. A report by WHO suggests that the carer plays a critical role in dementia and is the focus of much debate (WHO 2008).

Next the main sources of dementia care in Ireland are examined to illustrate how the construct of care compares internationally and what must be done to address the burden placed on informal carers.

(2) Care: What is the Contribution of Formal or Informal Providers?

This section introduces the importance of considering informal dementia care in a threefold analysis: (a) an international comparison of the balance of formal and
informal care; (b) the need to support informal carers and; (c) interventions to maintain the carer-recipient dynamic.

An International Comparison of the Balance of Formal and Informal Care
Dementia is a major clinical and economic problem that is growing each year. United Kingdom figures on the distribution of care can be used as comparison by which to assess how prepared Ireland is (Figure 4).

![Pie chart comparison between Republic of Ireland (2007) and United Kingdom (2007)](image)

In Ireland the most recent figures were calculated by O’Shea et al. (2007) and in the UK similar data was produced by Knapp et al. (2007). Before comparing these figures, let us examine how they were derived.

In the Irish study by O’Shea et al. (2007), adjusted prevalence rates and costs from earlier study entitled ‘the Economic and Social Cost of Dementia in Ireland’ (O’Shea and O’Reilly 2000). In that study, the economic and social impact of dementia was assessed with respect to formal, indirect and informal costs, examining the resource implications over six areas: life years lost associated with early mortality, in-patient acute care, residential long-stay care, family care, and primary and social care in a community setting. This earlier research examined costs aggregated across all stages
of dementia care⁴ and motivates stage-related informal cost research presented in this thesis (for more details on the methodology, see Chapter 7). Measures of informal costs are drawn from earlier research by Blackwell et al. (1992) in which the opportunity cost method is associated to a random sample of carers. Chapter 3 adjusts these earlier estimates to present day values.

In the UK study by Knapp et al., the prevalence of dementia was elicited using an Expert Delphi Consensus. These prevalence figures were used to estimate numbers of people with dementia in the UK, in total, by sub-type, by severity, by time of onset (early or late), by differences between gender and by care settings. Drawing on comprehensive service use data (Schneider et al. 1999) and findings on informal care from the Caregiver Activity Survey (Davis et al. 1997), the study then estimated the costs of dementia attached to services, informal care and cost of lost productivity.

Figure 4 suggests that Ireland may have a greater reliance on informal care than the UK. With the presence of health and social care at 23%, in the UK, substantially less economic burden is placed on families. In 2007 O’Shea (O’Shea 2007) estimated the value of informal care using the opportunity cost method and indicated that the proportion of cost associated with informal care would rise to 76% if productivity loss (at national minimum wage) were also incorporated. These cost estimates reflect the societal value lost through sacrificing labour force to informal care. When comparing these estimates to those from the UK, on face value Ireland would seem to exhibit a high level of informal carer and inadequate investment in formal care.⁵

Dementia UK (Knapp and Prince 2007) further elaborates on informal care valuation by assessing annual costs of care by severity of disease and setting. These results reveal that, whilst levels of formal care (NHS and Social) remain relatively flat during dementia progression, demand for informal care increases (see Figure 5). This means that the formal services would not seem to adapt to the growing need as dementia progresses and the additional requirements of care are met by informal

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⁴ As the Irish estimates of informal care employed examine informal care aggregated across all stages, caution is advised when comparing with stage-adjusted cost in the UK estimates at the same time (Knapp 2007). A further note of caution in the comparison: national idiosyncrasies are likely to have been present in the nursing-home markets. However, both studies comprehensively review formal service utilisation data.

⁵ It has been argued that it is informal care acting as a complement to or driver for the availability of formal services (Bolin 2008); however, this point is likely to hold independently of the impact of direction of causality.
care. This raises a hypothesis that in Ireland the demand for informal care over time is increasing with progressive stages motivating the stage-specific valuation.

![Annual Costs of Care by Setting and Severity (Knapp et al., Dementia UK, 2007)](image)

**Figure 5:** Annual costs of care by setting and severity [Knapp, Prince et al., Dementia UK, 2007].

In Ireland, stage related costs of informal care have not yet been calculated. Applying the proxy-good value associated with specific symptoms of dementia helps account for total social welfare and preferences of the informal carers in accepting a formal substitute for their time. Chapter 7 explains in full detail the approach taken to estimate the hours of care per day at each stage of dementia and then how formal care costs are applied to stage specific symptoms in a proxy-good valuation.

Commonly, informal care is valued in terms of an opportunity cost of lost earnings. Spiess and Schneider (2003) noted that North European women who start or increase informal care showed a reduction in working hours. Henz (2004) found that a third of carers reported a disrupted work routine commonly resulting in stopping working. The analysis is extended to explore potential lost income resulting from current dementia care in Ireland, specifically examining absenteeism, productivity loss (presenteeism), early retirement or resignations to assuming a de facto role of carer. The role of cohabitation in making these changes is analysed to indicate underlying determinants leading to work-life changes.
The level of carer burden placed on informal care is significant but may be avoidable through appropriate services and intervention. For example, Schoenmakers et al. (2009) systematically review seven randomised control trials, (n=3,424) showing a small but statistically significant change in carer burden through drug treatment and concludes that the first line in treatment and intervention should be in assisting the carer to cope in their new role.

In summary, informal care serves as a major provider of dementia care and requires valuation as an integral part of the overall management of dementia. Part of appropriately valuing informal care is to ensure that carers’ inputs are understood and supported; so the next section presents evidence on supporting the carer and avoidance of carer burnout.

The Need to Support Informal Carers

“It is one of the truly heart-warming things about Alzheimer’s that so many partners and offspring quietly take on another’s chores and devote themselves, quite selflessly, to the care of someone they love.”

(Hampson and Jurd 2000, p.54)

Caring for a family member or relative has been referred to as the “hidden patient” where the carer often experiences adverse physical, mental and social outcomes (Fengler and Goodrich 1979). Caregiver burnout therefore presents a significant and immediate threat to the balance of care for people with dementia.

Professional and nonprofessional caregivers face multiple burdens which, if left unmanaged, can lead to burnout (Angermeyer 2006). Both face a similar degree of burden and require support to perform their role. The crucial difference in the case of informal care is that it is, by definition, unorganised and there is no limit on the hours individuals provide. The first objective for research is to explore the links between the carer’s perceptions of available services and how these perceptions are explained
by availability, or access to such services (Chapter 2 introduces this analysis, providing its basis in current Irish elderly policy).

Informal care is the mainstay in dementia care, but by its nature it is not formally organised and carers are prone to negative consequences from providing care. Various studies (Cuijpers and Stam 2000, Truzzi et al. 2008, Zarit et al. 1998, Yilmaz et al. 2009) have associated burnout with emotional exhaustion, decreased personal accomplishment and depersonalisation (an uncaring reaction towards care-recipient).

Cuijpers and Stam (2000) measure burnout using the Maslach Burnout Inventory\(^6\) (MBI), a measure designed in the United States for measuring occupational burnout in people-oriented professions, such as health care, social services, criminal justice and education. The study establishes at baseline that burnout is best explained by the level of emotional exhaustion and finds that burnout is most significantly explained by the level of supervision required and by the worry and strain placed on the relationship with the patient.

Truzzi et al. (2008) examine burnout in carers of Alzheimer’s disease by looking for correlations to socioeconomic and clinical variables, again by applying the MBI. They find the prevalence of burnout to be 17.4% and that burden of care is the only variable associated with burnout. Again, they concur that emotional exhaustion is the driving factor and find that severity and psychiatric morbidity are the most prevalent dimensions.

Yilmaz et al. (2009) further examine predictors of burnout in family caregivers for Alzheimer’s disease and find significant relationships with the caregivers’ anxiety, submissive approach for coping and the patient’s self-maintenance. All studies agree that greater research to determine the causes and consequences of burnout in the family caregivers is required.

In summary, the evidence suggests that burnout is directly linked to how carers react to such changes and to the patients’ stage of severity and level of psychiatric morbidity, all of which form the central focus of this thesis.

Irish and UK research generally agrees on the finding that informal care is a main stay in dementia care; however, the interaction between formal and informal care remains unclear. Recent empirical studies have indicated that informal care acts to complement first-line formal services (doctor, hospital care) and may replace formal community care (such as paid domestic care) (Bonsang 2009). This concept of informal care being a viable substitute may arguably decrease as the level of disability increases and only holds whilst the level of disability is low and does not require skilled care. This raises a question for research: should services for formal dementia care increase in tandem with need, severity or complications and if so, by how much?

The research summarised so far would indicate that, although Ireland health care spend is comparable to the OECD average, dementia may currently have half the OECD average level of available resources and the state’s contribution is around 6% of the total cost of dementia care. Results of the proxy-good method aim to indicate the level of potential service costs offset by informal care, arguing that the level of burden can be best captured by examining the formal market value of the care provided informally. It is maintained that there is a need to explicitly consider the efficiency of resource allocation for formal dementia care over competing disease related groups (reflecting the input by informal care). The next section examines what can be done to maintain this carer-recipient dynamic.

**Interventions to Help Maintain the Carer-Recipient Dynamic**

Within the global costs of dementia care (Wimo and Prince 2010), informal care is estimated to contribute 41.7%\(^7\). It is estimated that in Ireland 60–70% of individuals with dementia are living at home. Contribution by the formal sector in Ireland to the management of dementia appears to be minimal and decision makers need to allocate resources efficiently between dementia and other non-related chronic disease states (e.g. cancer, heart disease and stroke). Furthermore, assuming that a ring-fenced budget for dementia was to be put in place, such a budget is best allocated to resources or interventions which produce the greatest gains (technical efficiency).

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To indicate technical efficient interventions within dementia, research into the clinical and cost-effectiveness of interventions needs to be reviewed. Examination of the research for dementia specific informal care interventions reveals only limited economic documented evidence to indicate the long-term gains of such interventions (although this is more a reflection of the complexity of such research than an indication that interventions are not cost-effective).

As part of a health technology assessment Shaw et al. (2009) conducted a systematic review of studies on respite care services for the frail elderly. On study quality, the review concluded that large variations existed in the way research measured outcomes and therefore very few studies met inclusion criteria. Out of 104 papers initially identified, only 5 studies considered both the clinical and cost-effectiveness of carer respite (generally explained by a lack of a common outcome variable). Of the 5, 2 studies found some indication of a cost benefit.

Gaugler, Jarrott et al. (2003) found that intervention groups accessing subsidised adult day care at least twice per week reduced the informal carer’s time spent on behaviour problems, thereby lowering caring role overload and depression in carers. In a subsequent cost analysis, Gaugler, Zarit et al. (2003) demonstrated a cost-effectiveness ratio over the control group not receiving day care. The cost-effectiveness ratio amongst adult day service users indicated that the cost to improve caregiver outcome by 1 unit of depression was $2.90 per day. For a one unit improvement in role overload, the cost was $6.38 per day. Importantly, this study concludes that dementia caregivers who use these services consistently and for longer periods of time maximise effectiveness. Additional gains are produced by encouraging early utilisation of services during the caregiving career to increase the range of benefits.

Donaldson and Gregson (1989) conducted an economic evaluation of community support initiatives with a particular focus on family support units (FSU) in providing day and respite care. To ascertain the effectiveness of FSU, the study measured time spent in the community up until individuals were either admitted to long-term care or died. The formal costs of care and support services utilised whilst living in the community were also measured, as were the informal costs and benefits to the carers.
The study concludes that, despite additional costs of service, day care was cost-effective in part by observed savings accrued in reduced long-term bed utilisation.

Studies that have collected cost and effects data together are found to be limited and the synthesis of evidence from systematic reviews may provide effects data with good statistical power and robustness for decision analytic modelling. Systematic reviews are widely considered a gold standard in model-based economic evaluations. The effectiveness parameters resulting from meta-analysis of several randomised control trials provide greater certainty when associated with related local costs. Whilst it is the intention in this thesis to attempt to construct model-based economic evaluations, data resulting from one such meta-analysis is presented to illustrate the diverse range of interventions that effectively support the informal carer.

In their article ‘Helping Caregivers of Persons with Dementia: Which Interventions Work and How Large Are Their Effects?’ Pinquart and Sörensen (2006) summarise recent advances in the support of informal carers with the aim of clarifying which interventions offer the greatest effect. Evidence was gathered using a systematic search strategy and evidence on the effectiveness of interventions for carers was gathered from a total of 127 randomised control trials and draws on experiences containing approximately 5,930 participants.

For any particular interventions, a minimum of five controlled studies were required to meet the inclusion criteria. Data was extracted on caregiver burden, their subjective well-being (SWB), ability/knowledge of caregivers, depression, symptoms of care recipient and their risk of institutionalisation. Next five categorises of intervention were compared to ascertain the relative treatment effect. Finally this review conducted subgroup analysis to determine the effect of study characteristics to consider other potential sources of heterogeneity. The five categories of intervention were as follows.

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8 Collecting cost data was found in Ireland was evaluated in the early stages of this thesis and was not found to be feasible within the scope of this thesis (Trépel, 2009). Future planned research aims to examine the absence of the agreed costing framework and the proxy-good valuation is a contribution towards this debate.

(1) **Psychoeducational interventions** which are defined as structured training for carers and use role play and problem solving to prepare carers for their role. In contrast to a support group, this form of education is primarily focused on educating the carer. This was found to have wide-ranging impacts on several outcomes. To find more specific parameters on effectiveness, a series of systematic reviews appear in the literature. One review of the effectiveness of psychosocial interventions for carers of people with dementia (Pusey 2001) indicated inconclusive results from previous trials and concluded that more robust study designs were required. To motivate further research, a Scandinavian review by Stoltz (2004) examined both quantitative and qualitative research, concluding that there remained inconclusive evidence of any quantitatively robust effect but indicating family carers wish to network with peers for learning needs or social purposes.

(2) **General support** which as the name suggests is a more passive form of informal intervention. This intervention is similar to group counselling and offers the carers the opportunity of social interaction with people in a similar situation. The main outcome was found to be reduced social isolation and was associated with increased utilisation of formal services (Gonyea and Silverstein 1991).

(3) **Respite** which is planned, temporary relief for caregivers and can include day care, in-home and overnight respite. The hours of care required, particularly in late stage dementia, can be high. The main significant improvements were in the decrease of burden and depression and an increase in subjective well-being. The magnitude of the effects was small but the author finds that very few studies measure long-term effects. More recently, a Cochrane review evaluated respite care for people with dementia and their carers finding inconclusive evidence of benefits for the recipients or their carers (Lee Cameron 2008); the results reflect the lack of high quality research and call for better designed trials in this area. As with studies of clinical effect, limited robust studies which quantify the associated costs of respite care exist; Gaugler, Zarit et al. (2007) provide a feasible methodological framework to apply in future trial designs.

(4) **Cognitive behavioural therapy** (CBT) which is a form of therapy which develops a behavioural repertoire to help carers better cope with their situations. It is widely established that carers are at risk of depression through their caring (Alspaugh et al.
1999) and by instilling behaviours which enhance subjective well-being CBT is indicated to have a large effect on reducing depression.

(5) Counselling/case management which are blanket terms for methods which deal with family conflict with relevance to the carer role. Overall, the main outcome of counselling is to improve the feeling of burden experienced by the carer and, specifically, supportive interventions improve subjective well-being by helping the carer adapt to the role (Cooke et al. 2001). To further elucidate the effects of case management and to present the associated costs, the Personal Social Services Research Unit (PSSRU) conducted a quasi-experimental study of intensive case management (Challis 2002). By matching individuals on a number of key variables in the intervention arm and control group, the study concluded that after two years 51% remained at home, compared to 33% in the comparison group. Cost analysis finds that the total societal cost of case management to maintain individuals in the community is higher than the comparison group: £23,402 versus £19,053 per annum, respectively. The authors suggest these results are likely to indicate cost-effectiveness, particularly where the desired effect is to remain within the community. Furthermore, as case management in this study was initiated following institutionalisation in the first year, the gap between the group’s costs reduces in the second year.

Summarising Pinquart and Sörensen systematic review, interventions have domain-specific outcomes such as reducing burden, avoiding depression in caregivers, sustaining subjective well-being, enhancing carer ability and knowledge to cope with caring. These findings are further backed up by intervention specific research, but the general consensus is that the study design is a major limitation in this field.

The review recommends that optimal outcomes for caregivers and recipients are achieved by tailoring interventions to the specific goals of the individual (e.g. the needs of an employed carer supporting a parent may be different to that of a spouse). Combinations of interventions have been found to increase the positive effect on the various outcomes and were associated with a reduced risk of patient institutionalisation, particularly where “lasting changes in the lives of the caregivers” were made. The authors conclude that future research needs greater standardisation for effective comparison.
In summary, two risks are imposed on carers in their role which need to be considered when allocating resources for their support. Firstly, carers are most likely to reject the role during early stages of caring, therefore early intervention is important. Secondly, the duration of care giving is likely to be enhanced where the carer receives formal interventions.

This evidence should serve to indicate that, while trial designs may be flawed, various interventions are available. Etters (2007) reviews caregiver burden among dementia patient caregivers and further concludes that it is the ability to properly assess dementia patient–caregiver dyad that is critical to reducing negative physical and psychological health outcomes. Given that implementing any such interventions is unlikely to be cost neutral, the direct costs within a constrained health budget will require robust economic evidence. Etters et al. conclude that the variation in recipient-carer dyads needs to be assessed and the spectrum of heterogeneity reduces the ability to control the evidence available. Such potential variation in a scenario creates uncertainty for third party payers (e.g. a government or insurer) and may create substantial financial risk to their overall budget. In conclusion, further improvements in pragmatic research design may be required to address current uncertainty.

Given the potential uncertainty, and associated financial risk of providing care, the tendency is for countries to preferentially allocate research resources in search of a cure for dementia. International evidence would suggest that Ireland is currently investing eight times the European average on brain-related research (Sobocki et al. 2006), which is predominantly focused in the clinical and pre-clinical area.
Cure: Can the Prognosis in Dementia Be Altered?

A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

Nature Reviews Immunology 7(2), p. 162 (Perry et al. 2007)

The multi-causal characteristics of the various dementias entails that a cure may be represented by a continuum of outcomes ranging from improved quality of life, to significant symptoms control, to retarded onset and even disease reversal. In the search for a cure, researchers must meaningfully understand what a change in prognosis would look like (controlling for individual variation) and given this understanding, clearly define a positive outcome (which is likely to require greater understanding of the subtypes of dementia).

What does a dementia cure look like?
To date, there are no treatments available that reverse or halt disease progression and only modest reduction in progression has been demonstrated by medications or (more recently) cognitive training. The main pharmacological agents available are cholinesterase inhibitors (Ach-I) which inhibit the breakdown of neurotransmitter acetylcholine. Clinical studies have indicated improvements in symptoms and slowing of the progression in Alzheimer’s disease and certain other progressive dementias. Despite these findings, it has been widely argued that there is no

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10 Reduced level of acetylcholine is found in certain forms of dementia and associated with the reduced ability to form memories.
definitive proof that the disease course is actually altered (Clegg et al. 2001, Loveman et al. 2006). Memantine is a newer class of pharmacological drug which has the property of inhibiting an N-methyl-D-aspartate receptor (NMDAR). This action has been found to benefit those diagnosed with moderate to severe Alzheimer’s disease, particularly functional and cognitive decline. It is argued that there is little significant clinical improvement over the expected trajectory and that better defined studies may show benefits (Areosa and Sherriff 2003).

Only recently has the survival time for people with dementia been established in a prospective population cohort study (Xie et al. 2008). From a sample of 13,004 people, 438 who developed dementia were identified and followed between 1991 and 2003. The study established a median survival time for individuals diagnosed with a dementia of 4.1 years with an interquartile range of between 2.5 and 7.6 years. Variance in life expectancy is found to be significantly influenced by age, sex, marital status and compounding health status (such as frailty at the time of diagnosis). Specifically, younger onset dementia (under 70 years old) is associated with life expectancy of up to 10.7 years while the older old (aged over 90) are expected to live 3.8 years. Men lived on average 4.1 years while women 4.6 years. On average, a married woman is likely to live the longest, with the results from the Xie study suggesting a life expectancy of 7 years following diagnosis (2.8 years longer than married men). Single women have the worst prognosis living on average 3.3 years and 4.0 years in single men. Those who self-rated their health as ‘excellent’ survived an average of 4.9 years while those who self-rated their health as poor lived an average of 3.8 years, and the majority of variation was in females. The self-rated health in males associated presented a relatively flat prognosis.

Apart from an understanding of the life expectancy in dementia, dementia research also requires a better measure of quality of life. As dementia is in principle progressive, measurement of longevity and symptom control are limited and insensitive as measures of treatment effect. To ascertain to a greater degree how patients’ lives improve as a result of treatment, rigorous psychometric measures of health-related quality of life are required (Banerjee et al. 2006). Specific measures are required to be appropriate at all stages of dementia severity and particularly (in latter stages where communication breaks down) should be adapted to provide insights via a proxy (usually the caregiver). In response two health-related quality of
life measures were developed: DEMQOL and DEMQOL-Proxy. The first (DEMQOL) is a 28-item questionnaire which involves interviewing the person with dementia and the second (DEMQOL-Proxy) interviews the next of kin where cognitive impairment is substantial.

Moving Forward with Dementia Research

In application, the DEMQOL was used to evaluate Memory Clinics and indicated substantial gains in quality of life resulting from enhanced access to services (Banerjee et al. 2007). The study also revealed that contact rates with specialist services are found to be exceptionally low in dementia, ranging from 15 to 20% (Perry et al. 2007). Whilst evidence on clinical effectiveness of treatment remains relatively poor, this new approach to research reveals quality of life improvements are possible.

A Delphi experiment was conducted to elicit expert opinions in the absence of empirical data (Comas-Herrera et al. 2010). A panel of leading experts in the field of dementia research were asked to reach a consensus on the expected gains of scientific advances. The panel were moderately optimistic about the potential impact of scientific advances, but concluded that the likelihood of Alzheimer’s disease disappearing in the next 50 years was minimal. The panel examined projected future expenditure, agreeing that long-term care would increase somewhere in the range of 36% to 60% by 2031. Such an increase would fall short of the required increase in service level of 65% (which in itself is based on the modest assumption that there would be no change in incidence rate or cost of care or institutionalisation rates). Overall, findings suggest that (at best) there may be a small reduction in the prevalence of dementia in the next 50 years.

In 2008, government investment in Ireland on health related research was €199 million per annum (Health Research Group and Department of Health and Child 2008). Using data provided by the three leading public health-research funding bodies (Figure 6) suggests that 2.58% of the total could be spent on dementia specific research.11

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11 As no central database keeps account of research spend in Ireland, an audit of the investment in research associated to dementia in Ireland was a task undertaken by the Health Research Board and Science Foundation Ireland; their co-operation in providing these figures are greatly appreciated.
International comparisons of investment in brain research (Sobocki et al. 2006) would suggest that Ireland has the highest public per capita spend in Europe. Figure 6 would suggest that 40% is dedicated to dementia research. Given the returns of dementia research to date (vis-à-vis prevention of, provision of care or cure for dementia), public research spend should be refocused on strategies that reverse the loss in quality of life over the life expectancy of individuals (and their families).

The main message of searching for a cure is that while concerted efforts may lead to breakthroughs (e.g. from biomarkers or through drug combinations), policy planners are advised to work on the assumption that the discovery of a dementia cure is not imminent. Dementia research should be prioritised to inform the development of a robust national dementia strategy with guidelines addressing services capacity and enhancing the efficiency of the system.

Having established that research may be better focused on service delivery, the next section reviews national dementia strategies. Taking a sample of three countries with

Independent communication with the Higher Education Authority established the average investment they have made, primarily in changing infrastructure in Ireland. Comparative figures are limited.
comparable health expenditure to Ireland (namely UK, Australia and Norway) this section aims to illustrate what is feasible within a given budget.

1.2.ii A review of international dementia strategies

At the time of writing, dementia care is undergoing strategic change at the national and international policy levels. This thesis aims to place the specific research questions within a current international context. To achieve this, three national dementia strategies from countries comparable to Ireland are reviewed. All national strategies contain three pillars required for successful implementation: improve services outcomes, support informal carers and better monitor service demand. This thesis illustrates methodological approaches to provide information for each.

This section reviews dementia strategies planned or underway in three comparable health systems (UK, Australia and Norway) and position tangible research outcomes which are relevant to the future dementia strategy in Ireland.

(1) Living well with dementia: A National Dementia Strategy

The dementia strategy in the UK (Department of Health 2009b) envisages that dementia services will be positively transformed in three main areas. The first area is improvement of public and professional understanding and improved attitudes, thereby enhancing access to services and available provisions. Secondly, the programme will enhance diagnosis, treatment and support. Finally, the strategy provides an integrated pathway for dementia care (providing guidelines from initial diagnosis through to palliative care) with the aim of optimising quality in both formal and informal settings.

Living well with dementia explicitly details how the plan will be implemented and defines seven priorities. Firstly, every individual should have good quality early diagnosis and subsequent interventions. Secondly, community support services are to be enhanced. Thirdly, the strategy will also implement a previously defined Carers Strategy, which will provide information services, emergency respite and training programmes for carers (Department of Health 2008). Fourthly and fifthly, quality of
care in general hospitals and in care homes is to be enhanced. Sixthly, a central element is the implementation of up skilling the workforce to effectively work with dementia. The final priority is to ensure viability of the implementation through a *Joint Commissioning Framework for Dementia*; this was devised by the Department of Health (Department of Health 2009a) in which local commissioners establish demand for services by following World Class Commissioning Guidelines.

In summary, this strategic policy is closely linked with other policy initiatives (e.g. *Carers Strategy*), contains a detailed implementation plan and has dedicated resources to fund research and development. Importantly, the strategy provides a clear timeline in which the strategy will be implemented, explicitly making links to the national *Carers strategy* and is supported by commissioning guidance (Joint Commissioning Framework).

(2) **National Framework for Action on Dementia 2006–2010**

During the Australian Health Ministers Conference in 2006, the government agreed to the implementation of a *National Framework for Action on Dementia 2006–2010* (Australian Government Department of Health and Ageing 2006). The policy was developed to ensure a better quality of life by delivering ‘coordinated, effective support systems for people living with dementia (those with dementia, their carers and families’). To deliver this vision, the policy posits two objectives: Australians working together to make a positive difference and the government working with services to ensure access followed by an integrated care pathway.

The policy centres on seven principles. Firstly, people with dementia are valued and respected giving them a right to dignity and quality of life. Secondly, carers and families are valued and supported and their efforts are recognised and encouraged. Thirdly, people with dementia, their carers and families make decisions about care (patient centred). Fourthly, services will ensure the appropriate responses to individuals at various stages of the dementia continuum and fifthly, these services will be appropriate to their social, cultural or economic background, location and needs. Sixthly, central to this is an enhanced workforce which delivers quality care.
And the final principle places communities in a central role in the quality of life of people with dementia, their carers and families.

Implementation is based on five actions. Firstly care and support services should be flexible and respond to the changing needs. Secondly, access and equity of information, support and care are to be ensured regardless of location or cultural background. Thirdly, information and education is to be delivered and should be evidence-based, accurate and provided in a timely and meaningful way. Fourthly, dementia research will prioritise prevention, risk reduction and delaying the onset of dementia, as well as focusing on the needs of people with dementia, their carers and families. Finally, workforce and training strategies will be implemented to deliver skilled, high quality dementia care. Each action is broken into specific tasks and assigned to an appropriate ‘lead agent’ (e.g. government, state or territory). An implementation and evaluation framework assigns roles and responsibilities, defines collaborative agreements and ensures transparency and accountability in a governance structures (see Figure 7).
Figure 7: Governance structure, National Framework for Action on Dementia 2006–2010 [Source: (Australian Government Department of Health and Ageing 2006, p.18).]
In summary, the dementia strategy in Australia is based on a national vision which makes the role of the community central to its principles. The implementation is based on agreed outcomes with a clear and transparent governance structure.

(3) **Dementia Plan 2015: Making the most of the good days**

The Norwegian *Dementia Plan 2015: Making the most of the good days* (Engedal 2010) is a sub-plan within the *Care Plan 2015* (Helse- og 2007). Central to this is the policy *Directorate for Health and Social Affairs 2007*, which states “Glemsk, men ikke glemt” (Forgetful but not forgotten) and prioritises challenges, needs and recommendations for the elderly population.

The *Dementia Plan* (2015) focuses on three main areas: day programmes, living facilities better adapted to patient needs and increased knowledge and skills. The policy is guided by five principles. Firstly, ‘proper dementia care is proper care for everyone’ is a link to the *Care Plan 2015* and integrates the overall aim for quality and capacity to all users of care services. Secondly, an ethos of ‘openness and inclusion’ aims to counteract stigmatisation and discrimination related to dementia. Thirdly, an integrated chain of care ensures continuity and continued interaction with services. Fourthly, it has the objective of ‘Small is Beautiful’, whereby investment by the Norwegian State Housing Bank will endeavour to build smaller specialised units. Finally, it focuses on *respect and dignity* where quality of care services are tested, facilitating a form of ‘ethical reflection’ guiding health and social services.

Strategies and actions are divided into five groups, all of which are subdivided into long-term goals (post 2015) and actions for the first four years (up to 2015). The first strategy includes ‘quality development, research and planning for dementia care’ setting a long-term aim of delivering greater expertise through four years of research, development measures and local planning. The second ‘boosts capacity and improves skills’ by initially increasing continuing education (including in-service training) with the long-term aim of delivering the required number of specialised residences by 2015. The third strategy is to improve coordination and medical follow-up; the long-term aim of having correct specialist services is achieved by a four year programme evaluating regional action plans. The fourth strategy is “active care”, which will in the long term lay down the fundamental elements of integrated care services through short-term implementation models of respite care (including day care) and enshrining the rights to day programmes in law. The fifth strategy, ‘partnership with families and local
communities’ sets long-term goals for formal and informal care; while short-term goals are delivered through training caregivers, enhanced information campaigns and better coordination of volunteer work.

In summary, the Norwegian plan delivers long-term goals through short-term four year action plans. The strategy will enhance service quality, build capacity, improve collaboration, implement integrated care and enhance solidarity in all sectors of care. Ultimately, the plan is part of an overall strategy for carers and sets realistic goals to deal with future trends.

1.2.iii Ireland: A future dementia strategy

The previous three examples provide indications of the construct of dementia strategies in countries with a similar share of GDP allocated to health care. Whilst it could be argued that these countries have inherent differences in population size\(^{12}\), (resulting in varying economies of scale), population density\(^{13}\) and overall financial wealth\(^{14}\) (GDP per capita), the characteristics in these countries are overall more similar than different.

The main message from all the strategies is that change is not simply the results of a wish list of services but requires a detailed implementation plan with clear governance (as shown in Figure 7). Scarcity of resources needs to be explicitly considered and the source of required investment must be confirmed (e.g. Norway). Recognition of the importance of informal care should be stated. Care pathway are integrated, co-ordinating where possible with related policy initiatives.

In April 2010, a ministerial announcement declared a commitment to a national dementia strategy for Ireland. The strategy will be informed by social policy research funded by Atlantic Philanthropies and submitted to Government in December 2011. This commitment arises from recent international debate on dementia strategy where the need for an Irish dementia strategy was indicated. The argument presented indicated that Ireland had no national statutory policy or formal legislation to provide appropriate care for the elderly causing shortcomings in dementia care which needed to be strategically remedied (Cahill 2010).

\(^{12}\) Population size 2011 (million) Ireland: 4.59; UK: 51.9; Australia: 21.5; Norway: 4.86 (Wolfram Alpha)

\(^{13}\) Population density (people/km\(^2\)) Ireland: 66.6; UK: 256; Australia: 2.82; Norway: 16 (Wolfram Alpha)

\(^{14}\) GDP per Capita ($, thousand) Ireland: 47.6; UK: 36.4; Australia: 53.3; Norway: 53.3 (Wolfram Alpha)
A strategy for dementia was initially outlined in the *Action Plan for Dementia* (O'Shea and O'Reilly 1999). The action plan provided a clear timeline (three years) produced through wide consultation with stakeholders and estimated that the government would have to spend an additional €45 million to implement the strategy. A commitment to implement the strategy can be found in the government document *Quality and Fairness – A Health System for You*. To date the action plan has not been implemented.

The *Action Plan for Dementia* and the subsequent “*Implementing Policy for Dementia Care in Ireland: The Time for Action is Now*” (O'Shea 2007) provided a detailed implementation plan. Whilst the reasons remain unclear, no committee was ever established and therefore governance was not made visible. One significant source of market failure in the Irish health system is the low level of administrative information within the system available to evaluate the efficiency of services. To develop the knowledge of dementia care in Ireland, this thesis examines survey data with econometric methods to explain the experiences of end-users in the Irish health system.

The scarcity of resources was a running theme in the *Action Plan for Dementia* and cost-effectiveness research was presented for various interventions available for dementia.

### 1.3. The Aim and Three Specific Research Questions

As has been shown in this Chapter, the levels of care required in dementia places a substantial burden on both formal and informal carers, and there is a growing international agreement that policy makers should implement evidence-based dementia strategies to cope with the growth forecasted in demand. Of the three potential lines of managing dementia (prevention, care and cure), community care is found to be the mainstay. Three national dementia strategies reveal the general consensus that greater attention needs to be paid to community care and specifically the informal carers as well as the need for more formal services to provide appropriate services to those with dementia. After many years of effort and policy debate, Ireland is currently in a position to change its approach to dementia management.

This thesis aims to investigate the determinants of dementia care in Ireland and Europe. By asking three specific research questions, this thesis aims to inform policy debate on key...
determinants of dementia care pertaining to (1) perceptions of care, (2) value of informal care and (3) the level of formal service utilisation.

(1) What factors determine the Irish dementia population’s perceptions of care?

Persons with dementia (and their carer) often go unobserved and therefore little may be known about the outcomes of care. This question aims to investigate variables which will determine the perceptions of care of the end-users. To provide the background to this question Chapter 2 reviews Irish ageing policy, Chapter 6 explains the methods for the analysis of the perceptions of care and the results of which are presented in 10.3.

(2) How much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care?

Dementia becomes progressively problematic and much of this progressive demand for met by informal care. Irish research has not previously investigated how dementia progression increases burden placed on informal carer. This question aims to estimate the hours of informal care provided per day as dementia progresses from early to late stages. The cost of informal care is important information to a health care decision maker and this question further asks, what is the value of the informal care? Chapter 3 provides the background for asking this question by reviewing cost of illness studies and explaining the choice of the proxy-good method. Chapter 7 details the methodologies for estimating the amount of care by stage and associating values of proxy-goods.

(3) How is formal service utilisation influenced by depression in dementia?

One in two people with dementia are depressed and comorbidity increases the need for care. Despite the magnitude of the problem, there has been little research to elucidate the impact of depression on service utilisation in dementia. The final research question aims to estimate how service demand alters with depression. Chapter 4 provides a review of the background literature on depression in dementia. Chapter 8 explain how the incremental change in demand associated to depression in dementia is estimated.

The research conducted and presented in this thesis aims to answer these questions and provides important information to Irish policy makers on what determines dementia outcomes. All the findings will be discussed in 14.1 V, explaining their significance and implication for policy or future research.
PART II
LITERATURE REVIEW
Part II – Overview

Part II presents the literature review related to this thesis. The following three Chapters provide the literature base within which each of the research questions is asked.

Chapter 2 examines Irish ageing policy to provide a contextual background to the question: what factors determine the Irish dementia population’s perceptions of care?

Chapter 3 reviews the cost of illness and in particular the value attributed in research to informal care in order to provide the basis for the question: how much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care?

Chapter 4 reviews the clinical and economic literature on depression in dementia to motivate the question: how is formal service utilisation influenced by depression in dementia?
Chapter 2. Ageing Policy in Ireland

At the time of writing this thesis, strategic reforms of dementia care are being considered in the Republic of Ireland. However, there exists limited knowledge in Ireland about the perceptions of care of the end-user (individuals with dementia and their carers) or more importantly what determines these perceptions. To provide a contextual background to the first research question (what factors determine the Irish dementia population’s perceptions of care?), this Chapter examines the evolution of ageing policy in Ireland (2.1) and how perceptions of elderly care can inform future policy (2.2).

2.1. Ageing Policy in Ireland

One in five people in Ireland are projected to be aged over 60 by 2020 and rapidly changing population age-structures require correct management to ensure social, health and economic challenges are met. Despite a period of economic prosperity which resulted in increased health care expenditure (see Chapter 1.2), many areas of the health service, including elder care, are underdeveloped (O'Neill and O'Keeffe 2003).

Chapter 1 showed that formal services for dementia (health and social combined) were estimated to make up only 6% of the total cost of dementia care with 37% of care being attributed to nursing home costs and 57% of costs falling on informal care (i.e. family and community) (O'Shea 2007). Comparing these figures with comparable findings from the UK – where the financial contribution of formal services is 23%, nursing homes 41% and the informal sector 36% (McCrone et al. 2007) – allocation to formal services may be a cause for concern. Furthermore, international comparisons by Knapp et al. (2007) suggest Ireland’s long-term elderly care services available to those with dementia are approximately half the OECD average level. This figures raise important policy questions, specifically for dementia care, but more generally, for ageing policy.

In January 1990 the National Council for the Elderly was established, succeeding the National Council for the Aged (established in 1981). One of the Council’s primary
aims was to implement *The Years Ahead – A Policy for the Elderly*, a policy document published in 1988. The report aimed to provide guidance on how services should best enable an elderly person to live at home and how those who are unable to live at home should receive appropriate treatment, rehabilitation and care. To achieve this, the authors reviewed:

- Role and function of existing health and welfare services;
- Appropriateness of existing health and welfare services;
- Comparative effectiveness, efficiency and cost of alternative models and settings;
- Planning norms for residential and community services.

From the findings, the report made ten recommendations:

1. Services should be comprehensive and co-ordinated.
2. Promoting health should be a primary concern.
3. Housing policy should precisely establish housing conditions for the elderly.
4. Care in the home should be enhanced by improving capacity of services.
5. Community care requires appropriate transport and support services.
6. General hospitals should liaise with community services to ensure appropriate admission and discharge.
7. Community hospitals should provide a range of elderly care services.
8. Those with mental illnesses such as dementia should have access to appropriate services, and psychiatrists with responsibility for the elderly should be appointed as a matter of urgency.
9. Partnerships between carers, volunteers and statutory agencies should be established.
10. Implementation should include appropriate financing and changes to legal frameworks obligating authorities to provide services.

In 1993, *The Years Ahead* was adopted as a government policy and became influential in shaping the policies for the elderly in the Health Boards.

The National Council for the Elderly (1994) convened a round table discussion to develop a focused programme for positive ageing. The aim of the event was to

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consider the degree of social integration of the elderly to better understand attitudes to age

ing, to develop theories of positive ageing and determine whether such a theoretical framework for Ireland could be developed.

Four years on the National Council for the Elderly conducted a review to evaluate the implementation of the official government policy (Ruddle et al. 1998). On evaluation the report states that the policy document was ‘no longer an adequate blueprint for the development of older people’s health and social services’ and that no legal framework had been established to implement the recommendations. It was further stated that almost no extra spending had been directed to older people over this period (O'Neill and O'Keeffe 2003).

On the 19 March 1997, the Minister for Health established the National Council on Ageing and Older People (NCAOP) with a remit to advise the Minister on all aspects of ageing and the welfare of the elderly. In 1998 a new strategy entitled Adding Years to Life and Life to Years was published (Brenner and Shelley 1998). This renewed strategy aimed to deliver more tangible objectives based on a review of the health status of the elderly, identifying appropriate models of good practice, setting priorities and outlining definitive recommendations on how health gain would be achieved.

The following year the NCAOP published An Action Plan for Dementia (O'Shea 1999). Chapter 1 described this early blueprint for dementia care in Ireland. In 2001, the Irish government made a commitment to implement strategies outlined in the policy document, Action Plan for Dementia (Department of Health & Child 2001). A commitment was made to provide greater specialised dementia services, improved training and a variety of community support initiatives over seven years. In 2007 further research recommendations indicated a reluctance to deploy the expected resources and hence a lack of progress was evident (O’Shea 2007).

In a review of health care for the elderly in Ireland, O’Neill et al. (2003) indicate that specialist medical and psychiatric services for older people had increased rapidly in Ireland. Nevertheless, the review found implementation policies to be inadequate and financial commitment absent. The authors conclude that progress in Ireland requires legislative initiatives similar to the Older Americans Act (1965).
In 2003, the NCAOP published *Healthy Ageing in Ireland: Policy, Practice and Evaluation* (O’Shea 2003) to provide a comprehensive dataset on activities for health ageing, to examine health promotion initiatives, to provide models of best practice and the criteria for evaluation. The report concludes that ageism is a critical issue affecting older people and resources were required to combat society stereotypes.

In 2005 the NCAOP presented *Planning for an Ageing Population: Strategic Considerations* (O’Shea and Conboy 2005). The report presents population projections until 2021, concepts of dependency in old age and the evidence base for planning for the elderly. On developing a society for all ages, the report calls for the recognition of the positive contribution of the elderly to society, planning, nurturing and intergenerational relationships, and for an understanding of dependency, the implementation of home based models of care, integrated medical and social care and reductions in health inequalities.

In 2009, under the Health (Miscellaneous Provisions) Act 2009, the National Council on Ageing and Older People was dissolved. However, as Chapter 1 indicated, the current government has recently provided a commitment to dementia care.

More recently, international debate on dementia strategy has reasserted the need for local dementia care reform (Cahill 2010). In Ireland, the budget for dementia care is primarily provided from that for elderly care and therefore it is important to consider the wider background of ageing policy in Ireland.

2.2. Understanding Determinants of Perceptions of Care and Future Ageing Policy

The review of ageing policy in Ireland would suggest that care for the elderly population is determined by the supply side. However, little is known as to how society’s perceptions of care are formed. Are social inequalities influential in dementia care? Does the method of payment influence the perception of quality? Does the information individuals receive influence outcomes?

Significant health inequalities exist across the social classes in Ireland (Battel-Kirk and Purdy 2007, Balanda and Wilde 2001). Access to adequate health care is often
influenced by socioeconomic status and geographical location (Burke 2009). Reduced access and a resulting health inequity would represent an increased risk to in dementia.

Chapter 6 will explain the methods used to examine end-user perceptions of care; 10.3 presents results of how these perceptions are explained by key determinants. The results are discussed in Chapter 15 with the aim of informing policy planning in Irish dementia care.
Chapter 3. Review of Cost of Illness Studies

This Chapter reviews dementia cost of illness research and specifically techniques for the valuation of informal care. This provides the foundation for asking the second research question in this thesis: how much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care? To date, dementia research in Ireland has not provided stage-specific valuations for informal dementia care and this Chapter explains how the proxy-good valuation method is an appropriate choice to value care at progressive stages of dementia in Ireland.

3.1. Cost of Dementia Care

The Irish health care budget in 2010 was €14.83 billion and as part of a national recovery plan was scheduled to reduce by €727 million in 2011 and €1.4 billion by 2014. Dementia care budgeting is separated from other mental health services in Ireland and specialist services are covered by old age services (such as geriatric medicine and old age psychiatric), neurology, a few specialist services (e.g. memory clinics and specialist nurse services) and community support services (generally delivered by charities such as the Alzheimer’s Society and the Carer’s Association).

To determine the required budget for general mental health services, O’Shea and Kennelly (2008) examined the composite of health, social and other direct costs in Ireland. Time discounting to present day values would suggest the required budget for all mental health services is approximately €1.4284 billion.\(^{16}\) As dementia primarily falls under elderly services, earlier analysis merits examination to provide an indication of the direct costs of dementia care.

Given the absence of a commitment to a strategy for dementia care, there exists no clear policy on what should be spent on dementia care in Ireland. As such the costs of dementia care in Ireland were estimated in 2000 to be £125 million (Irish Pounds) or £250 million if informal costs are also included (O’Shea 2000). Table 1 (below) updates these estimates to present a potential present day equivalent by applying recent number of people with dementia in Ireland, time discounting the cost to present day and converting them to Euros.

\(^{16}\) Health and social care: €716.8 billion; other direct care: €286.8 billion giving a total of €1.003.6 billion in 2002. Time discounting at a rate of 4% (as per HIQA guidelines), produces a present day figure of €1.4284 billion.
Table 1: Adjusted annual costs of dementia care in Ireland in 2011 [Source: O'Shea, O'Reilly (2000)].

<table>
<thead>
<tr>
<th>Type of Care</th>
<th>Average Annual Cost of Care per Person in 2011 (€)</th>
<th>Numbers with Dementia in 2011</th>
<th>Total Cost of Care in 2011 (€ m)</th>
<th>Distribution of Dementia Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-patient Acute Care</td>
<td>6,462</td>
<td>1,635</td>
<td>11</td>
<td>1.38%</td>
</tr>
<tr>
<td>In-patient Psychiatric Care</td>
<td>49,623</td>
<td>596</td>
<td>30</td>
<td>3.85%</td>
</tr>
<tr>
<td>Community Care</td>
<td>2,227</td>
<td>40,631</td>
<td>90</td>
<td>11.78%</td>
</tr>
<tr>
<td>Residential Care</td>
<td>34,432</td>
<td>5,031</td>
<td>173</td>
<td>22.56%</td>
</tr>
<tr>
<td>Weighted Average Cost of Formal Care</td>
<td>6,347</td>
<td>47,893</td>
<td>304</td>
<td>39.58%</td>
</tr>
<tr>
<td>Informal Care</td>
<td>11,416</td>
<td>40,631</td>
<td>464</td>
<td>60.42%</td>
</tr>
</tbody>
</table>

| Total cost of Dementia (Formal and Informal) | 16,029 | 47,893 | 768 | 100.00% |

Cost have been adjusted to the value in 2011 by applying a national agreed discount rate of 4% (HIQA 2010) and applying the IR£ to EURO conversion rate of 1.26872. The total number of people with dementia has been increased to 47,893 based on most recent estimates (Cahill 2011) and given that there has been no national strategy has formally increased in-patient resources for dementia, assuming that the increased in prevalence of dementia has been absorbed by community and informal care.
Table 1 suggests that the portion of the direct health care budget for dementia services was €304 million in 2011. Excluding the cost of informal care, the breakdown of formal services indicates three important factors. Firstly, over half of all the formal cost of dementia care is residential care (e.g. nursing homes). Secondly, despite the assumption that the majority growth in the dementia population continues to be cared for in the community, the proportion of total cost spent on community services may have only increased by 1.78% since 1998. And thirdly, based on the assumption that formal provisions for dementia care have not changed since 1998, the funds available for in-patient care (as a percentage of the total cost of dementia) would have reduced from 8% in 1998 to 5.23% in 2011.

O’Shea indicates that the total cost of dementia care would double if the opportunity costs of informal care were included this would increase the present day societal cost to €768 million. Despite this large increase in overall cost of care, the authors indicate that the opportunity cost only partially reflects the value of care provided informally and states that such costs do not account for quality of life lost or psychological distress involved in the complex care required in dementia. This suggests that appropriate valuation of informal care may merit more sophisticated methods which capture underlying utility changes associated with care; the next section gives an overview of the various methods available to value informal costs of dementia care.

### 3.2. Informal Cost of Dementia Care

As the model for dementia care has shifted towards community care (Brown 1985, Morrissey and Goldman 1984), greater demand has been placed on the informal sector. The formal service costs offset by care provided informally may be substantial, but as Chapter 1 illustrated, over reliance poses various risks such as carer’s productivity loss (Koopmanschap et al. 1995) and caregiver burnout (Almberg et al. 1997).
Informal care can be defined as the production of commodities (such as providing basic nutrition, household maintenance, personal care and safety) which maintain the household unit. Dementia’s progressively incapacitating nature increases carers’ likelihood of experiencing diminished personal, physical, mental, social and/or financial welfare. Therefore informal care is best defined as ‘the dutiful act of basic concern given an anticipatable lower yield of personal welfare’ (Sen 1997).

As informal care often constitutes a substantial proportion of the total costs of health care (particularly in dementia) recommendations for the conduct of economic evaluation (Gold et al. 1996, Drummond and McGuire 2002) agree that the time given by informal care should be captured and valued.

The policy perspective adopted when valuing input to care determines the cost associable to care (Drummond et al. 2005) and subsequent budget allocations. As informal care often accounts for a substantial proportion of the total cost of dementia, a longstanding debate over valuation methods for informal care exists (McDaid 2001, Koopmanschap et al. 2008). Variability of these estimates is driven in part by national idiosyncrasies in funding mechanisms and the economic perspective prescribed by local guidelines. For example, previous Irish estimates employed contingent valuation by willingness to pay (valuing one hour of informal care in 2000 between IR£2–IR£4) (O'Shea and O'Reilly 2000) – although this is not strictly the cost of informal care but the individual’s valuation offset against the costs of care (McDaid 2001).

The method for valuing informal care must decide how much ‘weight’ a policy gives to the informal carer’s contribution. Direct and indirect costs (particularly in research protocols) are generally fixed entities; however, informal care has the ability to adjust where patients’ symptoms improve. In this case, changes to informal care can be valued as an output of an intervention. As such, the cost weight associated with providing informal care is important as it weights the value in this change. To better understand these values, the next section examines the dynamics of care and associated utility changes.
3.2.i Dynamics of care

Demand for care attributed to dementia ranks highly compared with other diseases (Murray and Lopez 1996). This demand is correlated to progressive cognitive, functional and behavioural impairment (Angermeyer et al. 2006). As decline is generally irreversible, individuals tend towards a state where they are completely dependent on care. This examination of the dynamics of dementia care is intended to demonstrate how, in a free market, the majority of burden falls on informal carers.

For the purpose of understanding the dynamics involved in dementia, a model of care can be simplified to the interaction of three agents: a formal agent (a provider in the health, social or voluntary sectors), an informal carer (provided by family, friends or the general community) and one recipient with dementia. In a perfect world, caregivers would allocate their optimal amount of time to providing care forming a market equilibrium in which their utility gain from care is optimal without reducing profits. The combinations of caregivers’ actions enhance the recipient’s health and utility state by receiving care. The social welfare in this system would be optimal where there is perfect information between all agents.

Such a first best equilibrium depicts an ideal situation and ignores the many nuances of reality where the production of care outputs by either formal or informal sources can be affected by externalities. For example, a formal carer may prioritise other competing disease-related groups in their client list, the level of care may be restricted by their service coverage or frequency of provision required may reduce their profits. Likewise, informal care may conflict with ensuring household income stays at a reasonable level, may clash with other family priorities or the required level of care may be limited by geographical proximity to the care recipient.

Externalities (such as employment or alternative family priorities) may conflict with providing the required care and induce a potential deficit in the number of hours which may be made freely available to the care recipients. This would form a hypothetical threshold number of hours which any care provider could provide at their maximum utility.

After this threshold limit, providing the additional required hours of care will carry an ‘anticipated’ disutility and may also produce negative effects for the care
provider. Motivation to accept extra hours will require a commitment to mitigate risk to the patient (e.g. an unsupervised individual is at risk of self-harm, actions may also result in injuring others, all of which increases demand on already scarce resources). As one (or more) optimality conditions can no longer be satisfied, a second-best equilibrium forms where accepting the deficit hours comes with the anticipatable lower yield of personal welfare (Sen 1997).

If demand for dementia care is generally inflexible, deficit hours will exert pressure on the system. Either the informal carers must increase their hours beyond their maximum or further formal provisions will be consumed within budgetary restriction. In either situation, the system has now become inefficient in terms of overall welfare.

In Ireland it is estimated that 60–70% of individuals with dementia currently live in the community (Wimo and Prince 2010). Furthermore, empirical evidence shows that informal care is primarily a complement to formal services and can only be a supplement where symptoms are not advanced (Bolin et al. 2008). Dynamics of care may cause a second best situation and appropriate policies are required to ensure social welfare.

The next section will give an overview of valuation methods available in informal care and explains the reasons why policy should consider full shadow prices using the proxy-valuation method to alter the market equilibrium.

3.3. Valuation Methods in Informal Care

This section firstly introduces the concept of valuation in informal care, then overviews common methods for valuing informal care and finally compares the opportunity cost method to proxy-good valuation.

3.3.i Introduction to valuation methods

As has been repeatedly shown, whatever valuation method is adopted, the costs of informal care in dementia tend to be considerable. Nevertheless, informal costs are
generally only a secondary requirement when policy is considering resource allocation (HIQA 2010). The probability that an individual may at some time provide informal care is high (Timmermans et al. 2001) and this contribution toward the total cost of health care may be considerable. By definition, informal care is not organised formally and as such often goes unnoticed in the total health care budget (Koopmanschap et al. 2008). The process of caring may increase the informal carers level of distress (Hirst 2005) and greater exposure to risk factors for mortality (Schulz and Beach 1999). To counteract the assumption that informal care represents a ‘zero-cost’ substitute for formal care, research and policy have seen increased efforts to accurately account for the value of these health care provisions.

To direct health policy, a monetary value of informal care can be incorporated into the cost function of the various forms of economic evaluation. In considering the effectiveness parameters of a cost-effectiveness analysis, the health gain (often measured in QALYs) can be combined with cost estimates based either on the opportunity cost method or a proxy-good valuation (Koopmanschap et al. 2008). In cost-benefit analysis, the continent valuation method or conjoint measurement are more routinely applied. Consideration of informal costs of care enhances the advocated ‘societal prospective’ for economic evaluation (Drummond et al. 2005). In practice, the wider societal components (such as informal care) are often ignored in place of the more commonly adopted ‘health care budget perspective’ (HIQA 2010) but perspectives restricted to the direct budget must still account for possible adverse events associated with informal care.

Posnett and Jan (1996) indicate that choosing the correct value method for unpaid inputs to a production function are important, particularly as costs are shifted from the health care sector to the community. This paper divides the informal inputs into two kinds: Non-Market and Quasi-Market activities. Non-market activities would be time spent in travelling, waiting, consultation, treatment and rehabilitation whilst Quasi-Market activities (such as nursing, care or housework) are activities which are otherwise available in a market where a shadow price may exist. The authors indicate that Quasi-Market activities become most important when the intervention under evaluation entails significant differences in the balance of provision between institution-based and domiciliary care. This paper sets out the theoretical basis for valuation by opportunity cost, suggesting that differentiation of the shadow prices of
work from leisure time is required and further suggesting that opportunity cost has the limitation of not capturing the output in producing health.

One important reason valuations of informal care are not routinely incorporated in economic evaluations is that there exists no one standardised approach to such valuations within health care evaluation (McDaid 2001).

To ensure that valuations of informal care are equitable across varying disease types, comprehensive valuation should consider the opportunity cost of losing human capital, the overhead costs of providing care and the value a carer would attribute to their time lost. One should consider the stock loss associated with the competences, knowledge and personality qualities reflected in the individual’s human capital (Becker 1993).

The next section will overview valuation methods used for incorporating informal care into economic evaluation, examining specifically proxy-good valuation, the opportunity cost method, contingent valuation and conjoint analysis.

### 3.3.ii Overview of common valuation methods for informal care

This section presents an overview of four commonly applied methods for valuing the input of informal care, namely: (1) Proxy-Good Valuation, (2) Opportunity Cost Method (3) Contingent Valuation and (4) Conjoint Analysis.

1. **Proxy-Good Valuation**

The proxy-good valuation aims to value time spent on particular informal care tasks at the cost of the closest market substitute. As such, the value of time can vary in accordance with the tasks required and therefore this approach to valuation requires a list of tasks performed and the proxy values of each task. As the costs of informal care obtained by proxy-good valuation are purely monetary, they can be incorporated into the cost side of all common economic evaluations and can also be combined with measures of health related quality of life to indicate health effects.

The main advantage of the proxy-good method is that it is relatively straightforward, requiring the proxy value to be calculated once and thereafter applied consistently in
varying situations. The proxy-good method has the disadvantage of assuming that formal and informal care are perfect substitutes and that quality or efficiency of care are constant. This indicates that the preferences of the care recipient or provider are not captured and changes in utility as a result of care not represented.

(2) **Opportunity Cost Method**

The opportunity cost method is the standard economic approach to valuing informal care in terms of the benefits forgone as a result of spending time in providing informal care. The method is particularly relevant as women who start or increase informal care show a reduction in working hours (Spiess and Schneider 2003) and a third of carers reported a disrupted work routine commonly resulting in stopping working (Henz 2004). The foregone benefits (or opportunities) are commonly accepted to be represented by the foregone earnings. This implies that informal care is equal to the individual wage rate times and the hours of time spent on care.

Koopmanschap et al. (1995) argued for an extension of the opportunity cost framework as he argued that the productivity loss was temporary and therefore the associated cost should reflect this. Under this modified framework, Koopmanschap argues that, in the period of absence for care, the costs should cover for a temporary loss of earning from work and also the cost of the replacement worker. As many informal carers are retired, this approach would give greater weight to losing potential workforce participants to informal care.

(3) **Contingent Valuation**

Willingness to pay methods elicit a monetary value for caregiving and provide both a societal and individual valuation of providing care to offset against costs of providing care (McDaid 2001). These techniques are not as yet widely applied to value informal caregivers.

Contingent valuation using willingness-to-pay analysis (WTP) is often applied to calculate a cost benefit ratio forming a relationship to the social welfare function. Sen critiques this type of approach stating that eliciting a valuation through WTP may not be meaningful as the value of money will vary between individuals (Sen 1997). More recent theory suggests that WTP also does not capture a ‘process utility’ in which a carer derives a utility gain from care (Brouwer et al. 2005).
Conjoint analysis is a method whereby individuals must make explicit trade-offs between alternatives. It can be used as a method to allow caregivers to indirectly express their preferences between specific scenarios involving differing amounts of time spent caring and access to formal care services. Conjoint analysis is not widely applied to value informal care (McDaid 2001).

The opportunity cost and proxy-good valuation methods have been most widely used in informal care valuations. However, to date the proxy-good method has not been used to value informal dementia care in Ireland. The next section presents the arguments for the application of proxy-good valuation over the opportunity good method.

3.3.iii Proxy-good valuation versus opportunity cost method

These two methods, whilst similar in nature are, in many respects, conceptually different: the opportunity costs method provides a value for the inputs of care whilst the proxy-good method is essentially valuing output (van den Berg 2006).

Opportunity cost gives a lower value to informal care and on the assumption that care is best valued by lost income, the value (or utility) of the intensity of care required may not accurately captured (particularly when the progressive severity of dementia is considered). An alternative argument is that the value of informal care is best captured by examining the complexity of care required to manage specific symptoms and associating formal care substitutes (van den Berg 2006).

Adopting the societal welfare framework, the concept of Pareto efficiency can be considered.\(^{17}\) In the example mentioned earlier of allocation between three disease groups (such as cancer, diabetes and dementia), the overall welfare gain for the three allocations should be maximised. By convention, most economic evaluations primarily consider health as the object of maximisation and all other utilities outside

\(^{17}\) Pareto Efficient: The situation where, for any alternative allocation of resources, the gains of one group would not be greater than the loss of another group.
health are assumed to be equal between groups. In cases where effects of ill health fall on informal care, the disutility is not captured within the health maximisation framework.

In a study comparing the proxy-good values with those using the opportunity cost method, van den Berg (2006) asked informal caregivers how much time they had spent on a range of informal care tasks during the week before the interview. The study surveyed 218 carers for recipients with strokes (S) and 147 with rheumatoid arthritis (RA). The study defines a value elicited by considering opportunity costs as the *foregone hours* of: a. paid work, b. unpaid work and c. hours of lost leisure time. For the proxy-good, labour market rates are applied to *time spent* on specific tasks with measures of time per task elicited by recall. The essential comparison in this study is therefore the *time foregone* whilst caring, compared to the *time spent* on the specific task of caring. In comparing the results obtained, the author finds that the two methods ‘yield different results’; the opportunity cost yields substantially lower estimates of the hours per week foregone (S: 12.4, RA: 9.5) than those of the proxy-good (S: 20.2; RA: 27.4). Furthermore, when a monetary value is applied to the time, further differences emerge. The author concludes that one major limitation of the opportunity cost valuation is that overhead costs of the informal carer are not captured and therefore the true costs of the outputs produced are not captured.

When these concepts are returned to the problem of a budget allocation constrained by limited resources, this evidence is intended to better inform a decision to achieve the maximum total societal welfare. In deciding the correct budget allocation, a third party payer will be best informed by considering both the supply and demand side factors. On the demand side, each disease state will induce demand for formal and informal care. However, the level of formal care available is determined by the resources available and how efficiently resources are used in each disease state. Therefore observing formal service use is only informative where an individual’s use is positive and unconstrained by access. Should a disease state be inappropriately resourced, the level of formal service demanded may be observed in the quantity of informal care. In such a situation, the informal cost of care may become an outcome variable sensitive to change.
Accurately capturing the level of disease-specific burden placed on informal carers provides important information where budgets are allocated between disease areas. Placing the correct weights by intensity of care required can reflect the degree of utility loss by providing care. Furthermore, this utility loss is a dutiful act only undertaken where there may be some utility gain (e.g. from caring for a loved one or by being paid appropriately for a formal service provided). Therefore, the proxy-good method assigns a higher value to the cost of informal care and reflects changes in utility of care.
Chapter 4. Depression in Dementia

Depression occurs in half of all cases of dementia (Lyketsos et al. 2002); however little is known about how it influences demand for health care services. The third research question asked in this thesis is: how is formal service utilisation influenced by depression in dementia? This Chapter presents the literature review for exploring this comorbidity, by detailing the economic importance of prioritising depression in dementia (4.1), the varying agreements in differential diagnosis (4.2) and key psychometric properties of comorbid depression (4.3).

4.1. Depression in Dementia: An Economic Priority

Forecasts suggest that there will be 42 million people with dementia worldwide by 2020 (Comas-Herrera et al. 2010) and with half of these people experiencing depression (Lyketsos et al. 2002), their disaggregated contributions to service demand are important to elucidate.

Depression and dementia are the two most common psychiatric syndromes in the elderly (Alexopoulos et al. 1988) and independently, both feature in the top 10 most burdensome diseases worldwide. By their very definitions and the frequency in which they coexist, differentiation of the two states is challenging. However, the interaction between dementia and depression offers substantial opportunities to efficiently manage projected rising costs in the care of the elderly. It has long been established that over half of all non-demented elderly patients with depression progress to develop dementia within three years (Reding et al. 1985). In some cases, cognitive impairment of depression is sufficient for a diagnosis of dementia but such symptoms are reversible (Rabins et al. 1984).

With expenditure for dementia predicted to increase 394% in the next 30 years (Comas-Herrera et al. 2010), the associated contribution of coexisting depression may be substantial. Comorbid depression in dementia is associated with severe negative consequences for patients and caregivers, such as considerable distress, and reduction in quality of life, and can exacerbate cognitive and functional impairment (Lyketsos and Lee 2004). Patients may also become physically aggressive, having
more frequent serious wandering (Lyketsos et al. 1999) and 4% reported a 'wish to die' (Hoogendijk et al. 1999). Through exacerbating the complications of dementia, depression emerged as the most expensive comorbidity in the dementia patient population (Husaini et al. 2000).

Aggregated figures for dementia have suggested that dementia consumes an amount comparable to 1% of the global gross domestic product (Anders and Prince 2010). While these estimates are useful for alerting policy-makers to the role of dementia in the ‘baby boom’ era, it is worth reiterating depression and dementia are the two most common psychiatric syndromes in older age, they commonly coexist and are nebulous in boundary. Furthermore, depression taken individually ranks as the highest burden of disease in middle to high income countries, with an estimated 32.5 million depression cases of aged 60 and over. The question is: given that these two syndromes both exhibit high prevalence and high burden of disease, and have a nebulous boundary could this result in double counting? There is no clear-cut way one can answer this question; however, the methodologies described in Chapter 8 aim in part to disentangle the contribution to demand for health services.

This thesis proposes to examine the effects of depression in dementia health care utilisation through comparing the incremental marginal effects of depression with that within a matched control group.\textsuperscript{18} The outcome variable for health service utilisation is the continuous count variable measuring how often the respondent has ‘seen or talked to a medical doctor in the last 12 months’. The hypothesis tests to what extent health care utilisation is the result of comorbid depression; the estimated effect will inform services required in the future.

How depression in dementia alters health care utilisation is therefore a complicated problem. To lay the basis for disentangling this problem, the remainder of this Chapter reviews the differential diagnosis that exists for this comorbidity (4.2) and thereafter the psychometric characteristics of a gold standard screening tool for depression in dementia are considered (4.3).

\textsuperscript{18} The control group was formed by propensity score matching with respect to age, socioeconomic status, level of physical disability and cognitive impairment.
4.2. Varying Agreement of Symptoms for a Differential Diagnosis

The standard diagnostic practice for depression in dementia is a structured psychiatric examination by a trained, psychiatrist with specialist expertise. However, definitions of depression vary.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) provides a diagnosis of a major or minor depressive episode. However, DSM-IV diagnosis is criticised for not containing criteria for Alzheimer’s depression and therefore a potential lack of sensitivity. Likewise, previous editions of the manual (DSM-III and DSM-III-R before 1992) had similar limitations.

An alternative classification to DSM-IV was first proposed by Lyketsos (1997) entitled Alzheimer Associated Affective Disorder. This suggests patients develop atypical affective states in which patients’ exhibit anhedonia (loss of pleasure), anxiety, and irritability rather than the common symptoms of depression (dysphoria). Related research by Lyketsos (2002) found that major depression, reported in 22% of cases, had substantially greater impairment in ADL, non-mood behavioural disturbance (such as aggression), and more frequent serious wandering (after adjusting for dementia severity). The authors concluded that efforts to identify and treat depression in dementia were warranted.

In 2002, Olin proposed modified criteria for ‘Depression of Alzheimer's’ stating that depression that often accompanies Alzheimer’s is different from that of the general major depressive disorder (Olin et al. 2002). The major differential features from the conventional disease profile of depression are symptoms of withdrawal and social isolation. Based on these observations, changes to the DSM-IV-TR were proposed, including emphasis on loss of pleasure over the conventional loss of interest (i.e. apathy), inclusion of irritability as a symptom of depression and for increased specificity the removal of symptoms of ‘diminished ability to think or concentrate’. Olin’s criteria further suggested that the total number of symptoms (i.e. threshold level) required to meet criteria be reduced for diagnosing depression.
4.3. Psychometric Properties of Comorbid Depression

Given the debate over what constitutes depression in dementia, diagnostic practice varies. As such several standardised instruments for detecting depression in dementia patients are used.

Global neuropsychiatric rating scales are developed to rate patients with dementia and quantify depression in the context of other neuropsychiatric symptoms (Lyketsos and Lee 2004). These scales are brief and quick-to-administer and are composed of seven to nine items for each of the twelve domains. Popular in the mid-1990s, these scales established several important measures of neuropsychiatric symptoms: these include frequency and severity of symptoms, items that are specific to populations with dementia and standardised ratings of domain frequency (Medeiros et al. 2010). As a universal tool for neuropsychiatric symptoms in dementia, these recent studies find them to be accurate and of use for pragmatic clinical trials.

The most popular disease-specific tools for depression are the Montgomery-Asberg Depression Rating Scale (Montgomery and Asberg 1979) and the Hamilton Depression Rating Scale (Hamilton 1960); both are clinician-rated scales. The HAM-D is the recognised gold standard measurement in depression treatment studies; however, it was developed for use in cognitively intact patients. For this reason, specialised tool have been developed for depression in dementia.

The Cornell Scale for Depression in Dementia (CSDD) is an instrument specifically designed and commonly used for people with dementia, as it was found to have good accuracy for detecting depression (Alexopoulos et al. 1988). The CSDD has been found to be more sensitive to the detection of treatment effects at all levels of depression severity than both HAMD and NPI (Vida et al. 1994a).

Whilst there continues to be clinical debate on what constitutes depression in dementia, for the purpose of the study of health service utilisation, it is useful to examine the psychometric properties of the CSDD. This tool examines depression over five domains mood, behaviour, physical signs, cyclic functions and ideation (see below; items in bold print are depression measures particularly relevant to the analysis of SHARE):
1. **Mood related signs** measure anxiety, sadness, lack of reactivity to pleasant events, **irritability**.

2. **Behavioural disturbances** measured include **agitation**, retardation, multiple physical complaints and acute loss of interest.

3. **Physical signs** of depression in dementia are appetite loss, weight loss and **lack of energy**.

4. **Cyclic function** examine changes over the progress of a day, such as diurnal variation of mood, **difficulty falling asleep**, multiple awakening during sleep, early morning awakening.

5. **Ideation disturbances** include the common risk factors of depression such as thoughts of **suicide**, self-depreciation (self-blame, self-esteem, feeling of failure), **pessimism** and mood congruent delusions (delusion of poverty, illness or loss).

The CSDD is a comprehensive inventory of potential symptoms of depression specific to dementia. Vida et al. (1994b) established the tool as a highly accurate tool for major depression with sensitivity at 90% and specificity of 75%. Most studies of the CSDD to measure depression in dementia have been in acute setting as this tool is time consuming to administer and can prove burdensome to patient and clinician.

0 presents the various methodologies employed to answer the three specific research questions. Chapter 5 will in part introduce the Survey of Health Ageing and Retirement in Europe (SHARE), which includes a standardised measure of depression in the elderly population that contains many items relevant to depression in dementia. Chapter 8 provides a full description of the methodological approach taken to isolate the incremental effect of depression on health service utilisation in the dementia population.
PART III
METHODS
Part III – Overview

Part III presents and discusses the data, methodologies and limitations of this research. To reiterate, the aim of this thesis is to investigate the determinants of dementia care as they pertain to perception of care, value of informal care and the level of formal service utilisation. To explain the methods employed to achieve this aim, the methodological part of this thesis presents the following five Chapters:

Chapter 5 introduces the two datasets (ASI 2007 and SHARE) used in the analysis to answer the research questions, highlighting their appropriateness to the overall objective and their relevance to specific research questions.

Chapter 6 presents the regression methods used to investigate the question: what factors determine the Irish dementia population’s perceptions of care? This Chapter defines the variables, explains how data is analysed and provides the model specification for the series of logistic regression.

Chapter 7 explains the methods applied to answer the questions how much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care? The Chapter explains how informal inputs into care were measured, the range of individual characteristics, functional limitations and behavioural disturbance used to estimate informal care time by stage and how the proxy-good method was applied to these estimates.

Chapter 8 presents the third methods section relating to the question: how is formal service utilisation influenced by depression in dementia? The first section describes the dependent and independent variables. The next section describes preliminary logistic analysis to ascertain the role of conventional depressive symptoms in predictions of dementia to ascertain a baseline equation for matching. Next, one to one matching methods are detailed to explain how quasi-experimental conditions are created. The final section, presents how health care utilisation is modelled using two stage regressions.

Chapter 9 presents the limitations of the data and the potential implications for the findings to be discussed in PART IV.
Chapter 5. Datasets for a Study of Dementia (ASI 2007 & SHARE)

Two datasets were selected to provide specific information about the dynamics of dementia care. These were considered best placed to investigate the determinants of dementia care as they pertain to perception of care, value of informal care and the level of formal service utilisation.

An explanation of the methodological approaches taken to answer the three specific research questions requires a thorough understanding of the two datasets utilised. Each dataset has its own section which provides (i) clear information on the original purpose of each survey, (ii) to whom the responsibility of conducting the survey fell (and to what end) and (iii) what role the survey will play in the subsequent analysis.

Section 5.1 introduces the “A Carer’s Survey, 2007” (conducted by the Alzheimer Society of Ireland) showing its relevance to the first two research questions; (1) What factors determine the Irish dementia population’s perceptions of care? and (2) How much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care?

Section 5.2 introduces the Survey of Health, Ageing and Retirement in Europe (SHARE). This dataset is a comprehensive longitudinal study of the population over 50 in several European countries and as such has information which allows this thesis to research the question: how is formal service utilisation influenced by depression in dementia?

In this section, the Alzheimer Society of Ireland’s A Carer’s Survey, 2007 (from here forward referred to as ASI, 2007) is introduced.

To explain the original purpose of the survey, the Alzheimer Society of Ireland and its role as a service provider, its in-patient centred research and its advocacy work are introduced. To introduce ASI 2007, the next section explains the intention of the survey and to whom the responsibility for conducting the survey fell (5.1.ii). The final section (5.1.iii), answers the question, what role does the survey play in the subsequent analysis?

5.1.i What was the original purpose of the survey?

The Alzheimer Society of Ireland19 is a national voluntary organisation which aims to promote quality of life for those affected by Alzheimer’s and related dementias. It has become a leading national contact point and a specific service provider for people with a dementia in Ireland.

The original purpose of the ASI 2007 survey is best explained by examining the roles of the Alzheimer Society of Ireland. This section introduces the Alzheimer Society of Ireland and explains the purpose of the survey by reviewing three key activities of the Society, namely: (1) their network as a service provide that provides a vantage point to collect data on the dementia population in Ireland; (2) the Society’s track record in research and; (3) their policy agenda using evidenced-based approaches to advocate better dementia care.

(1) Service Provider Network

The Society was founded in 1982 through a small group of family members who recognised an unmet need for those with dementia and their carers. Today, the society has become a national voluntary organisation with six regional offices and services all over Ireland. Services aim to provide, home care, day care, overnight

19 The Alzheimer Society of Ireland, Alzheimer House, 43 Northumberland Avenue, Dun Laoghaire, Co. Dublin, Ireland. Phone: 353 (0)1 284 6616 Fax: 353 (0)1 284 6030 E-mail: info@alzheimer.ie Web: www.alzheimer.ie
respite at a national respite centre, family carer training, carer support groups, social clubs, a national contact helpline and an advocacy service. In total the society comprises 16 branches, employing around 700 staff members (as well as providing a total of 115 specialist services). As a result the Society's network cares for a total of approximately 3,000 members with dementia across Ireland. The national office in Dublin controls the core functions of the society coordinating information, fundraising, public relations, training, finance research and policy. The service is a run by a combination of fund raising and investment by the Health Service Executive (HSE).

(2) A Track Record in Research

Apart from providing services, the Alzheimer Society of Ireland, has become a nationally recognised advocate for the rights of those with dementia. As such, apart from catering for the everyday needs of those living with dementia, it also makes collaborative links with academic institutions to produce research with the aim of encouraging evidence-based policy in dementia. Since 2005, the society has produced four internationally recognised reports, which provide important insights into the needs of those living with dementia.

*In Early Onset Dementia: A Needs Analysis of Younger People with Dementia in Ireland* (Haase 2005), builds on the ‘Action Plan for Dementia’ (O'Shea and O'Reilly 1999). This research highlights that no specific programmes are currently available for those with early onset and that by 2016 there will be an estimated 5,000 people with early onset making up approximately 10% of the total dementia population.

The following year in conjunction with Trinity College Dublin, the Society examined the Perceptions of Stigma in Dementia: An Exploratory Study (Alzheimer's Society of Ireland and Trinity College Dublin 2006). This provided a salient qualitative investigation into the understanding, construct and fear of discrimination associated with stigma related to dementia. This research makes strong, grounded recommendations in terms of policy, service and information required to counteract stigma. Firstly, policy needs to form a priority for those with dementia which reflects the additional risk perpetuated by stigma. Secondly, that service level needs to form a dementia care continuum and that this integrated care pathway is must be the
responsibility of a community case manager. And finally, the society maintains that a minimum standard of information be provided at every diagnosis and that such a campaign should be augmented by enhanced public awareness.

Despite rigorous academic research and subsequent government commitments, Ireland’s attempts to reform dementia care have been unsuccessful. Policy analysis suggest a lack of governance structure to drive the process (Kinsella and Leddin 2010, p12-39) and avoidance of financial commitment (Keane and O'Neill 2009, p. 147-170 ) are often the main hurdles in implementation. In 2007, the Society worked with Eamon O’Shea (Irish Centre for the Study of Gerontology, Galway) to outline the implementation strategy for his ‘Action Plan for Dementia’ proposed in 1999 (O'Shea and O'Reilly 1999). The aptly entitled report Implementing Policy for Dementia Care in Ireland: The Time for Action is Now (O'Shea 2007) repositions the strategy providing explicit budgetary requirements based on grounded economic techniques. The report calls for a significant public investment in dementia care and that dementia should be established as a national health priority.

The most recent formal publication by the Society examines the continuation of care for people with dementia. In collaboration with Professor Murna Downs (Professor of Dementia Studies and head of the international research centre, Bradford Dementia Group20), the Society examines the Irish family carer's experience, where a relative transitions into a nursing home (Downs et al. 2010). This research focuses on the decisions, experiences and changes in roles of the care provider as people with dementia move into long-term care. The research calls for greater persuasive, proactive and preventative leadership by community-based practitioners (e.g. GPs, late life psychiatrists and social workers) and clearer governance lead planning on proactive planning admissions and accountability in assisting people to navigate through the health system.

As the summary of the four papers presented here would indicate, research focuses on the direct needs of the end-user and recommendations are action orientated. This research highlights a developed research structure (be it non-academic) and provides a platform for policy initiatives.

20 http://www.brad.ac.uk/health/dementia/
Drawing from their unique contact point, the Society has produced the evidence base required by many decision makers, and senior staff at the Society regularly engage in the political debate. Recently, the economic downturn in Ireland placed pressure on the public health budget and the Society presented economic arguments to defend funding received from the Health Service Executive (HSE) for the services the Society provides to the Irish population with dementia.

In pre-budget talks the Society lobbied to protect current community funding (approximately €14.61m), extend coverage to a waiting list of 1,000 people with dementia (requiring a further €4.6m) and develop a structure of case management for those with early onset (€0.35m). To support the argument, extracts from this thesis were presented in a report to members of Dáil Éireann specifically raising concern that dementia expenditure may be half the OECD average and that future dementia research needs to focus on correcting systemic inefficiencies in dementia care (Trépel 2010). Whilst it should be accepted that international comparisons are subject to limitations, this point raised two key policy issues. Firstly, the low level of allocation to long-term care raises the question of whether dementia care is correctly resourced. Secondly, appropriate resourcing requires robust evidence and to provide such evidence, this thesis aims to examine perceptions of current care, demand for informal care and formal service utilisation. The pre-budget submission and associated report raised substantial media attention appearing in several national news articles and helped to stimulate the following political discussion.

Leading on from budgetary discussion and with renewed governmental commitment to a national dementia issues strategy, Nessa Childers, MEP, organised a national conference entitled Shared Priorities – The Dementia Agenda in Europe and Ireland. Preliminary results from this thesis were presented at the conference raising awareness of the need for clearer measures of output in Ireland’s commitment to a strategy. As such this thesis has joined the groundswell of research activity in forwarding the dementia strategy in Ireland.

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21 An extract from Chapter 1 were presented by the author at a pre-budget meeting in Dublin in October 2011 to Dáil Éireann with an audience of forty politician including the former Minister for Older People (Aine Brady, T.D.) and the current Minister for Finance (Michael Noonan, T.D.).

In summary, the Alzheimer Society of Ireland is a group that engages at the service level and also advocates patient rights through policy and research. The next section introduces the survey, detailing how it was conducted and to whom the responsibility for collecting data fell.

5.1.ii Who conducted the survey?

A Carer’s Survey, 2007 aimed to outline the experience of carers for people with dementia registered with the Alzheimer Society of Ireland. The questionnaire was adapted from a survey *Who Cares: The state of dementia care in Europe* conducted by Alzheimer Europe (2006). This earlier survey sampled approximately 1,000 caregivers for people with dementia in France, Germany, Poland, Scotland and Spain. Results revealed that at the time of diagnosis dementia carers were not well informed, were not receiving basic support services and were expected to contribute substantial finances towards services.

The Alzheimer Society of Ireland repeated the questionnaire (with minor changes) to obtain comparable local measures and to establish a European baseline. The main objectives of the society were to:

- Gain a profile of carers and persons with dementia;
- Understand carers’/persons’ experience of diagnosis;
- Evaluate information and support systems that are available to carers;
- Investigate the medication used by persons with Alzheimer’s Disease/Dementia;
- Gain an insight into training and knowledge that carers have or would like;
- To understand carer’s perceptions of the services currently available to them ('Living with Dementia – The Experience of Carers in Ireland' (Keogh 2007).)

A questionnaire comprising 43 questions was developed to assess various components of the care-recipient/caregiver dynamics. This questionnaire more or less replicated a questionnaire used in a number of European countries so as to facilitate multi-country comparisons (however, to date availability of this full survey is still pending). The collection of the data was commissioned through a professional
tendering process and Millward Brown Lansdowne (MBIMS, a market research consultancy based in Ireland) was selected to administer the data collection. The distribution of the survey was through the Alzheimer Society of Ireland’s existing network. Questionnaires were distributed to 720 randomly selected members registered on the society’s database. Carers were asked to complete the survey and return it directly to Millward Brown Lansdowne in a pre-paid envelope. Of the 720 distributed, a total of 270 questionnaires were returned giving a response rate of 38%. The fieldwork phase of this took place between the 2nd July and 10th August 2007 and the data was thereafter compiled by Millward Brown Lansdowne. The data was subsequently presented by the research and policy team at the Alzheimer Society.

5.1.iii What role does the survey play in the subsequent analysis?

This section explains how the survey was obtained for the research in this thesis, what preparatory work was required and what role the survey plays in the subsequent analysis.

In preparation for devising this PhD thesis, in the last week of January 2008 a series of meetings were organised in Dublin with relevant personnel for the topic under proposal, including meetings at HIQA and the Mental Health Commission, and with Old Age Psychiatrists, policy analysts at Trinity College and the Alzheimer Society of Ireland.

In organising initial discussion of this proposed research, the Alzheimer Society stated:

\begin{quote}
We have a research department which commissions research externally, carries out research, fund PhD work and supports other researchers who are pursuing a topic that is of interest to us here in the Society. We have a small research committee that examines all the external requests for support. Our decision to support a researcher is based on a number of factors including the type and nature of the research and its relevance to the Society as well as our capacity at the
\end{quote}
time of the request. We are currently supporting and gate keeping for a number of post graduates. Our aim is to support niche pieces of research that the Society can use to further the policy and practice agenda for people.

For research undertaken for this PhD, no funding at any time was requested from the Society and reports to support its pre-budget submission were provided pro bono.

The initial meeting with the Society was on the 30 January 2008 and was attended by Grainne McGettrick (Policy Officer) and Catherine Keogh (Care Practice Coordinator). The primary aim of this meeting was to detail the proposed research and ascertain local knowledge in order to make the economic research relevant to Irish dementia policy.

At the meeting, Ms Keogh reviewed her work in conducting the Alzheimer Society of Ireland – A Carer’s Survey, 2007. At this time, the survey represented the most up-to-date snapshot of the experiences of carers in Ireland for individuals with dementia. A report and a presentation had at that time disseminated the findings; however, as the survey had been undertaken by a market research agency (MBIMS), only summary statistics had been produced for the Society and MBIMS retained the primary data.

On explaining the potential relevance to the topic of this thesis, the Society initiated contact with MBIMS to obtain the primary dataset. After an exchange of correspondence, the dataset and a codebook were provided for this research. The dataset was initially compiled in SPSS and was later converted to STATA for econometric analysis. The Society provided a copy of the questionnaire used in the survey (see Appendix 1).

Following preparation of the data for analysis, the potential for further analysis was evaluated using summary statistics (for more details, see Chapter 10). The analysis aimed to examine two key questions: firstly, what were the outcomes of dementia care in Ireland and secondly, how much informal care was provided.
On examining the viability of data for the first aim, it was found that the survey had collected various explanatory variables and question 43 of the survey had collected information on the carer’s perceptions of care and services. Further information on the preparation of the data for analysis using logistic regression is provided in Chapter 6.

The survey was found to be particularly useful for analysing the level of informal care as all respondents were asked to indicate how many hours per day of care this provided. Furthermore, ASI 2007 measured impairment in various activities of daily living, behavioural disturbance and also logged the most recent stage of dementia. From these variables, using Tobit analysis and recent costing guidelines from HIQA, the following research question was posed: how much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care. Full details of the set up and subsequent analysis are provided in Chapter 7.

In summary, ASI 2007 was obtained from the Alzheimer Society of Ireland, independently prepared and analysed, and summary statistics are presented in Chapter 10 and results related of the first of the specific research questions is presented in 10.3 and Chapter 12.
5.2. Survey of Health, Ageing and Retirement in Europe (SHARE)

This section introduces the *Survey of Health, Ageing and Retirement in Europe* (SHARE). Following the same format as Section 5.1, this section will answer the following three questions about SHARE:

1) What was the original purpose of the survey?

2) Who conducted the survey?

3) What role does the survey play in the subsequent analysis?

5.2.i What was the original purpose of the survey?

*The Survey of Health, Ageing and Retirement in Europe (SHARE) is a multidisciplinary and cross-national panel database of micro-data on health and socioeconomic status as well as the social and family networks of more than 45,000 individuals aged 50 and over.*

In response to calls by the European Commission for a European Longitudinal Survey of Ageing provided through co-operation of member states, SHARE was created in 2002 at the Mannheim Research Institute for the Economics of Aging,\(^{23}\) which today is part of the Munich Centre for the Economics of Aging (MEA). Data collection for Waves 1–3 was primarily funded by the European Commission through the fifth framework programme. SHARE was primarily co-ordinated by Axel Börsch-Supan (MEA) with team members also in Italy and the Netherlands. Today, more than 150 researchers from various disciplines and from a variety of leading international teams form the working groups for SHARE. Overall 18 countries were or are involved with SHARE (details summarised in Table 2 below).

\(^{23}\) [http://www.mea.uni-mannheim.de](http://www.mea.uni-mannheim.de)
Table 2: Summary of the countries participating in Survey of Health, Ageing and Retirement in Europe [Source: SHARE].

<table>
<thead>
<tr>
<th>Country</th>
<th>2004</th>
<th>2006</th>
<th>2008</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Austria</td>
<td>1,885</td>
<td>5.73%</td>
<td>1,334</td>
<td>3.70%</td>
</tr>
<tr>
<td>Belgium</td>
<td>3,793</td>
<td>11.53%</td>
<td>3,147</td>
<td>8.72%</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>0</td>
<td>0.00%</td>
<td>2,793</td>
<td>7.74%</td>
</tr>
<tr>
<td>Denmark</td>
<td>1,692</td>
<td>5.14%</td>
<td>2,575</td>
<td>7.14%</td>
</tr>
<tr>
<td>France</td>
<td>3,165</td>
<td>9.62%</td>
<td>2,930</td>
<td>8.12%</td>
</tr>
<tr>
<td>Germany</td>
<td>2,999</td>
<td>9.12%</td>
<td>2,553</td>
<td>7.07%</td>
</tr>
<tr>
<td>Greece</td>
<td>2,884</td>
<td>8.77%</td>
<td>3,233</td>
<td>8.96%</td>
</tr>
<tr>
<td>Ireland</td>
<td>0</td>
<td>0.00%</td>
<td>1,124</td>
<td>3.11%</td>
</tr>
<tr>
<td>Israel</td>
<td>2,573</td>
<td>7.82%</td>
<td>0</td>
<td>0.00%</td>
</tr>
<tr>
<td>Italy</td>
<td>2,542</td>
<td>7.73%</td>
<td>2,959</td>
<td>8.20%</td>
</tr>
<tr>
<td>Poland</td>
<td>0</td>
<td>0.00%</td>
<td>2,450</td>
<td>6.79%</td>
</tr>
<tr>
<td>Portugal</td>
<td>0</td>
<td>0.00%</td>
<td>0</td>
<td>0.00%</td>
</tr>
<tr>
<td>Slovenia</td>
<td>0</td>
<td>0.00%</td>
<td>0</td>
<td>0.00%</td>
</tr>
<tr>
<td>Spain</td>
<td>2,371</td>
<td>7.21%</td>
<td>2,172</td>
<td>6.02%</td>
</tr>
<tr>
<td>Sweden</td>
<td>3,031</td>
<td>9.21%</td>
<td>2,715</td>
<td>7.52%</td>
</tr>
<tr>
<td>Switzerland</td>
<td>995</td>
<td>3.02%</td>
<td>1,454</td>
<td>4.03%</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>2,965</td>
<td>9.01%</td>
<td>2,644</td>
<td>7.33%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>32899</strong></td>
<td><strong>100.00%</strong></td>
<td><strong>36089</strong></td>
<td><strong>100.00%</strong></td>
</tr>
</tbody>
</table>
SHARE also forms part of a larger global ageing research agenda by being harmonised with the Health and Retirement Study\(^{24}\) (HRS) conducted at the Institute for Social Research (ISR) at the University of Michigan, USA and the English Longitudinal Study of Ageing \(^{25}\) (ELSA), led by Professor Sir Michael Marmot and jointly run by teams at University College London (UCL), the Institute for Fiscal Studies (IFS), the National Centre for Social Research and the University of Manchester. There are also several national studies following a similar model to SHARE being developed in Ireland: for example, The Irish Longitudinal Study on Ageing\(^{26}\) (TILDA) co-ordinated through Trinity College, Dublin, is due to release its first round of results towards the end of 2011 or beginning 2012. Furthermore, in the Asian continent there are four similar studies underway, namely:

- The Longitudinal Aging Study in India (LASI)\(^{27}\) coordinated through the Harvard, Centre for Population and Development Studies, USA;
- The Japanese Study of Aging and Retirement (JSTAR)\(^{28}\) under the Research Institute of Economy, Trade and Industry, Hitotsubashi University, Japan;
- The Korean Longitudinal Study of Aging (KLoSA)\(^{29}\) organised by the Korea Federation of Small Business Building Seoul, Korea;
- Chinese Health and Retirement Survey\(^{30}\) (CHARLS) conducted through the China Centre for Economic Research at Peking University China.

The reason for this recent surge in longitudinal data collection of the elderly population is primarily the projected growth in the elderly population and the indications that the mainstays of retirement research (e.g. Retirement History Study (RHS) conducted in the USA between 1969–79) were no longer adequately addressing issues related to the ageing population and their associated retirement phase (Suzman et al. 1995).

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\(^{24}\) [https://ssl.isr.umich.edu/hrs/start.php](https://ssl.isr.umich.edu/hrs/start.php)
\(^{25}\) [http://www.natcen.ac.uk/elsa/](http://www.natcen.ac.uk/elsa/)
\(^{26}\) [http://www.tcd.ie/tilda/participants/](http://www.tcd.ie/tilda/participants/)
\(^{27}\) [http://www.hsph.harvard.edu/pgda/lasi.html](http://www.hsph.harvard.edu/pgda/lasi.html)
\(^{30}\) [http://charls.ccer.edu.cn/charls/](http://charls.ccer.edu.cn/charls/)
Whilst the evolution of such studies has stimulated debate on best practice, there is a general agreement on the need to move towards harmonisation of common indicators of ageing internationally. The main benefit of SHARE is that it encompasses cross-national variation in public policy, culture and history across a variety of European countries. SHARE benefits from having rigorous procedural guidelines and programmes to ensure that cross-national comparisons are viable.

5.2.ii Who conducted the survey?

SHARE has at the time of writing released three waves of research since its inception in 2002. This section provides important information on the robust conduct of this international survey over four parts; (1) how SHARE was initially developed, (2) and initially stress tested, (3) how the protocol ensured results were generalizable and (4) how SHARE is released publically to the research community.

(1) The Initial Development of SHARE

The development of SHARE involved initially eleven working groups who produced the initial survey which was subsequently implemented in eight countries. Working with specialists from relevant fields, the group designed a draft questionnaire predominantly based on the American Health and Retirement Study (HRS) and the English Longitudinal Survey on Ageing (ELSA). A plenary session (which included delegates from each country) was undertaken to ensure that each respondent would have an optimum time period in which to complete the SHARE survey. It was decided that that time should be 80 minutes per respondent and in this time the survey would overview relevant health, economic and family issues. Researchers from HRS and ELSA advised throughout the process.

The original survey was written in English. At this time eleven countries were responsible for implementation and had to gain approval on language-specific survey instruments before field testing locally. Furthermore, each country team was responsible for observing legal requirements and subcontracting, and had to negotiate a contract with the Munich Centre for the Economics of Aging (MEA). Furthermore, software consultants were commissioned to design Computer-Aided Personal
Interview (CAPI) survey software, which safeguarded respondents in terms of safety and confidentiality regulations.

(2) Stress testing the SHARE

As with any research, a pilot stage was critical to ensure the viability of the proposed method. The survey was initially tested by the National Centre for Social Research (London) sampling 80 British households (with respondents aged between 50 and 96). SHARE introduced grip strength as a measure of physical health. Cognitive tests were piloted in Germany and Italy whilst other collaborating countries were finalising their negotiations.

The fifth draft was finalised in March 2003, the cognitive test refined and a stand-alone case management software system was completed. Following that, there was a training period and surveys were translated for each country. In June 2003, all countries participated in a pilot phase. Generally the questionnaire was well received by all countries, but was found on average to be running 15% over the required 80 minute duration. Pilot data was analysed in the AMANDA project and results showing the feasibility of the survey were presented in a plenary session in September 2003 (Börsch-Supan 2003). Prior to the final rollout, a pre-test stage corrected any errors found in the pilot, producing an eighth version. The new version was tested in a sample of 100 respondents to ensure its reliability and validity. The sample was successfully transferred into both SPSS and STATA formats, while indicating the need for some final changes (Version 9). After checking translational issues, a final version (Version 10) was released for data collection.

(3) Protocol for data collection

To ensure consistency in the survey’s data collection and to obtain results that were generalizable and comparable, the SHARE team devised a ‘train the trainer’ programme. The intention was that each country would be sent trainers from the participating team to provide initial training. The sessions were two days in length and gave an overview of the questionnaire, demonstrated the use of laptops with installed CAPI, gave specific training on software and concluded with mock interview sessions.
To ensure that the data collected was of a high quality, professional survey agencies were selected in all participating countries. The first wave in 2004 was of eleven European countries, namely Austria, Belgium, Denmark, France, Germany, Greece, Italy, the Netherlands, Spain, Sweden and Switzerland (Table 3 below summarises the dates of initial collection).
Table 3: Description of the first wave of SHARE detailing the country, the time of data collection, additional collection of sample vignette and supplementary data collected. [Source: SHARE, 2004].

<table>
<thead>
<tr>
<th>Country</th>
<th>Core Sample</th>
<th>Vignette</th>
<th>Supplementary Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>May-Oct 2004</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Belgium</td>
<td>Jan-Jul 2005</td>
<td>Jan-Jul 2005</td>
<td></td>
</tr>
<tr>
<td>Denmark</td>
<td>May-Oct 2004</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Germany</td>
<td>May-Oct 2004</td>
<td>May-Oct 2004</td>
<td></td>
</tr>
<tr>
<td>Greece</td>
<td>May-Oct 2004</td>
<td>Jan-Mar 2005</td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td>May-Oct 2004</td>
<td>Aug-Dec 2004</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td>May-Oct 2004</td>
<td>Aug-Dec 2004</td>
<td></td>
</tr>
<tr>
<td>Spain</td>
<td>May-Oct 2004</td>
<td>Nov-Dec 2004</td>
<td></td>
</tr>
<tr>
<td>Sweden</td>
<td>May-Dec 2004</td>
<td>Nov-Dec 2004</td>
<td></td>
</tr>
<tr>
<td>Switzerland</td>
<td>May-Oct 2004</td>
<td></td>
<td>Nov-Dec 2004</td>
</tr>
</tbody>
</table>

*Source: SHARE 2004. Adaptation of SHARE Book Methodology, p.75*
In the ‘core sample’ fieldwork respondents received the same version of the questionnaire. In the vignette sample respondents received one of two different versions of the vignette questionnaire, which were randomised by interviewer. In November 2004, a supplementary sample of 950 households was fielded in Sweden, which was required as a result of low number of first round of interviews.

Data collected included health variables (e.g. self-reported health, health conditions, physical and cognitive functioning, health behaviour, use of health care facilities), biomarkers (e.g. grip strength, body-mass index, peak flow), psychological variables (e.g. psychological health, well-being, life satisfaction), economic variables (current work activity, job characteristics, opportunities to work past retirement age, sources and composition of current income, wealth and consumption, housing, education), and social support variables (e.g. assistance within families, transfers of incomes and assets, social networks, volunteer activities).

Summary findings provided by SHARE relate to health (with a specific finding of a strong correlation to education), socioeconomic factors (focusing on income in retirement) and family (and the availability of support). As the initial findings of SHARE are relevant to the question posed in this thesis, they will be summarised here before they are subjected to analysis.31

In terms of health, SHARE has revealed a strong relationship between education and health among the older population. This holds not only on the individual level (better educated individuals are healthier than less educated) but also across European nations. Comparing average education and average health levels in SHARE, countries reveal that in particular the East European and Mediterranean countries are characterised by low levels of education and health simultaneously. In contrast, populations in Northern European countries and Switzerland are both healthier and better educated.

Economic findings illustrate a wide variation in the adequacy of income in the over 50s population across Europe. In Ireland, Eastern European countries (such as Poland and the Czech Republic), as well as Southern European countries (such as Greece, Italy, Spain, and in Israel), SHARE finds that more than 50% of households

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31 Summary of stated author reports to be found at http://www.share-project.org/t3/share/index.php?id=361
in these countries have problems in making ends meet. In Denmark, the Netherlands, Sweden and Switzerland, the ratio of the population without adequate finances was found to drop to approximately 20%.

On research into family networks, SHARE finds that support was largely dependent on geographic accessibility. SHARE further exposes regional patterns in family ties which dictate the strength or weakness of the family network. SHARE further documents that in nearly all European countries parents will tend to have one child living within a 25km radius of them, with whom they are found to have a high rate of weekly contact. Therefore, as yet they find no evidence of a decline in the relationship between parent and child.

(4) Public Release

In each wave SHARE is initially released confidentially to collaborating researchers in SHARE, as well as those who were initially involved in AMANDA. The aim of this stage is to refine the data by allowing researchers to find errors and report them before general release. The first public release took place at a meeting of members of the European Commission in Brussels at the end of April, 2005. The database was thereafter made available for scientific use by all researchers from academic and publicly financed research institutes. The larger scale release allows for further feedback of error and as a result, found SHARE producing Release 2. On the 24 May 2011, the latest releases of Wave 1 (2004) and Wave 2 (2006), entitled SHARE release 2.5.0 were released. At the time of writing this thesis, these two releases were the most up-to-date versions available and the analysis presented here is based on these two cross-sections.
5.2.iii What role does the survey play in the subsequent analysis?

Access to SHARE is available on application through the Research Data Centre located at the Tilburg University, Netherlands. The Centre was contacted to request access and the relevant declarations were made to assure that ‘under no circumstances the data will be used for other than purely scientific purpose’. By signing the user statement, the applicant is added to a list of users of the SHARE project. Following the application a username and password were assigned. Access to the data was through the SHARE Research Data Center online.

Following gaining access to the data, the questionnaire and codebooks for SHARE were assessed to identify relevant components for dementia, depression and service utilisation, full details of which are provided in Chapter 8. Having ascertained that the survey provided the scope to analyse the third research question (how is formal service utilisation influenced by depression in dementia?), the relevant sections of SHARE were downloaded for Wave 1 (2004) and Wave 2 (2006).

Data on household status, behavioural risk factors, cognitive function, depression, personal health, health care utilisation, demographic and answers to a drop-off questionnaire were merged into a single dataset. This was repeated for Wave 1 and for Wave 2. The two waves were then merged to form a panel with two time points.

Initially, panel analysis was considered for the proposed research question, however, given that Wave 3 (SHARELIFE) did not repeat the data collected in the previous two waves, the analysis described in Chapter 8 finally opted to use an enriched cross section (see this Chapter for more details).

The enriched cross section allowed for quasi-experimental conditions to be created and for regression analysis to create a model of health care utilisation in which the dementia population identified in Wave 2 could be contrasted to cohorts undiagnosed with dementia, but which possessed a similar profile. The model was intended to control for and measure the marginal effect of depression in dementia.

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32 To apply for access contact: Josette Janssen, CentERdata, Tilburg University, P.O. Box 90153, 5000 LE Tilburg, The Netherlands; e-mail: jjanssen@uvt.nl; fax: +31 13 4662764)
Chapter 6. Analysis of Perceptions of Dementia Care

What factors determine the Irish dementia population’s perceptions of care? is the first specific research question in this thesis. This Chapter explain the methods used to answer this question by describing how the survey was prepared for analysis (6.1), defines the dependent (6.2) and independent (6.3) variables for regression analysis and explains how data is analysed using and provide the model specification (6.4).

6.1. Data Preparation

The survey obtained for this analysis has previously not been utilised in academic research. As was illustrated in Chapter 5.1, the ASI 2007 examines the impact of caring for people with dementia in Ireland and having been conducted by a leading national community contact point for people with dementia in Ireland, this survey provides a cross section of the dementia population.

In 2007, the Alzheimer Society had 3,000 members nationwide and questionnaires were distributed to a random sample of 720 members on the Society’s database. A total of 270 questionnaires were returned giving a response rate of 38%. Initial data was compiled for descriptive analysis in SPSS and for the purpose of econometric analysis in this project, the data was analysed using STATA 10.0 for econometric analysis.

Once in a STATA format, the dataset required significant cleaning for subsequent analysis. Variables were indicated by their question numbers and required specific labelling. In cases where data was unclear, queries were directed to the market research agency, MBIMS.

A primary assessment of the data was undertaken to assess the cohort represented in the sample and its relevance to the first research question (a preliminary description is provided in Figure 8 below and detailed summary statistics are given in Chapter 10). Before progressing to produce relevant stylised statistics, or defining the dependent or independent variables, the data was quality check by reproducing summary statistics previously presented by the Alzheimer Society.
1.1.i Summary Description of Sample Characteristics

The sample population was representative of regional density and age distribution within the areas of Ireland surveyed (Dublin n=37, Leinster (outside Dublin) n=84, Munster n=105, Connaught n=22 and Ulster n=22). Carers sampled ranged in age from under 35 to over 85, median range 45–54 and mean 55–64. Most commonly carers were female (n=196) and were equally likely to be caring for a female or male (n=98 vs. n=96, respectively). However, when the carer was male (n=76), they were over six times more likely to be caring for a female (n=66 vs. n=10).

Survey respondents were most commonly caring for a ‘Mother or Father’ (n=121) or for a ‘Spouse or Partner’ (n=117), with the remaining recipients being ‘In-Law’ (n=11), ‘Friend’ (n=2), or ‘Other Relative’ (n=11) - ‘Professional Carer’ (n=2) and one relationship ‘Missing’ completed the survey but were ignored in the analysis.

The most common employment status was ‘retired’ (42.7%); however, the remainder were either not working because of a ‘caring role’ or ‘unemployed’ (29.59%), or were working ‘full-’ or ‘part-’ time (27.72%). As would be expected the distribution of the number of hours of care per day is dependent on employment status (Pearson chi2 (28) = 104.2590, p $<$ 0.001). Notably, of 71 in paid employment, 46 respondents (64.79%) indicate they had reduced their hours.

Having satisfied the preliminary inspection, summary statistics were produced to describe the underlying dementia (Chapter 10.1) and descriptive statistics of their associated informal carers (Chapter 10.2). Binary dependent variables to represent perceptions of care were defined (6.2) as were associated explanatory variables (6.3). Finally, a series of logistic regressions were specified, estimated and tested to study the determinants of perceptions of care (6.4).
6.2. Binary Dependents Variable: Perceptions of Care

The aim of this analysis is to provide insights into what determines individuals' perceptions of care in Ireland. To ascertain links between perceptions and their potential determinants, the final questions (below) in ASI, 2007 survey asked survey respondents to rate their views of care on a Likert scale in which responses to the statement ranged from strong disagreement to strong agreement. The questions appeared as follows:

![Survey question evaluating individuals’ perception of care in Ireland](Source: ASI 2007)

<table>
<thead>
<tr>
<th>Q43. Please indicate how much you agree or disagree to the below statements, by ticking the relevant boxes.</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>The level of care for the elderly is good in Ireland</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caring for the elderly is a public matter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Services available are sufficient for my needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The quality of services available is very high</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The cost of healthcare is reasonable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The cost of healthcare and services should be covered by society</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Responses to these statements form the basis of qualitative dependent variables \( y_i \) for analysis. Given the Likert scales in this dependent variable, analysis would usually lend itself to techniques such as ordered Probit analysis (Newhouse 2000).

Initial observations of responses to this question indicate that respondents often had highly polarised views about the statement. Responses could therefore be grouped into three potential categories; disagreement, indecision and agreement. Given the
sample size and the nature of the question, forming a binary response indicating whether individuals disagree (i.e. score of 1 or 2) or agree (scores of 4 or 5) were found to be more insightful. Furthermore, indecision in the view of the statement (i.e. score = 3) were excluded from analysis on the basis that these responses did not convey information of perceptions of services. Converting ordered categorical variables to binary variables may have certain limitations and the implication of such limitations will be discussed further in Chapter 9.

Having formed the binary dependent variable, outcome for six analyses were defined, namely; (1) the level of care; (2) whether elderly care was a public matter; (3) the adequacy of services; (4) the quality of service; (5) cost and; (6) whether costs should be covered by society (i.e. by tax-based health insurance).

The six binary dependent variables were coded to indicate agreement with each statement highlighted below. Variables were transformed by show agreement with the statement as 1 (accounting for responses ‘Agree’ or ‘Strongly Agree’), disagreement as 0 (‘Disagree’ or ‘Strongly Disagree’) and a lack of opinion (‘Neither’) is omitted. From this procedure, the following six independent variables were formed:

**CARE:** The level of care for the elderly is good in Ireland  
**PUBLIC:** Caring for the elderly is a public matter  
**SERVICE:** Services available are sufficient for my needs  
**QUALITY:** The quality of services available is very high  
**COST:** The cost of healthcare is reasonable  
**PAYER:** The cost of healthcare and services should be covered by society

These terms will indicate each logistic regression in the tables of results.
6.3. Explanatory Variable

To explain the determinants of these six binary dependent variables, the significance of individual heterogeneity is explored using logistic regression. This analysis examines the role played by access to services and associated payment mechanisms; and the effect of patient non-disclosure and the significance of the individuals personal finance circumstance.

The first set of explanatory variables reference *formal services*, specifically General Practice, hospital and memory clinics, and binary indicator variables indicate if the individual has accessed the related service, forming *GP Use*, *Hospital Use* and *MemClinic*, respectively. Also within this *formal service* variable set, stated method payment source are included indicating whether the service was either state funded (e.g. *Hospital State*), paid by insurance (e.g. *Hospital Insure*) or out of pocket payment (e.g. *Hospital OoP*).

ASI 2007 finds that only half of all people with dementia are informed of their condition: the binary variable *Undisclosed* is included to explore the role of disclosure in predicting perceptions of care.

*Community services* is the second set of variables related to and including day, home, respite and residential care which are all provided in the community (The Alzheimer's Society of Ireland 2007). Such services are indicators of the level of support households (particularly the informal carer) receive to maintain the person at home for longer. Binary variables for each community service indicate whether the service was used and how it was financed.

Financial issues are the final set of variables that indicate the impact of personal finances. Binary variables were formed to indicate whether the ‘carer is confident of having sufficient income to care’ (*IncomeProblems*), ‘to pay medical costs’ (*CarerPayCosts*) and ‘to pay for additional help’ (*CarerPayHelp*).
6.4. Model Specification and Post-Estimation Tests

This final section details the specification of the regression model, the method taken to estimate the model and post-estimation techniques used to test the models.

6.4.i Model specification

The aim of the model is to examine whether the binary variables for the perception of care are explained by the explanatory variables. Under this construct, Equation (1) indicates the conditional expectation of the outcome \(y_i\).

\[
E(y_i|x_i) = P(y_i = 1|x_i) = F(x_i)
\]  

(1)

The function form \(F(.)\) adopts a nonlinear parametric modes choosing specifically the logistic regression model (Cramer 2003). The model can then be used to investigate how a series of regressors explain the respondent answers. The dataset collected vast arrays of factors which were hypothesised to be having a causal effect on service.

Equation (2) outlines the underlying theory that the binary outcome is a function of categories of explanatory variables.

\[
y_i = f(\text{Formal Services}; \text{Community Support}; \text{Disclosure}; \text{Financial Issues})
\]  

(2)

Formal Services indicated whether the individual accessed specific services and how they were required to pay for the service.

Community Support is similar to formal service, examining access and how such services were financed.

Disclosure of dementia is a hypothesis that this has an impact on outcomes.
Financial Issues capture controls for financial impact related to dementia care in this model.

The binary dependent variables were then regressed against explanatory variables using maximum likelihood estimation. For ease of interpretation, the regression coefficients are converted to odds ratios (more detail will be provided in the results section).

6.4.ii Post-estimation test

Having estimated the model, the hypothesis that the explanatory variables explain the outcome variable was tested using the Wald test. How well the expected results predict the observed fit is then measured by assessing the the models goodness of fit using a modified Hosmer-Lemeshow Test.

A Wald test is a model specification test. It indicates whether the relationship of the covariate matrix $X$ is significant. Therefore Wald tests indicate the significance of the overall model and that of coefficients of specific variables (Wald 1943). Wald’s test is used to test the effects of out of pocket expenditure, state funded services, access to formal services, diagnosis/disclosure, and financial impacts. Each set of explanatory variables were tested to ascertain whether the set significantly predicted the outcome variable.

‘Goodness of fit’ tests indicate how well the model’s predictions fit those observed in reality. Primarily the model can be evaluated from the McFadden Pseudo $R^2$. However, as the model is not linear interpreting this test’s statistics may not have direct meaning. The modified Hosmer-Lemeshow test is an alternative that measures categorical goodness of fit and accuracy of classification of the predictions (Hausman 1978).

Over the fitted non-linear model such as the logit, the modified Hosmer-Lemeshow test (3) compares whether the observed rate of an outcome equates to the predicted outcome rates in subgroups of the model population.
The number of subgroups (g) is dependent on sample size available. O is the number of subgroups observed, and E is the number expected (predicted), N is the number of individuals per group and \( \pi \) is the predicted probability (Hosmer and Lemeshow 2000). Hence, the larger \( H \) the greater the goodness of fit, rejecting the null hypothesis of no goodness of fit if the \( \text{Chi}^2 \) statistics is significant (e.g. if \( p<0.1 \)).

\[
H = \sum_{g=1}^{n} \frac{(O_g - E_g)^2}{N_g \pi_g (1 - \pi_g)}.
\]
Chapter 7. Proxy-Good Valuation for Informal Care

How much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care? This is the second research question of this thesis. The aim of this Chapter is to explain how informal inputs into care were captured giving a latent variable (7.1). First the explanatory variables used to estimate informal care time by stage are introduced (7.2), then summaries are provided of the range of individual characteristics (7.2.i), functional limitations and behavioural disturbance (7.2.ii). The last two sections explain how the Tobit model was specified to estimate the number of hours of informal care by stage and the required post-estimation test (7.3), and from these estimates how proxy-good valuation was applied (7.4).

7.1. Latent Dependent Variable: Daily Informal Care Time

Carers were asked approximately how many hours per day do you spend caring for the person with Alzheimer's disease/dementia. Their answers were categorically indicated over two hour intervals (see Table 4). However, ASI 2007 imposed an upper limit within this questionnaire forming an unobserved distribution of hours of care above 14 hours. For the purpose of analysis this becomes a latent dependent variable and how these unobserved hours of care are estimated will be explained in the following sections.

As ASI 2007 measured the variable categorically in two hour intervals, modelling methods required this to be approximated to a continuous variable underlying distribution; Allison and Foster (2004) indicate taking the median value in each range as appropriate to form a continuous dependent variable (see Table 4 for the assigned values).
Table 4: Illustration of how the continuous variable for the number of hours of informal care provided per day was formed from ordered categorical data by assigning a median value to the categorical values [Source: ASI 2007].

<table>
<thead>
<tr>
<th>Hours per Day of Care:</th>
<th>Median Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 2 Hours</td>
<td>1</td>
</tr>
<tr>
<td>Between 2 and 4 Hours</td>
<td>3</td>
</tr>
<tr>
<td>Between 4 and 6 Hours</td>
<td>5</td>
</tr>
<tr>
<td>Between 6 and 8 Hours</td>
<td>7</td>
</tr>
<tr>
<td>Between 8 and 10 Hours</td>
<td>9</td>
</tr>
<tr>
<td>Between 10 and 12 Hours</td>
<td>11</td>
</tr>
<tr>
<td>Between 12 and 14 Hours</td>
<td>13</td>
</tr>
<tr>
<td>14 Hours or more</td>
<td>14</td>
</tr>
</tbody>
</table>

Total

7.2. Explanatory Variables

Two sets of explanatory variables are specified to estimate hours of informal care, namely individual characteristics and functional limitations; this section describes these two sets of variables.

7.2.i Individual characteristics

The first set of explanatory variables selected provides individual characteristics at a demographic level (such as age, training to care, nursing home status), stage of dementia and work-cohabitation status.

Age as would be expected is a major factor associated with dementia.

Caregiver training is hypothesised to help carers to cope with their role and to assist with more efficient allocation of their time; this variable is included to estimate the effect of training on the hours of care provided.

Access to nursing homes is limited in Ireland and this variable is included as a control for the impact being a resident in a nursing home has on informal care.

Stage of current dementia was captured by asking respondents what stage their doctor had most recently indicated. Responses were either “Early Stage/Mild”, “Middle Stage/Moderate”, “Late Stage/Severe” or “No Stage/Severity was
Mentioned”. Regression analysis omits “No Stage/Severity Mentioned” and takes it as the reference standard of the other stage related parameters.

A Work-Cohabitation status variable is formed more specifically for the employed group to examine the effect of cohabitation on employment for the informal carer, contingent on whether the carer was in employment. Those not working either because of retirement or resigning showed much less variation in the hours they provided and, as such, interaction terms for the unemployed were not constructed.

7.2.ii  Functional limitations and behavioural problems

Functional limitations and behavioural problems are the two most common groups of symptoms of dementia and are directly related to how much care an individual requires.

Functional impairments were assessed in ASI 2007 by asking survey respondents to indicate the limitations their related recipient currently demonstrated. In accordance with classification guidelines (Roley 2008), these responses were categorised into household activities of daily living (HDL), general activities of daily living (ADL) and instrumental activities of daily living (IADL).

Psychiatric symptoms commonly associated with behavioural disturbances were assessed. Respondents were asked to indicate symptoms currently present and in a separate questions, which symptoms ranked as the most problematic.

33 Analysis of the number of symptoms would suggest “No Stage/Severity was Mentioned” has a similar distribution to those with late stage dementia.
7.3. Model Specification and Post-Estimation Tests

Drawing together the dependent and independent variables described above to estimate the number of hours of informal care provided, this section describes how the model is specified (7.3.i) and what post-estimation tests were performed (7.3.ii).

7.3.i Model specification

The amount of time spent providing informal care \( (y_i) \) was measured to an upper limit of 14 hours per day \( (y_u) \), which required the application of a censored regression model to predict a latent variable \( (y_i^*) \), informal care time. Such top coding of the hours per day spent caring (i.e. censored above 14 hours) necessitated a censored regression Tobit model (Tobin 1958). The original application of the Tobit model was used to describe non-negative dependent variables; however, a variation of the Tobit (Amemiya 1985) applies the top censoring limit \( (y_u) \) according to Equation (4).

\[
y_i = \begin{cases} 
y_i^* & \text{if } y_i^* < y_u \\
y_u & \text{if } y_i^* \geq y_u
\end{cases}
\] (4)

In this model the latent variable \( y_i^* \) above \( y_u \) cannot be observed while the matrix of independent variable \( (x_i) \) can be fully observed. Maximum likelihood estimation is shown to be valid and consistent to estimate such Tobit models (Wendelin 2005) and allows the prediction of hours of informal care including those over 14 hours based on explanatory variables. To ensure comparable representation of early, mid and late stage dementia, inverse probability weighting is applied to the regression (Wooldridge 2002). The significance of groups of regressors is examined using the Wald test (Wald 1943) and the influence of the overall specification is assessed using a link test (Pregibon 1980).

The following empirical specification is applied:

\[
\hat{y}_i = f(\text{Demographics, Stage, Employment}; \ HDL, ADL, IADL; \ Behaviour \ Problems)
\] (5)
Individual effects are captured in demographics features, stage of disease and employment status. Functional limitations are accounted for by activities of daily living in the household (HDL, such as cooking, cleaning), general (ADL, such as dressing, eating), and instrumental activities (IADL more complex tasks such as using the telephone, socialising). Dementia symptoms may also necessitate supervision where individuals have behavioural problems. In contrast to individual effects, demand related to functional and behavioural problems are better regarded as commodities consumed to maintain the individual in the community (Netten and Davies 1990).

Formal services were also included but not presented here as they were found to have no effect on the amount of informal care. To assess the influence of formal care, two additional categories of variable were used to assess the impact of service use: formal service use (relating to GP or hospital access) and community services use (indicating use of day care, home care and respite (these variable sets were defined earlier in Chapter 6.3)). Wald testing indicates the significance of ‘Formal’ as p=.4763 and ‘Community’ as p=.7358 from which it is concluded that formal services do not directly predict the informal care provided. These findings confirm the complementary nature of informal care and suggest that formal service does not actively supplement informal care.

7.3.ii Post-estimation test

The key assumption of the Tobit model is normality. No standard test for normality exists for the Tobit model as available tests which may be applied to ordinary least square (OLS) are invalid as the fitted values and residuals do not share the same properties as OLS. To test for normality in the residuals, Cameron and Trivedi (2010, pp.535–7) outline the procedure using generalised residuals to generate the key components to test the null hypothesis of normality for the Tobit model. To outline this test, the conditional moments test computes an inverse Mills ratio, generalised residuals and function of these residuals. A Lagrange multiplier test for normality is then applied using the likelihood scores.
7.4. Assigning Proxy-Values to Estimated Hours of Informal Care

The proxy-good valuation method applies the shadow prices of producing specific outputs of care in an assumed perfect market. This framework captures the value of the opportunity cost associated with human capital and overhead costs and should reflect a point of indifference in substituting informal care for formal services. Since the informal care time lost in accepting care is equal to the formal services gained through averted burden of care, the proxy-good valuation represents a socially optimal solution to valuing informal care.

The Health Information and Quality Authority (HIQA) published economic evaluation guidelines in 2010 which deliver a formal framework for calculating the proxy-good values (HIQA 2010). Under these guidelines, health care decision makers are advised to concentrate on direct costs specific to the public health care budget [p.15]; but this perspective may result in a default view that informal care is a ‘free resource’. To counteract this potential pitfall of underestimating the total cost of dementia, this study attributes a cost to informal care by applying proxy-good values in the Irish health service. This forms a compromise between the direct and societal viewpoint by building in the informal carer’s productivity loss and overhead costs whilst applying a value to the specific outputs of care through the Irish formalised costing framework.34

In line with the HIQA HTA guidelines labour costs are calculated using salary scales which are available through the Department of Health and Child. To this, the non-pay costs are also added using the Department of Taoiseach’s Regulatory Impact Analysis guidelines, excluding non-pay costs such as equipment or consumables. The total salary cost is the sum of the midpoint payroll salary plus PRI and inputted pension costs (13.1% of the payroll). Ultimately, the HIQA guidelines require the total staff cost, which is the total salary cost plus overheads (40% of the midpoint payroll); an example of the calculation can be found in Appendix 2.

34 Health Information and Quality Authority: Health Technology Guidelines, p.15.
Chapter 8. Propensity Score Matching and Two-Stage Regression

How is formal service utilisation influenced by depression in dementia? is the final and potentially most complicated research questions in this thesis. The methodologies in this section aim to isolate an effect size of comorbid depression on service utilisation.

Before being able to comment on this aim, several questions must be answered by running preliminary procedures. Depression and dementia have been shown in 4.3 to have nebulous boundaries and specific psychometric properties that can accurately measure comorbid depression; this raises the first question does depression predict dementia? Furthermore, dementia predominantly affects the elderly and to obtain the incremental effect of depression in dementia requires comparing a sample with similar characteristics to the dementia population; this provides the second preliminary question: how is service use influenced by a diagnosis of dementia compared with a similarly matched group?

To build the answer to the final research question, this Chapter describes methodologies over three sections and each section will introduce the dependent variable, the theory for choosing the dependent variables and the applied econometric techniques.

Section 8.1 explains how preliminary logistic analysis ascertains the role of conventional depressive symptoms in predictions of dementia. This establishes a baseline equation for matching in the next stage. Section 8.2 gives an overview of the propensity scores matching, reviewing the theoretical basis and explaining the process applied to undertake one-to-one matching to create quasi-experimental conditions. Section 8.3 presents how health care utilisation is estimated using a two stage regressions procedure and how the two match subgroups are used to indicate an incremental effect of depression in dementia.
8.1. Predicting Dementia and Assessing the Role of Depression

While the nature of dementia is not clear cut it can be considered as a continuum (McKhann et al. 1984). This section explains preliminary analysis to assess how comorbid symptoms of depression influence predictions of dementia. Firstly the variables of interest are defined (8.1.i) and then the procedure of specifying models to understand interaction is explained (8.1.ii). A summary of the variables is given in Table 5.

8.1.i Dependent and Independent variables

To understand the purpose of modelling the interactions between depression and dementia, this first section introduces the variables in SHARE of interest by describing the nature of the dependent variable (1) and then the selected explanatory variables (2).

(1) Dependent Variable

Individuals with a diagnosed dementia were actively excluded from SHARE 2004 and in the subsequent SHARE 2006 individuals were asked whether they had been diagnosed with dementia. In this second wave individuals’ dementia status is indicated by a binary limited dependent variable. It is worth noting at this stage that this variable does not capture the extent of the individual’s dementia but only whether individuals have been diagnosed with a dementia. As individuals with dementia were systematically excluded from entering SHARE 2004, this can be taken as an indicator of whether individuals were diagnosed with dementia between 2004 and 2006.

(2) Explanatory Variables

Dementia has certain risk factors which for the purpose of this analysis can form explanatory variables to predict dementia. Common factors which predict dementia are selected as explanatory variables using (a) Age (b) Functional Limitations (c) Cognitive Function and (d) Education (more specifically as a control for social
determinants of health). The explanatory variable of interest is depression and various different indicators are tested across.

(a) **Age**
Probability of dementia doubles with every five year increase after 65 years (Gao et al. 1998) and in the ‘oldest old’ (past 90) increases are exponential (James and Schneider) and continuous. The effects of ageing may not have a direct linear effect on the prediction of dementia therefore an age squared ($age^2$) is also specified.

(b) **Functional Limitations**
As was shown in Chapter 7, functional impairment is a significant symptom of dementia. Barberger-Gateau et al. (1993) associate the incidence of dementia with activities of daily living (ADL) and instrumental activities of daily living (IADL) indicating them as important in this equation. In testing model specifications suggest that impairments in instrumental activities of daily living may not be linear, therefore a squared term is included ($IADL^2$).

(c) **Cognitive Function**
The SHARE survey of the over 50s asked respondents to take a test of their cognitive function. Five tests were undertaken forming useful explanatory variables; recall first (recall of a list of ten words presented), recall delay (revisiting the words after time has passed), orientation (ability to recall facts such as the days of the week), verbal fluency (ability to name several animals) and numeracy (test of basic maths). These tests were repeated in both waves of SHARE and to enrich the model and control for inherent ability, two lagged individual variables was extracted by individual from SHARE 2004: recall-delay (04) and numeracy (04). In the absence of repeated measures in the third wave in SHARE 2008, forming this enriched cross section provides a compromise to capture an effect over time as it is the rate of cognition decline that is of greatest importance in diagnosing dementia.

(d) **Education**
Educational level is not a direct predictor of dementia but is cited as a social determinant of health status (Marmot and Wilkinson 2006) and as playing a part in successful ageing (Béland and Zunzunegui 1999). To categorise education level, the International Standard Classification of Education (ISCED-97) is used; this classifies the individual’s maximum education from ISCED-0 (no formal schooling) to
ISCED-6 (post-graduate education). These variables are aggregates (ISCED (1–2), ISCED (3–4) and ISCED (5–6)) with ISCED (0) omitted (forming the reference point).

(e) **Depression Indicators**

The main purpose of this analysis is to observe the effect of depression in confounding or enhancing a prediction of dementia. From the psychiatric point of view, there appear two confounding problems between depression and dementia:

1) McAllister et al. (1983) define *pseudo-dementia* as the situation where individuals appear to have symptoms of dementia, (particularly loss of memory, vagueness and lethargy) which may actually be depression related (unlike dementia, as a depressive syndrome the situation is reversible).

2) Brommelhoff et al. (2009) suggest that depression may be prodromal to dementia (i.e. late life depression is thought to be a precursor to dementia).

These form potential confounders in estimating the effect of depression in dementia and these are tested by including various permutations of the depressive symptoms in alternating model specifications.
Table 5: Description of independent variables used in logistic regression to predict depression [Source: SHARE 2006].

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Age of SHARE Respondent</td>
</tr>
<tr>
<td>Age(^2)</td>
<td>Age of SHARE Respondent Squared</td>
</tr>
<tr>
<td><strong>Functional Limitations</strong></td>
<td></td>
</tr>
<tr>
<td>ADL</td>
<td>Number of Limitation in Activity of Daily Living</td>
</tr>
<tr>
<td>IADL</td>
<td>Number of Limitation in Instrumental Activity of Daily Living</td>
</tr>
<tr>
<td>IADL(^2)</td>
<td>Number of Limitation in Instrumental Activity of Daily Living, Squared</td>
</tr>
<tr>
<td><strong>Cognitive Function</strong></td>
<td></td>
</tr>
<tr>
<td>Recall first</td>
<td>Immediate recall</td>
</tr>
<tr>
<td>Recall delayed (04)</td>
<td>Recall after a specified time</td>
</tr>
<tr>
<td>Verbal fluency</td>
<td>Verbal fluency</td>
</tr>
<tr>
<td>Orientation</td>
<td>Orientation in time</td>
</tr>
<tr>
<td>Numeracy (04)</td>
<td>Mathematical performance in 2004</td>
</tr>
<tr>
<td>Numeracy</td>
<td>Mathematical performance</td>
</tr>
<tr>
<td><strong>Educational Status</strong></td>
<td></td>
</tr>
<tr>
<td>ISCED-97 (1–2)</td>
<td>Education Level – ISCED-97: 1é–2</td>
</tr>
<tr>
<td>ISCED-97 (3–4)</td>
<td>Education Level – ISCED-97: 3–4</td>
</tr>
<tr>
<td>ISCED-97 (5–6)</td>
<td>Education Level – ISCED-97: 5–6</td>
</tr>
<tr>
<td><strong>Depression Indicators</strong></td>
<td></td>
</tr>
<tr>
<td>Depression (2004)</td>
<td>Last month, have you been sad or depressed?</td>
</tr>
<tr>
<td>Depression (2004)</td>
<td>Last month, have you been sad or depressed?</td>
</tr>
<tr>
<td>Pessimism (2004)</td>
<td>What are your hopes for the future?</td>
</tr>
<tr>
<td>Pessimism (2004)</td>
<td>What are your hopes for the future?</td>
</tr>
<tr>
<td>Suicidality (2004)</td>
<td>Last month, have you felt that you would rather be dead?</td>
</tr>
<tr>
<td>Guilt (2004)</td>
<td>Do you tend to blame yourself or feel guilty about anything?</td>
</tr>
<tr>
<td>Sleep (2004)</td>
<td>Have you had trouble sleeping recently?</td>
</tr>
<tr>
<td>Sleep (2004)</td>
<td>Have you had trouble sleeping recently?</td>
</tr>
<tr>
<td>Interest (2004)</td>
<td>Last month, what is your interest in things?</td>
</tr>
<tr>
<td>Interest (2004)</td>
<td>Last month, what is your interest in things?</td>
</tr>
<tr>
<td>Irritability (2004)</td>
<td>Have you been irritable recently?</td>
</tr>
<tr>
<td>Irritability (2004)</td>
<td>Have you been irritable recently?</td>
</tr>
<tr>
<td>Appetite (2004)</td>
<td>What has your appetite been like?</td>
</tr>
<tr>
<td>Appetite (2004)</td>
<td>What has your appetite been like?</td>
</tr>
<tr>
<td>Fatigue (2004)</td>
<td>Last month, too little energy to do the things you wanted to do?</td>
</tr>
<tr>
<td>Fatigue (2004)</td>
<td>Last month, too little energy to do the things you wanted to do?</td>
</tr>
<tr>
<td>Concentration (2004)</td>
<td>How is your concentration?</td>
</tr>
<tr>
<td>Concentration (2004)</td>
<td>How is your concentration?</td>
</tr>
<tr>
<td>Enjoyment (2004)</td>
<td>What have you enjoyed doing recently?</td>
</tr>
<tr>
<td>Enjoyment (2004)</td>
<td>What have you enjoyed doing recently?</td>
</tr>
<tr>
<td>Tearfulness (2004)</td>
<td>In the last month, have you cried at all?</td>
</tr>
<tr>
<td>Tearfulness (2004)</td>
<td>In the last month, have you cried at all?</td>
</tr>
</tbody>
</table>
8.1.ii Model specification and post-estimation tests

The extent to which the binary dependent variable *dementia* \((y_i)\) is explained by the explanatory variables \((X_i)\) is tested through various regression specifications. A logistic regression is used to examine the likelihood of being diagnosed with dementia based on the sets of explanatory variables. Equation (6) calculates the individual’s propensity score of dementia \((p_i)\) by applying a logistic regression.

\[
\ln \left[ \frac{p_i}{1 - p_i} \right] = \alpha_0 + \beta_k X_i + e_i
\]  \hspace{1cm} (6)

A *baseline* equation is specified to predict dementia based on age, level of functional impairment level of cognitive impairment and education.

\[
y_i = f(Age; Functional Impairment; Cognition; Education)
\]

The specifying of the model to also include various dimensions of depression from SHARE Wave 1 and/or Wave 2 can indicate changes in the model’s predictive efficiency to provide an effect of depression. Formally the specification is:

\[
y_i = f(Age; Functional Impairment; Cognition; Education; Depression)
\]

The role of depression in predicting dementia was examined by testing the incremental gains in model efficiency over four further model specifications varying in the variable set *Depression*; the name of the four models are indicated as follows:

1. **Threshold**: In this specification the predictive value of clinical depression prior to diagnosis *Euro-D>3(04)*, test prodromal depression, *Euro-D>3(06)* indicates coexistence and *Euro-D>3(04&06)* test the effect of individuals being depressed at both time points.
2. **EuroD06** tests individual symptoms of depression in SHARE 2006.


To compare the incremental change in model efficiency, a series of tests are performed on each of the five models. The significance of the model is presented in the Wald $\chi^2$ statistic; the McFadden Pseudo $R^2$ gives a partial measure of proportional variability in the model; AIC, BIC provide matrices to compare model performance; and Hosmer-Lemeshow tests for goodness of fit (previously detailed in Chapter 5). Having tested the models, measures of sensitivity indicate the accuracy in predicting individuals with dementia; this is denoted as $p(\bar{y} = 1 | D = 1)$ where $D$ is the indicator of dementia and $y$ is the indicator of logistic regression outcome.

### 8.2. Propensity Score Matching

In observational data, individual level treatments are not generally blinded. Therefore it is less straightforward to indicate the counterfactual, that is what would have happened if an individual was treated ($D=1$) or not ($D=0$). So the concern becomes to isolate a treatment effect $\delta y/\delta D$ where all things are held constant (*ceteris paribus*).

This section presents the variables required to construct quasi-experimental conditions by one-to-one matching and explains the empirical basis of obtaining the average treatment effect. This process is used to form two comparative populations as if randomly assigned their treatment: the treatment group having dementia and the control not.

#### 8.2.i Dependent and independent variables

The results of the five estimations stages in Section 8.1 are used to inform the parameters used in one-to-one matching. Results presented in Chapter 13 find that depression plays little additional role in improving the predicting power of the *baseline* equation for dementia. Therefore the *baseline* equation provides the most reliable prediction of dementia and therefore this specification is used in a matching procedure.
8.2.ii Specification in one-to-one matching

In SHARE, the outcome of interest is a binary variable (y) which indicates assignment of a diagnosis of dementia (D) and a vector of observable individual characteristics X in N individuals; see Equation (7).

\[(y_i, D_i, X_i; i = 1, 2, ..., N)\] (7)

The method of propensity score matching has been applied to various policy analyses (Bryson et al. 2002, Vinha 2006, Rosenbaum and Rubin 1983). Rosenbaum and Rubin (1983) firstly demonstrated that adjustment using scalar propensity score was sufficient to remove bias because of all observed covariates. Bryson et al. (2002) discuss the role of matching in labour market policy analysis, explaining the intuition and relevance of propensity score matching to such research. Vinha (2006) extends the literature by discussing the methodology for both the binary treatment case as well as for the multiple treatment case.

The objective of matching is to calculate the mean impact in a treatment group (typically denoted as T=1) compared to an untreated comparator group (T=0) to give outcomes of treatment, y₁ and y₀, respectively. Equation (8) shows that the treatment effect is the difference in outcomes with or without the treatment for the treated group.

\[E(y_1|T = 1) - E(y_0|T = 1)\] (8)

This presents an unobservable counterfactual \(E(y_0|T = 1)\) since the individual’s outcome would be without treatment cannot be observed. As assignment to the treatment group (in this case, being diagnosed with dementia) is not random, the treatment can be determined by some set of covariates (x). The covariate vector provides the basis to estimate the effect of being treated over a control group with similar characteristics. These two groups simulate the conditions to capture the
treatment effect of a random experiment. Formally, equation (9) denotes this difference as:

$$\varphi = E(y_1|x, T = 1) - E(y_0|x, T = 0).$$  \hspace{1cm} (9)

This depicts the relation of the outcome (in this case health care utilisation) conditioned by the covariate matrix (age, education, level of physical disability and cognitive impairment) conditional on whether individuals’ are treated (in this case having been diagnosed with dementia). For this to be valid requires two conditions referred to in matching literature as conditions of ‘strong ignitability’ (synonymous with conditional independence or confoundedness).

Firstly a strong assumption is that of conditional independence, which states that the treatment effect conditional on \(X\) is independent of the outcome \(y\), formally written as Equation (10).

$$y_{0,1} = \perp D|X.$$  \hspace{1cm} (10)

Complete random assignment would control for individual level heterogeneity in a large enough randomised sample over the vector space \(X\) implies the conditional assumption (11).

$$y_{0,1} = \perp D.$$  \hspace{1cm} (11)

The second matching assumption must ensure that for each value of \(X\), there will be both individuals who are treated and untreated (12).

$$0 < \Pr[D = 1|X] < 1.$$  \hspace{1cm} (12)

The third assumption is that the average outcome of not being treated would be the same independent of the treatment assignment \(D\) and therefore \(y_0\) does not determine an individual’s participation. This is known as the conditional mean independence assumption as described in Equation (13).
On the basis of the three assumptions, a target population is defined based on propensity scoring, which defines the conditional probability of treatment participation based on a given $X$ (14).

$$p(x) = \Pr[D = 1|X = x].$$  \hfill (14)

This implies that $D \perp x|p(x)$ means that individuals with the same propensity score should be similar in vector $X$. Ultimately, this removes correlation of $X$ on the treatment assignment.

Equation (15) calculates the treatment effect.

$$\Delta = y_1 - y_0$$ \hfill (15)

In (15) $\Delta$ is the difference between outcome in the treated and untreated groups. Therefore the average treatment effect (ATE) is

$$ATE = E[\Delta]$$ \hfill (16)

The estimate of $N$ individuals $\bar{ATE}$ is repeated for each individual (i) by country (j) independently and is given by equation (17).

$$\bar{ATE}_j = \left[ \frac{1}{N} \sum_{i=1}^{N} [\Delta_i] \right]_j$$ \hfill (17)

Equation (18) rewrites this average treatment effect with respect to $X$.

$$ATE = E[\Delta|X = x]$$ \hfill (18)

This implies that the conditional assumption is (19).

$$ATE = E[y_1|x, D = 1] - E[y_0|x, D = 0]$$ \hfill (19)
To estimate the second term \( (E[y_0|x,D = 0]) \), the outcomes are rewritten as 
\[ y_1 = \mu_1(x) + u_1 \quad \text{and} \quad y_0 = \mu_0(x) + u_0. \]
Applying the conditional independence assumption and conditional mean assumption Equation (19) is rewritten as Equation (20).

\[
ATE = \mu_1(x) + \mu_0(x).
\] (20)

This approach assigns the control group and provides the average treatment effect of diagnosing dementia on health care usage at each country level.

To control for country level variations, the matching procedure is individually repeated in each country. In this application, matching is on a one-to-one basis meaning that for individuals (i) assigned to the treatment group, an individual within their country (j) and with a similar propensity score is matched to them. This procedure provides a sample of 730 between the treatment and control group.

Results of matching are presented in Chapter 14.2 comparing the whole survey and at the country specific level, and comparing health care utilisation in the full SHARE 2006 sample (n=33,332), for the treatment group (i.e. those with dementia, n=365) and for the control group (n=365).
8.3. Modelling Health Care Utilisation and Obtaining an Incremental Marginal Effect of Depression in Dementia

Having constructed a quasi-experiment, the final phase examines the determinants of health care utilisation in the dementia population using a two stage model and compares the control group with those with dementia. This section reviews the variables required in this analysis (8.3.i), the model specification and post-estimation test (8.3.ii) and how the incremental effect of depression in dementia is obtained (8.3.iii).

8.3.i Dependent and independent variables

To define the model of health care utilisation, this section introduces (1) the dependent and (2) the explanatory variables assigned in the two step regression.

(1) Dependent Variable

This analysis aims to isolate the effect of depression on service utilisation within two groups identified using the matching methods reviewed in the previous section (8.2). The outcome variable for health service utilisation \( y_i \) is the continuous count variable measuring how often the respondent has ‘seen or talked to a medical doctor in the last 12 months’. Results presented in Chapter 14.3 demonstrate that the doctor contact rate has common hallmarks of health service utilisation data with a large mass of zero services users, a left skewed distribution of the majority of service users and a long right tail indicating a low proportion of service users with extremely high rates of contact.

(2) Explanatory Variables

Three sets of variables are used to explain health service utilisation: depression indicators, demand variables and country controls; for a full summary of the explanatory variables, please see Table 6 presented below.

The first set of explanatory variables examine depression indicators. The primary outcome of interest is the impact of a depression score over the clinical threshold to
indicate a clinical case of depression (Euro-D >3). Individual symptoms of depression are included in the model to control for specific symptom effects on service use (e.g. service response to suicidal ideation would ideally increase average contact rates). Finally, the level of service use in 2004 conditional on being depressed in 2006 is included (HealthcareUse(04)| Euro-D >3); this controls what could be service use related to a history of depression (a prodromal to dementia) and specifies that the effect size of Euro-D >3 on service use relates to depression occurring within dementia and not ex-ante to diagnosis (prodromal depression effect).

The second set of variables control for individual demand. Firstly, the individual health care use in the previous wave (HealthcareUse(04)) provides a historical indicator of underlying health (i.e. health care use in 2004 is likely to be a good predictor of use in 2006). To control for the effects of other comorbid conditions, a continuous variable indicating the number of comorbid conditions (excluding dementia and depression) is assigned at the individual level. The final demand variable captures the rate of contact with a specialist hospital doctor; this is included to control for the proportion of contact that is explained by specialist contact.

35 Whilst the literature reviewed in Chapter 4.3 might indicate the threshold level should be varied for depression in dementia, for the purpose of comparison with the non-dementia matched group, this standard clinical threshold is maintained.

36 SHARE indicates 11 potential chronic specific states (e.g. cancer) but modelling each individually does not overly improve the model efficiency over NumberChronic and detracts from the main message.
Table 6: Description of independent variables used to explain health care utilisation in the two-step regression

[Source: SHARE].

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Depression Indicators</strong></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>Last month (LM), have you been sad or depressed?</td>
</tr>
<tr>
<td>Pessimism</td>
<td>What are your hopes for the future?</td>
</tr>
<tr>
<td>Suicidality</td>
<td>Last month, have you felt that you would rather be dead?</td>
</tr>
<tr>
<td>Guilt</td>
<td>Do you tend to blame yourself or feel guilty about anything?</td>
</tr>
<tr>
<td>Sleep</td>
<td>Have you had trouble sleeping recently?</td>
</tr>
<tr>
<td>Interest</td>
<td>Last month, what is your interest in things?</td>
</tr>
<tr>
<td>Irritability</td>
<td>Have you been irritable recently?</td>
</tr>
<tr>
<td>Appetite</td>
<td>What has your appetite been like?</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Last month, too little energy to do the things you wanted to do?</td>
</tr>
<tr>
<td>Concentration</td>
<td>How is your concentration?</td>
</tr>
<tr>
<td>Enjoyment</td>
<td>What have you enjoyed doing recently?</td>
</tr>
<tr>
<td>Tearfulness</td>
<td>In the last month, have you cried at all?</td>
</tr>
<tr>
<td>Euro-D &gt;3 Indicator of depression in 2006</td>
<td></td>
</tr>
<tr>
<td>HealthcareUse(04)</td>
<td>Euro-D &gt;3 Healthcare utilisation during SHARE 2004 in depressed group</td>
</tr>
<tr>
<td><strong>Demand Variables</strong></td>
<td></td>
</tr>
<tr>
<td>HealthcareUse(04)</td>
<td>Healthcare utilisation during SHARE 2004</td>
</tr>
<tr>
<td>NumberChronic</td>
<td>Individual’s Number of diagnosed chronic diseases, squared</td>
</tr>
<tr>
<td>Specialist</td>
<td>Rate of Contact with a Specialist in the last year</td>
</tr>
<tr>
<td><strong>Country Variables</strong></td>
<td></td>
</tr>
<tr>
<td>Health Expenditure (%GDP)</td>
<td>Share of gross domestic product spent on health</td>
</tr>
<tr>
<td>GateKeep</td>
<td>Whether access to specialist services requires GP referral</td>
</tr>
<tr>
<td>Fee For Serv</td>
<td>Indicator of ‘Fee for Service’ payment mechanism</td>
</tr>
<tr>
<td>Capitation</td>
<td>Indicator that GP are paid by ‘Capitation’ payment mechanism</td>
</tr>
<tr>
<td>Physician Density</td>
<td>Number of Physicians per 10,000 of the population</td>
</tr>
</tbody>
</table>

The final set of variables capture idiosyncratic features of the health system at the country level. Previous estimation using a similar approach include similar indicators; Sturm et al. (1995) variables are Health Care Expenditure (%GDP), Gate Keeping, payment mechanism (Fee For Service and Capitation) and more recently Solé-Auró (2011) included Physician Density when analysing the impact of migration status on health service use.
8.3.ii  Model specification and post-estimation tests

Given the features of the dependent variable outlined above in Section 8.3.i, the data is best analysed over two stages: the first stage is a selection equation which essentially examines whether any services are used or ‘accessed’, and the second stage examines the conditional mean, given that service is positive.

In the first step, a selection equation using a logistic regression will accommodate for the mass of zero users and predicts the individual’s probability of positive service usage based on explanatory variables (presented below). The second step is an equation which fits a regression for quantity of services used, using a generalised estimation equation and a generalised linear model (Manning et al. 1981).

The empirical specification for this is:

\[
\text{[Any Utilisation]}_t = f(\text{Depression}_t, \text{Demand}_t, \text{Country}_t) \tag{21}
\]

\[
\text{[Service Utilisation|[Any Utilisation = 1]}_t = g(\text{Depression}_t, \text{Demand}_t, \text{Country}_t) \tag{22}
\]

To efficiently estimate the conditional mean (equation (22)), features of the long right tail in the distribution must be considered. A general linear model (GLM) is applied as it has the benefits of specifying the distribution family and canonical link function. Given the exponential decline in the positive (conditional) contact rate, several families were applied, namely: Negative Binomial, Poisson and Gamma distributions. Their performance was tested by comparing their information criteria (AIC, BIC). Based on the information criterion for Negative Binomial (6.949535, -1251.105), Poisson (12.10645, 780.2048) and Gamma (6.839374, -1227.064), the gamma probability density function is chosen to provide the goodness of fit in the long right tail. The GLM further specifies a log link function to provide the relationship between the linear predictor and the mean of the distribution.

Both Equations (21) and (22) are interested in observing the effects of Depression controlling for individual effects which affect Demand and Country, factors influential to service use and access. Demand variables include Healthcare use [04], a lagged variable indicating usage in SHARE 2004, and the squared number of
chronic diseases (NumberChronic). In the conditional model (Equation (22)), the demand variable set also includes the rate at which individuals access a specialist services in the conditional mean.

The results of the matching show that on average the two matched groups have similar rates of service use; however, variation is observed at the country level (although this finding is limited by diminishing sample size (more details presented in Chapter 9)). To control for variation in health care use across Europe (for both the full sample and with matched groups), the country level health system characteristics were included.

To measure the effects of depression, depression indicators are included in both Equations (21) and (22). Aggregated score for depression over a clinically relevant threshold (Euro-D>3) indicates that an individual would potentially require treatment for the underlying depression. Specific symptoms of depression taken from the Euro-D questionnaire (Depression – Tearfulness) indicate which specific indicators influence demand. And finally, a depression specific interaction term indicates level of healthcare usage in 2004 given the individual is depressed (Healthcare Use (04)| Euro-D>3).

The equations were estimated using maximum likelihood and Wald tests are performed on the overall model and specific parameters. AIB and BIC were performed in specifying the model and the Hosmer-Lemeshow test was performed for goodness of fit. Finally, to compare efficiency of the AnyUse equations, specification presents the probability that a predicted negative user is actually a negative user (Pr[y=0|D=0]).

8.3.iii Incremental effect of depression in dementia

From the analysis so far outlined, the main aim is to isolate the incremental effect of depression in dementia. Having been satisfied that the baseline equation provides an average treatment effect of dementia compared with a similarly matched group, running the two step procedure in each group provides comparable regression coefficients; calculating the marginal effect at the mean (MEM), denoted by:
\[ MEM_{iD} = \beta_{iD} \beta \bar{x} \]

where D is the dementia status for the individual i.

As the population are standardised with respect to the covariate matrix used in the matching procedure, the MEM can be compared to provide an incremental marginal effect of depression in dementia over the control group.
Chapter 9. Limitations in the Data and Findings

Several limitations should be considered before the results (PART IV) are presented. This final Chapter presents the limitations of the data, the potential implications for the findings and the expected limitations of the findings. Section 9.1 examines the external limitations of the two selected surveys and section 9.2 discusses limitations in the method employed to answer the three specific research questions.

9.1. External Limitations of the Data

External limitations for this research are defined as limitations beyond any reasonable control of the research described in this thesis. As this research draws on data collected in two surveys, the focus in this section is on the scope or coverage of the survey and any potential limitations of the design. Each survey is reviewed separately with section 9.1.i on ASI 2007 and 9.1.ii on SHARE.

9.1.i ASI 2007

Alzheimer Society of Ireland – A Carer’s Survey (ASI 2007) is used to answer two specific research questions:

- What factors determine the Irish dementia population’s perceptions of care?
- How much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care?

To assess the validity of the results presented in this analysis, potential limitations are assessed in two keys stages: (1) Scope assesses limitations in the coverage, representativeness and potential sources of potential bias and (2) questionnaire design examines potential implications of the questions responded to in the survey.
(1) Scope of ASI 2007

To assess limitations in the scope of ASI 2007, this section examines potential deficits in four stages; (a) coverage, (b) representativeness (c) whether a dementia cohort is accurately captured and (d) the original purpose of the survey.

(a) Coverage

The coverage of the ASI 2007 survey in regions across Ireland is illustrated in Figure 10 and examination of this coverage uncovers two potential limitations. Firstly, the relative sample sizes may either over or under represent the dementia populations in certain regions of Ireland. For example, the Connaught region has competing providers to the Alzheimer Society, therefore the coverage of their database may not fully capture such regions. Secondly, whilst the Society offers a national contact point it does not equally cover all areas of Ireland and thus results in the sample do not capture every region of Ireland.

Figure 10: Coverage of the sample captured in ASI 2007 [Source: ASI, 2007].
(b) Representativeness

This section asks was the sample of 270 randomly selected candidates representative of the Society’s database and how representative is the sample surveyed of dementia across Ireland?

Is ASI 2007 a representative sample of registered members of the Society?
To illustrate how representative the ASI 2007 is of all the registered members of the Society, the observed samples can be compared with those that would be expected from the Society’s database. Specifically, data routinely captured on the Society database allows comparison across four relationship categories of the caregiver to the recipient: namely wife, husband, son, and daughter.

<table>
<thead>
<tr>
<th>Relationship</th>
<th>ASI DATABASE</th>
<th>ASI 2007</th>
<th>Expected</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>Percent</td>
<td>Freq.</td>
</tr>
<tr>
<td>Wife</td>
<td>161</td>
<td>0.286477</td>
<td>70</td>
</tr>
<tr>
<td>Husband</td>
<td>100</td>
<td>0.177936</td>
<td>47</td>
</tr>
<tr>
<td>Son</td>
<td>89</td>
<td>0.158363</td>
<td>25</td>
</tr>
<tr>
<td>Daughter</td>
<td>212</td>
<td>0.377224</td>
<td>96</td>
</tr>
<tr>
<td>Total</td>
<td>562</td>
<td>1</td>
<td>238</td>
</tr>
</tbody>
</table>

Chi 2 (3) 5.263  p value 0.1535

Table 7a: Comparison of the relationships of the caregivers to recipients; observed frequencies from the society’s national database (left), observed frequencies from ASI 2007 (middle) and expected frequency calculated from the national database. Chi squared test statistically compares the ASI 2007 observed relationship with expected relationships. [Sources: Alzheimer Society of Ireland National Database and ASI 2007 Survey].

Results of the Pearson $\chi^2(3)$ comparing observed with expected relationships is 5.263. This implies a p statistic of 0.1535 indicating no significant difference in respondent type to member registered on the ASI database.

Is ASI 2007 Representative of Dementia as Captured by SHARE?

To indicate whether the ASI 2007 is representative of dementia in a more general population, the age ranges of individuals with dementia in SHARE (Börsch-Supan 2003) is used to calculate expected values.
Table 7b: Observed categorical age profile of the dementia populations in SHARE 2006 and ASI 2007; expected frequency calculated from SHARE and statistically compared using a Pearson Chi-Squared test.

<table>
<thead>
<tr>
<th>AgeCat</th>
<th>SHARE DATA</th>
<th>Observed</th>
<th>Expected</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>Percent</td>
<td>Freq.</td>
</tr>
<tr>
<td>64 or under</td>
<td>36</td>
<td>0.0885</td>
<td>18</td>
</tr>
<tr>
<td>65-74</td>
<td>78</td>
<td>0.1916</td>
<td>49</td>
</tr>
<tr>
<td>75-84</td>
<td>186</td>
<td>0.457</td>
<td>131</td>
</tr>
<tr>
<td>85 or Over</td>
<td>107</td>
<td>0.2629</td>
<td>72</td>
</tr>
<tr>
<td>Total</td>
<td>407</td>
<td>1</td>
<td>270</td>
</tr>
</tbody>
</table>

| Chi 2 (3) | 2.083 | p value | 0.5554 |

Statistical comparison of ASI 2007 age profile to that expected from SHARE 2006 provides a Pearson Chi2 (3) statistic of 2.083. This infers a p statistic of 0.5554. This suggests that the age profile in ASI 2007 is not significantly different from SHARE 2006. As SHARE was a random selection of individuals over 50,\(^{37}\) this comparison provides confidence that ASI 2007 is indeed a random selection of people with dementia and therefore representative of the known dementia population in Ireland.

(c) **Does the Sample Accurately Capture Dementia?**

The rates of undetected dementia in Ireland is high whilst provider confidence in diagnosing is low (Cahill et al. 2010), so it is to be expected that the sample will not be completely representative of the dementia population. There is the potential that the sample may over represent care in mid stage dementias for three reasons: in early stage, dementia may not be differentiated from normal cognitive decline (Nestor et al. 2004); at mid stage individuals are more likely to recognise the need for support services and in late stage, increased level of disability makes community care redundant (Dura and Kiecolt-glaser 1990). So the sample can be assumed to be subject to unavoidable censoring.

In the sample, 171 individuals indicated a current stage of dementia, out of which 10.06% in early stage, 50.84% mid stage and 39.11% were in the late stages of

\(^{37}\)SHARE is not considered to any extent a gold standard for this comparison but is reliable for three main reasons. Firstly, the two datasets were collected at similar time points of ASI 2007 vs. SHARE 2006 thereby excluding time trends on dementia. Secondly, SHARE data on dementia is a random population sample and therefore has good internal validity. Finally, at the time of writing this thesis, SHARE provided the largest sample size of individuals with dementia available.
dementia. This profile is representative of users of the ASI and the age profile is consistent with that observed in other surveys. Various approaches are possible to address this limitation in the data, including in the analysis specifically concerning stage related effects, a stage-related weighting in the regressions to reduce the related effects.

**Original Purpose of the Survey**

The final limitation in the survey comes from a potential conflict of interests in funding the project. As with Alzheimer Europe’s *Who cares? The state of dementia care in Europe* (2006), funding for the market research agency was provided by Lundbeck pharmaceuticals and for this reason there is a clear interest in market dynamics and certain questions enquire whether anti-dementia medicine was used (Q34–37). Whilst this potential conflict of interest is a concern, all research presented in this thesis is independent and the survey was professionally undertaken by a reputable market research agency functioning independently from the funding body. The interest in market dynamics is a strength for the health economic research and pharmaceutical related questions were not required.

In summary, the scope of ASI 2007 has three limitations; (1) geographical coverage could be improved; (2) whilst the sample is representative of member of the Society and has the expected age profile, there is likely to be certain unavoidable stage-related censoring; and (3) the survey was privately funded raising concerns of potential conflicts of interest.
(2) **Questionnaire Design**

This section examines particular components of the ASI 2007 questionnaire which are relevant to the analysis. Specially, three questions require discussion in relation to the results presented in this thesis, namely: (a) Q43 for the dependent variable ‘the perception of care’, (b) Q7 for the dependent variable measuring the amount of informal care provided and (c) Q31 capturing the stage of dementia at the time of the survey. The final section (d) presents one further limitation not directly related to any results produced in this research, but briefly outlines questionnaire limitations in Q42 related to valuation using the opportunity cost method.

(a) **Q43 – Dependent variable for Perceptions of Care**

The questionnaire presented to respondents was entitled *Alzheimer’s Disease Research Questions* and was sent to caregivers of people identified as having a dementia. Twenty-three out of the forty-three questions in the questionnaire relate clearly to the individual with dementia stating “*the person with Alzheimer’s disease / dementia*”. The final question (Q43) concludes the survey by asking respondents to rate their satisfaction by requesting “Please indicate how much you agree or disagree with the statements below, by ticking the relevant boxes”. This statement and the proceeding options have the limitation of not referring to “*the person with Alzheimer’s disease / dementia*” and to whom they refer has some ambiguity. For the purpose of the results and conclusion presented in this thesis, it is assumed that by the final question, the respondent’s *perception of care* be made as a proxy in the dyad of the caregiver and their related recipient.

(b) **Q7 – Censored Dependent Variable for Hours of Informal Care**

The second research question was interested in examining the hours of informal care. In the ideal research design, informal care would be recorded using diaries on a daily basis (see Chapter 3 for more details). The survey method employed by ASI 2007 requires respondents to recall their hours of care. This raises the first limitation that recall may not be accurate and is prone to over- or under-reporting.
The second limitation is that the question assessing the amount of time spent caring \textit{per day} (Q7) was top coded at 14 hours. In the ideal situation this variable should be continuous from 0 to 24 hours. Whilst not ideal, the latent dependent variable can be estimated using a censored regression Tobit model (full details were provided in Chapter 7).

\textbf{(c) \textit{Q31 – Current Stage of Dementia}}

In obtaining a cost of informal care of the dementia stage at the time of the survey, Q31 asked “Which stage or severity of Alzheimer’s disease / dementia has the doctor indicated the person is currently experiencing? Please tick one box only.”

In an ideal situation, the stage of dementia would be ascertained at the time of the survey by an appropriate health profession. Given that this was not available within this research protocol, it is important to raise several potential limitations. Firstly, assuming that the respondent has been informed, the question required that individuals are able to recall their stage; however, the questionnaire does provide the option “I don’t know/ can’t remember” to address this situation. More importantly, where a stage is recalled accurately by the respondent, there is an additional assumption that the stage was validly captured in a structured manner by the reporting physician. Future surveys should assess the stage at the time of the survey and repeating data collection to allow for panel analysis.

\textbf{(d) \textit{Q42 – Informal Care and Labour force Participation}}

An alternative method to valuation by proxy-good would be the use of the opportunity cost method. To calculate an opportunity cost related to informal care would require information on the reduction in hours of paid employment and further information on the level and wage rate prior to assuming the informal care role.

Q42 asked specific questions about such changes; however, as a result of study design, the data has been deemed not suitable for analysis (for further information please see Appendix 3).
9.1.ii SHARE

The Survey of Health Ageing and Retirement in Europe (SHARE) was funded by the European Commission through the Framework programmes 5, 6 and 7 and therefore the scope (1) of the survey is radically different to that of ASI 2007. There are more specific issues to consider which relates to the variables selected for analysis (2).

(1) Scope

For consistency, this section considers the three areas covered on scope previously, namely; (a) coverage, (b) representativeness and (c) does the sample accurately capture dementia; however, issues relating to funding are not a concern in SHARE.

(a) Coverage

SHARE aims to cover multiple countries across Europe and one major limitation emerges from this endeavour. Apart from ten core countries, there appears to be substantial variation in the coverage in the additional SHARE over time. One concern specific to this analysis is the entrance of three new countries in 2006, namely Ireland, Poland and the Czech Republic.

The uneven international coverage over time particularly in Ireland, Poland and the Czech Republic who joined in 2006), caused substantial variation in SHARE’s total sample size causing variation in the rates of diagnosed dementia within each country. Furthermore, with new entrances it is unclear which SHARE recruitment protocol these new entrance followed (i.e. Wave 1 or Wave 2). This has the limitation of potentially introducing additional heterogeneity to the dementia subpopulation if individuals were not actively excluded for dementia in their first wave of sampling.

As further waves of SHARE become available from 2012, future research into the dementia population may benefit from focusing on the core countries that have full coverage over time.

The second coverage issues inherent in SHARE relates to Wave 3 “SHARELIFE”. The decision was made by SHARE to supplement a repetition of the measures obtained in Wave 1 and 2 with a retrospective review of life events. Whilst this provides useful data for analysis, this compromised SHARE’s ability to function as a panel for analysis.
(b) **Representativeness**

As an international survey, SHARE has gone to great lengths to ensure the sample collected is representative of the over 50s populations sampled (a full description of the recruitment protocol was given in Chapter 5.2).

(2) **Questionnaire Design**

SHARE is a well-conceived multidisciplinary database of health, socioeconomic and family variables. As was presented in Chapter 5.2, data collected was often strictly controlled by using computer assisted interviewing. Nevertheless, there are several potential limitations to consider which relate specifically to variables used in the analysis, namely: (a) the dementia status variables (b) health care utilisation variables and (c) the measures of depression.

(a) **Dementia Status Variable**

In SHARE 2004 (Wave 1) individuals with dementia were actively excluded from the survey. However in SHARE 2006 (Wave 2), respondents were asked to report along with other chronic conditions whether they had been diagnosed with dementia. In an ideal world, dementia should be assessed by an appropriate health care professional and therefore SHARE has the limitation that the dementia status is self-reported. This may raise concerns on the accuracy of the indicator and the sample may contain false positives and may miss false negatives.

(b) **Health Service Use Variable**

In SHARE, respondents were asked to indicate how many times they had “seen or talked to a medical doctor in the last 12 months”. As with the measure of informal care seen in ASI 2007, there is a potential concern of recall bias. The most robust forms of analysis of health service use occurs where administrative data is collected by a third party payer for reimbursement purposes and this data is made available to the research community (several examples are available in the USA and Switzerland). Given the size and scope of SHARE, whilst this question has limitations, the data from this question is considered valid.
A second minor limitation is that SHARE datasets contain an upper limit of 98 contacts per year; this is not considered overly meaningful to any outcomes of analysis.

(c)  **Depression Measured Using the Euro-D**

At the time of data collection, SHARE employed Euro-D to measure depression. As was discussed in Chapter 4, depression in dementia may not share the same hallmarks as traditional depression; however, this is tested thoroughly in the analysis.
9.2. Internal Limitations in the Findings

For the three questions posed in this thesis, this section examines limitations in the internal validity of the results of the method applied and each questions posed will be scrutinised. Firstly, limitations in the analysis of perceptions of care are discussed (9.2.i), secondly potential limitations in valuation of informal care are reviewed (9.2.ii) and finally the analysis of the impact of depression on dementia health care utilisation is reviewed (9.2.iii).

9.2.i Limitations in the analysis of perceptions of care

The first question asked was: what factors determine the Irish dementia population’s perceptions of care? The method employed was an analysis of a set of six binary variables indicating the individual’s perception of care and service.

This analysis has the internal limitation of the questionnaire originally collecting data on a five point Likert scale and in converting these variables to a binary form; the score of 3 (neither agree nor disagree) was omitted.

Variation in the response to this question (particularly where a score of 3 was recorded) results in a reduced sample size and variation between adjacent analyses. For this reason, comparisons across the outputs of the regression analysis should be made with the reservation that the sample in each regression will be subtly different and no two sets of determinants should be compared with one another.

9.2.ii Proxy-good

The second question asks: how much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care? As was shown in Section 9.1.i, the dependent variable contains an upper limit of 14 hours and the explanatory variables ‘stage of dementia’ are self-reported. The first limitation is that the regression coefficients should not be as an effect of \( x_i \) on \( y_i \) as this assumes there is the linear regression model. For this reason any interpretation of the coefficients should acknowledge this limitation. The coefficients would be better interpreted as
the combination of change in \( y_i \) above the censoring threshold (weighted by the probability of being above this threshold) and the change in the probability of being above the limit, weighted by the expected value of \( y_i \) if above (McDonald and Moffitt 1980).

### 9.2.iii Service utilisation

The final question asks: how is formal service utilisation influenced by depression in dementia? To answer this question, Chapter 8 detailed a series of steps required to isolate this effect. During these steps, there are two main limitations to consider in the interpretations relating to (1) the regression predicting dementia and (2) the country sample sizes in the matching experiment.

#### (1) Limitations in the Regression Predicting Dementia

When testing the effects of various depression variables in explaining the likelihood of dementia in the SHARE sample, the aim is to test various specifications above a baseline predictive model to quantify the effects of depression. The baseline model specified in Chapter 8 was:

\[
y_i = f(Age; Functional Impairment; Cognition; Education)
\]

This draws on data from an enriched cross section which includes lagged variables taken from SHARE 2004, such as recall-delay (04) and numeracy (04) which is included to control individual heterogeneity in cognitive ability.

Over the baselines, four additional specifications of the baseline equation were made to include parameters for depression. In SHARE 2004 there was a total of 32,899 individuals and in SHARE 2006 (with the inclusion of Ireland, Poland and the Czech Republic) the total increased to 36,089. Where a lagged depression variable is included, there is a drop in the sample size from 33,321 (in the baseline equation) to 17,798 (in the threshold equation). These reductions are explained by omission of data in the Euro-D scales; where one point is missing the individual is excluded from the regression. As a result, caution is advised in comparing individual regression outputs.
Matching Experiment: Country Sample Sizes Variables

To isolate a comparative group matched across the relevant parameters, the second part of this research conducted a matching procedure. The process of matching is performed on a one to one basis within each of the included countries and the results are presented in Table 21.

The level of dementia identified by the country imposes a limitation in the numbers of individuals for comparison by country. As such, the analysis itself does not have a limitation but the underlying treatment group for matching (i.e. dementia=1) varies considerably and in two countries (Ireland and Switzerland), sample size of dementia falls 10 individuals. From the data available in SHARE, there is no way to explain why certain regions rates of dementia should be so low. Furthermore, no country accrues greater than 50 individuals with dementia. This can be explained by the method by which individuals with dementia were excluded and on this basis the conditional likelihood of developing dementia between 2004 and 2006. However, despite country by country variation, on aggregate, results will show that mean health service utilisation is comparable between the treatment and control group. For these reasons, results from the matching procedure are considered valid at the European level and interpretations at country levels must accept this limitation.
PART IV
RESULTS
Part IV – Overview

PART IV presents results of the investigations into the determinants of dementia care as they pertain to perception of care, value of informal care and the level of formal service utilisation.

Chapter 10 summarises results from ASI 2007 by providing a description of the dementia population, their informal carers and specific descriptive statistics related to the two research questions using ASI 2007.

Chapter 11 presents results of the analysis into what factors determine the Irish dementia population’s perceptions of care? A series of six regressions were performed and the regression coefficients are examined to infer what causes individuals’ perceptions.

Chapter 12 gives the results relating to the question: how much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care? The analysis of informal care time is subdivided by dementia stage and further subdivided into the amount of time spent on specific tasks at specific stages. The Chapter concludes by presenting the estimated value of informal care time at the progressive stages of dementia.

Chapter 13 analyses the SHARE dataset, presenting descriptive statistics of the dementia population and then examining the relationships between depression and dementia.

Chapter 14 provides results obtained to answer the question: how is formal service utilisation influenced by depression in dementia?
Chapter 10. Descriptive Statistics of Dementia (ASI 2007)

To introduce the population with dementia as observed in ASI 2007, this Chapter aims to describe specific features of the population and draw meaningful inferences in relation to the objective of this thesis. Specifically, this Chapter presents data on the demographic profile of the dementia population in ASI 2007 (10.1), how informal care is provided to those with dementia (10.2) and the specific summary statistics related to the first two research questions (10.3).

10.1. The Dementia Population

ASI 2007 captures a previously unpublished snapshot of the dementia population in Ireland. This Section presents summary features of the dementia population captured by ASI 2007, presenting statistics on general demographics (10.1.i), a summary of the stages of dementia (10.1.ii), where individuals with dementia live (10.1.iii) and trends in their diagnosis (10.1.iv).

10.1.i Age and gender of those with dementia in Ireland

Figure 12 divides the sample of individuals with dementia in ASI 2007 by age and gender) and illustrates four important features captured by the sample frequency of dementia. Firstly, for both male and female, the number of people with dementia is increasing with age, indicating that the sample is in line with expectations. Secondly, ASI 2007 finds a small minority of people with dementia below the age of 65 and some lower than 55 within the female population.
Thirdly, the age category 75–84 has higher dementia frequency than the 85+ group indicating the population age median and most likely indicating that age profile is limited by general life expectancy. This would raises the question of whether individuals are at highest risk of dementia around this age range. These facts have been previously established in the international literature and give further indication that ASI 2007 is a representative sample of the dementia population.

Certain differences in the sample by gender become apparent in the over 65s where a substantial divergence in sample frequency is apparent for those aged over 85
(Figure 12), where the ratio of females to males is approximately 2.5 to 1, in line with general distribution by age in Ireland.38

![Bar chart showing incidence of dementia by gender and age in ASI 2007.](http://www.wolframalpha.com/input/?i=age+distribution+ireland)

Figure 12: Incidence of dementia by gender and by age in ASI 2007 [Source: ASI 2007].

This shows that the frequency in males is lower for all age groups apart from the 55–64, where it is roughly equal. This further suggests that females may be more likely to experience dementia independent of ageing. However, it is clear that a time trend also exists and that the frequency of dementia drops substantially in the over 85s. This is most likely a result of the greater average life expectancy of females over males.

38 [http://www.wolframalpha.com/input/?i=age+distribution+ireland](http://www.wolframalpha.com/input/?i=age+distribution+ireland)
10.1.ii Stage of dementia

The need for care changes as dementia progresses and therefore stage related dynamics captured in ASI 2007 provide important insights. This section presents statistics on three important dynamics: (1) the individuals’ stages of dementia from diagnosis correlated to the time since that diagnosis (2) and the current stage correlated to time since the diagnosis (3).

(1)  Dementia Stages at the Time of Survey

At the time of this survey, the majority of individuals with dementia sampled were in middle stages dementia, where symptoms start to become more pronounced (Figure 13). Stage comparisons indicate that the proportion of males with middle stage dementia is higher than females. However, this seems to reverse in latter stage dementia where there are more women compared with men.
This is most likely explained by the fact that the life expectancy of females is higher than males. For dementia, Xie finds that females life expectancy is on average 4.6 years while men is 4.1 years (Xie et al. 2008); findings from ASI 2007 concur with this more rigorous assessment.

(2) **Stage at the time of Diagnosis versus Time since Diagnosis**

Xie et al. 2008 established important parameters for the average life expectancies for individuals with dementia and therefore an examination of time trends related to dementia stages provide important information. Figure 14 presents the stage at diagnosis and divides this stage by the time since diagnosis.
Figure 14: Dementia stage of individuals at the time of diagnosis divided by time since diagnosis [Source: ASI 2007].

These results suggest two key findings. Firstly, early stage dementia is most commonly reported at diagnosis independent of how much time has elapsed since the first diagnosis. Secondly, the largest proportion of mid stage dementias are found across three areas: either in those diagnosed in the last 6 months, in those between 2 and 4 years since diagnosis and in those who do not state a time since diagnosis. This suggests that whilst mid stage dementia is the most common stage in ASI 2007, individuals classified at mid stage may have had a diagnosis of dementia for very different amounts of time.
(3) **Time since diagnosis versus the current stage of dementia**

Of comparable importance is the relationship between how long an individual has been diagnosed with dementia and the stage of dementia at the time of the survey. Figure 15 suggests that a diagnosis more recently issued is likely to indicate either early or mid-stage dementia; however, the picture over time shows greater variation.

Focusing on early stage suggests there is a near linear decline between time periods since diagnosis. In line with general expectations, this suggest that individuals are less likely to be in early stages the longer the time since their initial diagnosis.

Middle stage is most likely to occur around 1–2 years after diagnosis and the data would suggest that the transition to late stage is most likely 4 years after diagnosis.

![Figure 15: Individual current stage of dementia divided by time since diagnosis [Source: ASI 2007].](image-url)
10.1.iii Where do those with dementia live?

ASI 2007 is a survey responded to by informal carers and gives details of their experiences caring for an individual living within an Irish community setting. This section discusses where the individual with dementia lives (as captured by ASI 2007) in two sections: (1) the accommodation status of individuals with dementia and (2) the regional distribution of those with dementia in ASI 2007.

(1) Accommodation Status

ASI 2007 identifies where individuals with dementia are most likely to be accommodated as they get older. Figure 17 breaks down where those with dementia are accommodated (at home in a residential facility or with a family member), whether this involves living with the survey respondent (their primary informal care giver) and for each what the age distribution is. From this scheme, three observations are drawn.

Firstly, the majority of respondents live at home (n=227) of whom most are likely to be living with their caregiver and most commonly aged between 75 and 84.

Secondly, a minority of people surveyed lived in nursing homes (n=8), all of whom were aged over 65. Whilst such a low sample number is unreliable, it is further noted that older individuals are likely to live with their caregiver (potentially indicating a spousal relationship) whilst individuals not living with a caregiver are younger (most commonly aged 65–74).

The final observation relates to individuals with dementia who take up residence with a family member. Statistics emerging from ASI 2007 would indicate that this arrangement is most likely to occur in the oldest old (i.e. aged 85+). This may generally reflect the situation, where those being cared for are living alone and moving in with a family member is the best solution for all. This raises an important
question whether the level of informal care may be determined by the cohabitation status; this notion will be analysed in Chapter 12.

Figure 16: Age ranges of people with dementia and the relationship to what accommodation they use and whether they live with their informal carer (right) [Source: ASI 2007].
ASI 2007 collects data from individuals registered with the Alzheimer Society of Ireland. Figure 17 plots the gender mix by region; this plotting generally indicates that the dementia sample is proportional in each region with a few exceptions.

Munster and Leinster would seem to depart from the average trends and start to show significantly more females than males. This is particularly noticeable in the Munster region where the number of females is over 50% higher than males.

Figure 17: Gender related response rate, subdivided by region [Source: ASI 2007].

As discussed in Chapter 9, the majority of the sample surveyed was found in Munster and Leinster; however, because of the variation of ASI coverage of Ireland, these proportions may not be nationally representative (see Figure 10). These findings would further suggest that ASI 2007 geographically favours Munster and Leinster...
and that competing providers in the Connaught area may have reduced the sample coverage.

To elaborate further on the type of sample by region, Figure 18 examines the underlying age trend.

Figure 18 captures the percentage age distribution within each surveyed region and suggests that Munster density function by age is comparable to other regions. From this finding it can be inferred that the differences observed in Munster for females is more likely gender-based than a result of age. Furthermore, as a percentage of the overall regional population, Connaught has the highest proportion of over 85s and

Figure 18: Percentage age distribution of individual with dementia by geographical region [Source: ASI 2007].
conversely a relatively low population under 75 (based on the Connaught sample of 10 out of total 270).

10.1.iv Trends in diagnosis

Trends in diagnosis are important indicators of the individual’s ability to gain therapeutic relief from symptoms, to access appropriate services and ultimately the services ability to provide for the dementia population. Chapter 1 considered whether dementia can be prevented and in the first survey of Irish GPs who provide care in dementia, Cahill et al. (2006) found a general lack of confidence in assigning a dementia diagnosis. Collected a year later, results from ASI 2007 examine three further trends in diagnosis, namely: (1) time from first GP contact to diagnosis, by region (2) the time to diagnosis and individuals’ stage after the elapsed time and (3) what proportion of individuals are informed of their condition.

(1) Time from first contact with a GP to diagnosis, by region

To examine how dementia dynamics underlying GPs’ approaches to diagnosing dementias in the community, Figure 19 examines the length of time from first visit to a primary care physician to getting a confirmed diagnosis for each region included in ASI 2007.
This Figure examines whether certain regions are better able to diagnose dementia and how efficiently the diagnosis is issued from the first contact with the GP. Furthermore, Chi$^2$ statistics are calculated to assess the validity of any significant differences observed. Three observations emerge:

The overall observation from the visual inspection and Chi$^2$ statistics is that each area has very different ‘time to diagnoses’.

Accepting the low sample number, Connaught would seem to have the fastest rate of diagnosis, with 80% being referred within four weeks of first contact.
The slowest response rate would seem to be within Dublin raising some concern given that Dublin City houses the majority of the specialist units and the greatest density of physicians in the country. This finding is at odds with previous findings that concluded there were difficulties in getting diagnosis in the rural settings, illustrating the need for greater outreach programmes (O'Keane et al. 2005), and future research may consider that urban settings present a different set of challenges in terms of accessing services (e.g. greater demand for scarce resources).

These finding can tentatively conclude that dementia diagnosis is influenced by region. However, it should be reiterated that ASI 2007 has limitations in its scope (and specifically geographical coverage) and therefore caution is advised in handling inferences regarding this regional profile.

(2) *Time to diagnosis and the subsequent level of diagnosis at that time*

The health system’s ability to provide appropriate intervention is determined by the point at which a diagnosis can be provided. Chapter 1.2 examined current strategies available for dementia and indicated that pharmacological treatments are only effective at certain stages of dementia. Figure 20 examines the stage of diagnosis and its relationship to the time of diagnosis.
This data suggests that more advanced dementias are more likely to be diagnosed within a shorter time frame. Specifically, the majority of people diagnosed within a week are those with advanced dementia. Individuals, who take over 12 months to obtain a diagnosis, are most commonly reported as ‘no stage or severity was mentioned’. This raises important concerns of dementia disclosure and risk associated with a delayed diagnosis.

Figure 20: Time to diagnosis and the subsequent level of diagnosis at that time [Source:ASI 2007].
(3) Are they aware of their condition?

One of the most shocking findings that emerge from ASI 2007 is the extremely low level of disclosure to people with dementia with half of all carers stating they were not informed of their care recipient’s condition (see Figure 21). These findings concur with Irish research on GPs showing under-detection in general practice (Cahill 2006) and further findings of under-detection of cognitive impairment in nursing homes (Cahill 2010). Results from ASI 2007 indicate that generally females are less likely than males to be informed.

![Q13. Has the person been informed about his/her condition?](image)

Figure 21: Percentages of individuals who have been informed about their condition, by gender [Source: ASI 2007].
After this question, those who stated they were informed were asked to indicate who had informed them. Figure 22 indicates that the diagnosis was communicated by the carer themselves. Where disclosure is indicated to originate from a formal source, the most commonly observed source is from a GP or geriatrician.

![Figure 22: Who informed the individual with dementia of their condition [Source: ASI 2007].](image-url)
To focus on formal disclosure, Figure 23 excludes any informal disclosure and is divided by gender. The results suggest people are most likely to receive a diagnosis from a geriatrician, then by a primary care physician and then a generic hospital doctor, an old age psychiatrist, a neurologist and, least frequently of all from a general psychiatrist.

Figure 23: Frequency that individuals with dementia were diagnosed by medical professional and by gender [Source: ASI 2007].
10.2. A Description of the Informal Carer

This section presents details of the informal carers who completed the survey, profiling who accepts this role of caring for individuals with dementia and highlighting the dynamics of the carer relationship. Specifically, this section presents a statistical description of the observed relationships between the care provider and the recipient (10.2.i), and informal carers’ employment status (10.2.ii) and the extent to which individuals have had access to nursing homes or hospital care (10.2.iii).

10.2.i The relationships between care providers and their recipients

This section examines the relationships formed between care provider and recipient with dementia in two parts: (1) the types of relationship informal carers have with their recipient and (2) the numbers of hours informal carers provide at the progressive stages of dementia.

(1) Informal Carers’ Relationships with their Recipients

To introduce the role of informal carers, Figure 24 provides an overview of the relationship they have with the recipient. Most commonly care is provided to a spouse or to a parent. In ASI 2007, caring for a parent is found to be more frequent and in such situations, the carer is approximately four times more likely to be female than male.
Considering this likelihood that it is often a daughter who will adopt the caregiver role, it is worth reflecting upon a potential change in the supply of female informal care in this age bracket. Up until 1974 females working in the public sector in Ireland were expected to discontinue work after marriage and commit to family rearing and whilst this formally applied to the public sector, it was widely adopted in other sectors. Figures from the European Nations Economic Commission for Europe suggest that the mean age of marriage has been increasing since the 1980s.  

http://w3.unece.org/pxweb/igraph/MakeGraph.asp?onpx=y&pxfile=052_GEFHAge1stMarige_r2011723388.px&PLanguage=1&menu=y&gr_type=1
Figure 25: Mean age of first marriage by year for females in Ireland [Source: UNECE].

Figure 25 captures this changing female dynamic and is likely to be a reflection of the transition from family to career orientation. This would suggest that females in 1980 (aged on average 24) would probably have raised a family up until the mid-2000s and could be expected to form the population (now with ages ranging from 45–54) which will potentially assume caregiver roles. To highlight this, their parents would be approximately aged 20 when they married in the 1960s (based on UNECE trend) and therefore would fall within the age range 75–85 (where Figure 11 indicates the highest frequency of dementia). Whilst not visible from this data, this raises the hypothesis for future research that Ireland could see a reduction in supply of informal care as a result of conflicting priorities such as firstly, having children
later in life and secondly, having a more developed career at the time of starting a family.

Returning to the summary statistics, the age profile of carers is examined to see whether there is any further evidence of this potential phenomenon. Figure 26 indicates the weight of the full sample by age groups of carers. As was mentioned in the previous paragraph, the most frequent age range for carers is found in females aged between 45 and 54.

A smooth decrease is found in the supply of informal care as age increases; however, there is a sharp decrease for the age groups under 45, which may further indicate the lagged shock coming through the system.

Figure 26: The age profile of informal carers divided by gender [Source: ASI 2007].
The combined weight of the group 75–84 is relatively high and may reflect the ‘Spouse Carer’ group.

Figure 27 presents the percentage by age category of recipient, giving the age range most likely to be caring for recipient at certain age ranges. For early onset (aged lower than 65), both categories indicate that a person of similar age is most likely to care for the recipient (e.g. a partner or sibling). This trend is also observed for recipients in the age range 65–74, but starts to change as those with dementia move over the 75 mark. At this stage, care reverts back to the age group of the previous generation (i.e. a carer for a parent): so in the 75–84 age range the most frequent carer age group is the 45–54. When individuals are aged over 85, the majority of care is delivered by carers in the age range 45–64.

![Figure 27: Distribution of informal carers’ ages categorised by age of the person with dementia [Source: ASI 2007].](image)
The correlation between age of the caregiver and recipient indicates that a substantial number of informal carer group lie within the age ranges of individual who could form part of the labour force. Whilst this feature can be observed in the current cohort, the transitional trends in the female labour force since the 1970s, it raises the question of whether the pattern of females assuming the informal carers role can be assumed to continue in the future.

(2) The Number of Hours of Informal Care Provided per Day by Dementia Stage

Forming a care-providing relationship can become demanding on the care provider’s time. Figure 28 divides care giving into two main groups: those who provide more than eight hours per day (above) and those providing less than eight hours (below).

![Figure 28: Distribution of dementia stage by whether carers do more or less than eight hours care per day. Source: ASI 2007.](image)
This Figure shows that the majority of care provided is greater than eight hours per day. Of the group providing over eight hours, the majority of recipients are either in middle or late stages of dementia. In the group providing less than eight hours, recipients are most commonly in the middle stages of dementia. Comparisons indicate that substantially fewer carers give below eight hours in late stage indicating that stage of disease has an important bearing on the level of care required.

10.2.ii Carers’ employment status

The levels of care observed in the previous section would indicate the need for co-habitation (confirmed earlier in Figure 16) but is likely to affect the carer’s employment status. In this section, a statistical overview is provided of carer employment status, examining (1) their reported employment status and (2) the age profile within each type of employment.

(1) Reported Employment Status of Informal Carers

Providing informal care is often related to a carer’s employment status. Figure 29 reports the frequency of employment status given by the informal carers captured in ASI 2007. The results indicate that most of the caregiver population is retired, which is unsurprising as 96.5% of this category are aged over 65. ‘Not Working Owing to Carer Role’ is the second most common employment status and this may presents concerns of reduction in labour force participation as 85% of this category is below the age of 65. The remaining two groups are balancing either full- or part-time employment with the caregiving role and make up 27% of the overall sample.
Figure 29: The frequency of carers by their employment status [Source: ASI 2007].

(2) **Distribution by Employment Status by Age of the Informal Carer**

Changes in employment status in this group are either those generally expected (e.g. retirement around 60–65) or as a result of the adopting of the care providing role. Figure 30 presents the frequency of age groups across each employment category.


This Figure clearly illustrates four trends by employed group:

**Full-time** employed are most commonly under 35 and decrease as a category with increasing carer age;

**Part-time** status has a mean age range of 35–44;

**Retired** rapidly increases as a category after the age of 65;

**Not working owing to carer role** seems equally likely for all those aged below 65 with approximately one in three choosing this option.
These findings would seem to concur with the notion propounded by Koopmanschap (1995) of a friction cost where providing informal care represents transient absenteeism. To examine this further, Figure 32 examines the carer’s financial status in relation to their employment to indicate the presence of friction in providing care.

![Diagram of Figure 31](image)

Figure 31: Whether informal carers have sufficient income to look after their recipient, divided by employment status [Source: ASI 2007].

Figure 31 presents whether individuals feel they have sufficient income to look after their care recipient and divides the sample by their employment status (categorical names are now abbreviated). Examination of each of the groups separately suggests:

*Retired* are most likely to feel they have sufficient income and, across the three categories this declines. This suggests that the retired group become less likely to indicate financial problems compared with the others.
Resign to care are most likely to feel they have insufficient income.

Full-time employment is most likely to definitely have sufficient income.

The Part-time employed group are most likely to “probably not” have sufficient income.

In summary, this finding would suggest informal care is a potential source of friction between employment and the ability to provide care. And that the recipients may be dependent on the carers’ financial means at the point of their life in which there is demand for their care.

10.2.iii Access to nursing home or hospital care

Nearly all the ASI 2007 sample lived either at home or with a family member; however, the individuals may have also stayed in either a nursing home or a hospital. Figure 32 examines the number of people who have been in a nursing home or a hospital since their diagnosis and the figures disclose that nearly two-thirds of respondents sampled have not been in either facility. Out of those who had, males’ most common length of stay was between one and two weeks.
Figure 32: Has the person with dementia been admitted to a nursing home or hospital care before (left) and if so, how long was their stay [Source: ASI 2007].

Females most commonly also spend ‘one to two weeks’ but closer examination would indicate that the female distribution is skewed towards longer length of stay. However, as the average age of females is higher, this observation may be correlated to the female sample’s age profile and associated increased demand.

In summary, this section has provided a statistical description of the informal carer as captured in ASI 2007. The remainder of this Chapter presents statistics specific to the first two research questions.
10.3. Summary Statistics Related to the Specific Research Question

This section summarises the statistics related to the variables analysed in the following two Chapters. The aim of this overview is to establish the nature of the dependent and independent variables of the regression analysis in two parts: those relating to the determinants of the perception of care (10.3.i) and secondly, those associated with the informal costs of dementia care (10.3.ii).

10.3.i Determinants of the perception of care – summary statistics

This section details summary statistics related to the research question: what factors determine the Irish dementia population’s perceptions of care? To provide the basis of results presented in Chapter 11, related variables are described in two parts; (1) the six dependent variables detailing the distribution of opinions to each statement and, (2) the explanatory variables, which are described statistically.

(1) Perceptions of Care

Figure 34 describes the six indicators of perceptions of care. Most commonly carers strongly disagreed that the level of elderly care was good in Ireland and strongly agreed that care should be a public concern. When asked if the service was sufficient, 30.8% strongly disagreed and the issue of whether quality was very high most commonly had respondents neither agreeing nor disagreeing. Most noticeable is that 46.4% of people strongly disagree that the cost of health care is reasonable and, similarly, that 43.4% strongly agree that care should be covered by society.
Figure 33: Categorical variable of perceptions of care [Source: ASI, 2007].
Modelling of perceptions of care is to be explained by access to, use and financial aspects of formal services and community support services, whether individuals have had their condition disclosed to them and whether their informal carers have financial issues related to providing care for them. Table 8 summarises the underlying frequencies of these explanatory variables and four key observations are made:

Approximately one in two respondents indicate use of primary care services; 52.2% indicated this service as being state funded. Access to hospital services would seem to be limited to 7.04% of the sample, of which 63.13% indicate this to be state funded.

In terms of community support services, 45.56% use day care, 56.67% use home care and 29.26% use respite services.

Only half were informed of their condition, most commonly from their informal carer or their primary care physician.

Financially, 7.78% of carers indicate having to pay medical expenses and 48.15% say they have to pay for additional help. When asked if they felt they had sufficient income to look after the person, only 7.35% said they definitely did, 31.02% probably did and the remaining 61.64% probably or definitely did not.
Table 8: Summary of statistics of the explanatory variables used to explain perceptions of care [Source: ASI, 2007].

<table>
<thead>
<tr>
<th>Response Categories</th>
<th>Response Frequency</th>
<th>Percentage of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group of carer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;35 Years</td>
<td>13</td>
<td>4.81%</td>
</tr>
<tr>
<td>35 - 44</td>
<td>28</td>
<td>10.37%</td>
</tr>
<tr>
<td>45 - 54</td>
<td>71</td>
<td>26.30%</td>
</tr>
<tr>
<td>55 - 64</td>
<td>58</td>
<td>21.48%</td>
</tr>
<tr>
<td>65 - 74</td>
<td>55</td>
<td>20.37%</td>
</tr>
<tr>
<td>75 - 84</td>
<td>40</td>
<td>14.81%</td>
</tr>
<tr>
<td>85+</td>
<td>5</td>
<td>1.85%</td>
</tr>
<tr>
<td><strong>Gender of carer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>76</td>
<td>28.15%</td>
</tr>
<tr>
<td>Female</td>
<td>194</td>
<td>71.85%</td>
</tr>
<tr>
<td><strong>Age group of person with Alzheimer's/dementia</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45 - 54</td>
<td>3</td>
<td>1.11%</td>
</tr>
<tr>
<td>55 - 64</td>
<td>15</td>
<td>5.56%</td>
</tr>
<tr>
<td>65 - 74</td>
<td>49</td>
<td>18.15%</td>
</tr>
<tr>
<td>75 - 84</td>
<td>131</td>
<td>48.52%</td>
</tr>
<tr>
<td>85+</td>
<td>72</td>
<td>26.67%</td>
</tr>
<tr>
<td><strong>Who first made the diagnosis of Alzheimer's/dementia</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurologist</td>
<td>25</td>
<td>10.04%</td>
</tr>
<tr>
<td>Geriatrician</td>
<td>78</td>
<td>31.33%</td>
</tr>
<tr>
<td>Old Age Psychiatrist</td>
<td>37</td>
<td>14.86%</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>16</td>
<td>6.43%</td>
</tr>
<tr>
<td>Psychiatric Nurse</td>
<td>18</td>
<td>7.23%</td>
</tr>
<tr>
<td>Hospital Doctor</td>
<td>38</td>
<td>15.26%</td>
</tr>
<tr>
<td>GP/Primary Care Physician</td>
<td>37</td>
<td>14.86%</td>
</tr>
<tr>
<td><strong>Has the person been informed about his/her condition</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>129</td>
<td>49.62%</td>
</tr>
<tr>
<td>Yes</td>
<td>131</td>
<td>50.38%</td>
</tr>
<tr>
<td>Yes (stating by health professional)</td>
<td>91</td>
<td>35.00%</td>
</tr>
<tr>
<td><strong>If Yes, by whom:</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| GP/Primary Care Physician | 33 | 25.19%)
| Hospital Doctor     | 22                 | 16.79%                  |
| Neurologist         | 8                  | 6.11%                   |
| Geriatrician        | 5                  | 3.82%                   |
| Old Age Psychiatrist| 11                 | 8.40%                   |
| Psychiatrist        | 6                  | 4.58%                   |
| Carer (i.e. Survey Respondent) | 41 | 31.30% |
| Psychiatric Nurse   | 1                  | 0.76%                   |
| Unknown             | 12                 | 9.16%                   |
| **Services accessed and their associated payment mechanism** | | | |
| GP Services:        |                    |                         |
| Accessed            | 141                | 52.22%                  |
| State funded Service| 141                | 52.22%                  |
| Out of Pocket Payment Required | 14 | 5.19% |
| Hospital Services:  |                    |                         |
| Accessed            | 19                 | 7.04%                   |
| State funded Service| 12                 | 4.44%                   |
| Covered by insurance| 3                  | 1.11%                   |
| Out of Pocket Payment Required | 2 | 0.74% |
| Day care Services:  |                    |                         |
| Accessed            | 123                | 45.56%                  |
| State funded Service| 71                 | 26.30%                  |
| Out of Pocket Payment Required | 89 | 32.96% |
| Homecare Services:  |                    |                         |
| Accessed            | 153                | 56.67%                  |
| State funded Service| 103                | 38.15%                  |
| Out of Pocket Payment Required | 67 | 24.81% |
| Respite Services:   |                    |                         |
| Accessed            | 79                 | 29.26%                  |
| State funded Service| 92                 | 34.07%                  |
| Out of Pocket Payment Required | 27 | 10.00% |
| Residential Care:   |                    |                         |
| Accessed            | 14                 | 5.19%                   |
| State funded Service| 18                 | 6.67%                   |
| Out of Pocket Payment Required | 20 | 7.41% |
| Carer pays medical costs (including medication) | 21 | 7.78% |
| Carer pays for additional help to care | 130 | 48.13% |
| Carer has sufficient income to look after person | 245 | 86.91% |
| Definitely          | 18                 | 7.35%                   |
| Probably            | 76                 | 31.02%                  |
| Probably Not        | 73                 | 29.80%                  |
| Definitely Not      | 78                 | 31.84%                  |

*Professional Carers are ignored in subsequent analysis
Sample number variation is a result of missing data within the response category
10.3.ii Informal cost of dementia care – summary of related statistics

This section presents two sets of summaries of statistics (1) on the dependent variable the distribution of the daily hours of informal care and (2) related to the explanatory variables, frequencies of individual characteristics, functional limitations and behavioural disturbances.

(1) Daily hours of Informal Care

Informal care is found to be highly demanding for the carers interviewed in ASI 2007. As was presented earlier, only around one in five carers manage to provide less than 8 hours care per day. And of the remaining, 66% provide more than 14 hours per day (see Table 9).

<table>
<thead>
<tr>
<th>Hours per Day of Care:</th>
<th>Median Value</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 2 Hours</td>
<td>1</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Between 2 and 4 Hours</td>
<td>3</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>Between 4 and 6 Hours</td>
<td>5</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Between 6 and 8 Hours</td>
<td>7</td>
<td>14</td>
<td>5</td>
</tr>
<tr>
<td>Between 8 and 10 Hours</td>
<td>9</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Between 10 and 12 Hours</td>
<td>11</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Between 12 and 14 Hours</td>
<td>13</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>14 Hours or more</td>
<td>14</td>
<td>169</td>
<td>66</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>258</td>
<td>100</td>
</tr>
</tbody>
</table>
(2) **Explanatory Variables**

This section provides statistics on (a) individual characteristics and (b) functional limitations and behavioural problems.

**(a) Individual Characteristics**

As stated in the methods section, the first set of explanatory variables related to individual characteristics of age, training to care, nursing home status, stage of dementia and work-cohabitation status (see Table 10).
Table 10: Summary statistics of individual characteristics; (1) demographic features: care recipients age, whether the caregiver received training and whether the person with demenit is living in a nursing home; (2) stage of dementia most recently indicated by the physician at the time of the survey, and; (3) work/cohabitation status of the informal carer [Source: ASI, 2007].

<table>
<thead>
<tr>
<th>Individual Characteristics</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographic Features</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age Range of Care Recipient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45 - 54 Years</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>55 - 64 Years</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td>65 - 74 Years</td>
<td>49</td>
<td>18</td>
</tr>
<tr>
<td>75 - 84 Years</td>
<td>128</td>
<td>48</td>
</tr>
<tr>
<td>85 or Over</td>
<td>72</td>
<td>27</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>267</td>
<td>100</td>
</tr>
<tr>
<td><strong>Carer Received Training to Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>228</td>
<td>87</td>
</tr>
<tr>
<td>Yes</td>
<td>33</td>
<td>13</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>261</td>
<td>100</td>
</tr>
<tr>
<td><strong>Living in Nursing Home</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>259</td>
<td>97</td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>267</td>
<td>100</td>
</tr>
<tr>
<td><strong>Current Diagnosed Stage of Dementia</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early Stage/Mild</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td>Middle Stage/Moderate</td>
<td>88</td>
<td>36</td>
</tr>
<tr>
<td>Late Stage/Severe</td>
<td>70</td>
<td>28</td>
</tr>
<tr>
<td>No Stage/Severity was Mentioned</td>
<td>70</td>
<td>28</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>246</td>
<td>100</td>
</tr>
<tr>
<td><strong>Work Cohabitation Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-Time, Live Together</td>
<td>19</td>
<td>7</td>
</tr>
<tr>
<td>Full-Time, Live Apart</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td>Part-Time, Live Together</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>Part-Time, Live Apart</td>
<td>21</td>
<td>8</td>
</tr>
<tr>
<td>Retired</td>
<td>114</td>
<td>43</td>
</tr>
<tr>
<td>Resigned to Provide Care</td>
<td>79</td>
<td>30</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>264</td>
<td>100</td>
</tr>
</tbody>
</table>

Variation in total report frequency results from missing responses
Several important observations are made:

The age distribution is skewed towards the more elderly with the median range 75–84.

Caregiver training was provided to 13% of individuals.

Residence in a nursing home was minimal with 97% of care recipients living at home or with their carer.

The majority of individuals with dementia were either Middle Stage/Moderate, or Late Stage/Severe. A substantial number were unaware of their stage, reporting No Stage/Severity was Mentioned. A minority of individuals were captured at Early Stage/Mild.

The majority of the sample was not in employment (73%) having either retired (43%) or resigned to care (30%). The remainder were either Full-Time (13%) or Part-Time (14%).
Figure 34 further describes the number of reported symptoms at each progressive stage of dementia.

![Distribution of the Number of Reported Symptoms by Dementia Stage](image)

Figure 34: Number of reported dementia symptoms in early, mid and late stage dementia [Source: ASI 2007].

This illustrates important differences in the range of reported symptoms at each stage, specifically:

- **Early stage** ranges from a minimum of 2 to a maximum of 22;
- **Mid stage** ranges from a minimum of 3 to a maximum of 34;
- **Late stage** ranges from a minimum of 9 to a maximum of 36.
This suggest that early and late stage dementia have a limited range of symptoms whereas mid-stage dementia is much broader, ranging from a similar minimum to early stage and a maximum comparable to late stage.

(b) **Functional Limitations and Behavioural Problems**

The remaining explanatory variables capture important disease specific symptoms of the dementia population, namely functional limitations and behavioural problems.

Functional impairments are further divided into three sections. Under household activities of daily living (HDL), approximately 7 in 10 people had *problems cooking, cleaning* and *shopping*; this has important implications for the informal carer in providing additional assistance with maintaining a household. In terms of general activities of daily living, respondents most commonly have issues with hygiene *showering, bathing or washing* and less commonly with *eating or drinking*. Under instrumental activities of daily living the most common symptom was an *inability to follow conversations*, followed by problems *using the telephone*; these limited communications is a primary problem in the domain of instrument activities.

Psychiatric symptoms are captured by individuals with dementia exhibiting behavioural problems. The most common symptoms are *memory and confusion* followed by *concentration and attention*. The most commonly agreed as ranking as a major problem was *personality changes or mood swings* followed by *wandering.*
Table 11: Frequency of dementia specific symptoms: (1) functional limitations – symptoms affecting activities of daily living (HDL, ADL and IADL) and (2) psychiatric symptoms observed as behavioural problems necessitating supervision.

<table>
<thead>
<tr>
<th>Functional Limitations</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limitations Performing Household Activities(HDL):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleaning</td>
<td>175</td>
<td>66</td>
</tr>
<tr>
<td>Cooking</td>
<td>185</td>
<td>69</td>
</tr>
<tr>
<td>Shopping</td>
<td>181</td>
<td>68</td>
</tr>
<tr>
<td>Limitations in Activities of Daily Living(ADL):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dressing</td>
<td>166</td>
<td>62</td>
</tr>
<tr>
<td>Showering/Bath/Wash</td>
<td>204</td>
<td>76</td>
</tr>
<tr>
<td>Eating/Drinking</td>
<td>90</td>
<td>34</td>
</tr>
<tr>
<td>Limitations in Instrumental Activities of Daily Living (IADL):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Writing/Reading</td>
<td>176</td>
<td>66</td>
</tr>
<tr>
<td>Following Conversation</td>
<td>193</td>
<td>72</td>
</tr>
<tr>
<td>Using the Telephone</td>
<td>179</td>
<td>67</td>
</tr>
<tr>
<td>Hobbies/Interests</td>
<td>159</td>
<td>60</td>
</tr>
<tr>
<td>Group Activities</td>
<td>134</td>
<td>50</td>
</tr>
</tbody>
</table>

Psychiatric Symptoms

| Common Behavioural Symptom:                  |          |            |
| Wandering/Restlessness                       | 133       | 50         |
| Recognising People                           | 166       | 62         |
| Incontinence                                 | 129       | 48         |
| Inhibition/Poor Self Control                 | 74        | 28         |
| Concentration/Attention                      | 212       | 79         |
| Memory/Confusion                             | 234       | 88         |
| Agitation/Aggression                         | 124       | 46         |
| Personality Changes/Mood Swings              | 135       | 51         |

Behavioural Symptom (Indicated as Causing Major Concern):

| Personality Changes/Mood Swings              | 69        | 26         |
| Wandering/Restlessness                       | 59        | 22         |
| Recognising People                           | 45        | 17         |
| Comprehension of Language                    | 36        | 13         |
In summary, this Chapter has reviewed important summary statistics about the dementia population captured in ASI 2007, a description of the informal carer and specific details of the variables analysed to examine the first two research questions. The next Chapter presents results of the analysis related to the first research question: what determines perception of care in Ireland.
Chapter 11. What Determines Perceptions of Care in Ireland

This Chapter presents the results of the logistic regression analysing factors determining the Irish dementia population’s perceptions of care. Section 11.1 presents the results of six logistics regressions along with the results of post-estimation tests of each model. Section 11.2 examines the regression coefficients inferring their relationship in explaining the likelihood of individuals having positive or negative perceptions of care.

11.1. Six Logistics Regressions Modelling the Determinants of Perceptions of Care

This section presents the six models of perceptions of care in two parts: Section 11.1.i presents the regression outputs and Section 11.1.ii reviews the post-estimation test of each model.

11.1.i Table of regression

The aim of this first regression analysis is to examine the likelihood of individuals stating six perceptions of care relating to formal services, community support services, disclosure and financial issues. Table 12 presents the regression outputs of all six models indicating the six dependent variables (CARE, PUBLIC, SERVICE, QUALITY, COST and PAYER). For each model, the sign and magnitude of the coefficients for each explanatory variable are presented. The significance of each explanatory variable is tested and statistically significant variables are indicated by asterisks (*).
Table 12: Regression outputs indicating the influence, magnitude and statistical significance of explanatory variables in altering individuals' likelihood of reporting one of the six binary dependent variables of perceptions of care [Source: ASI 2007].

<table>
<thead>
<tr>
<th>Variable</th>
<th>CARE (1)</th>
<th>PUBLIC (2)</th>
<th>SERVICE (3)</th>
<th>QUALITY (4)</th>
<th>COST (5)</th>
<th>PAYER (6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP Use</td>
<td>-2.73</td>
<td>.592</td>
<td>-1.62</td>
<td>-1.93</td>
<td>.757</td>
<td>-.564</td>
</tr>
<tr>
<td>GP State</td>
<td>1.024*</td>
<td>-.326</td>
<td>.966</td>
<td>.150</td>
<td>-.955†</td>
<td>1.464*</td>
</tr>
<tr>
<td>GP Care OoP</td>
<td>.750</td>
<td>-.223</td>
<td>1.062</td>
<td>-.513</td>
<td>1.075</td>
<td></td>
</tr>
<tr>
<td>Hospital Use</td>
<td>-.256</td>
<td>4.609**</td>
<td>-1.684</td>
<td>1.295</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital State</td>
<td>-1.071</td>
<td>-.359†</td>
<td>3.246</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital Insure</td>
<td>1.180</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital OoP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MemClinic</td>
<td>1.151*</td>
<td>.801</td>
<td>.396</td>
<td>1.091</td>
<td>1.352</td>
<td></td>
</tr>
<tr>
<td>Undisclosed</td>
<td>-.906*</td>
<td>.120</td>
<td>-.583</td>
<td>-.881</td>
<td>-1.516*</td>
<td>.310</td>
</tr>
<tr>
<td>DayCare Use</td>
<td>.572</td>
<td>.880</td>
<td>.286</td>
<td>1.421*</td>
<td>.662</td>
<td>.702</td>
</tr>
<tr>
<td>DayCare State</td>
<td>-1.152</td>
<td>.103</td>
<td>.947</td>
<td>.163</td>
<td>-.045</td>
<td>-.043</td>
</tr>
<tr>
<td>DayCare OoP</td>
<td>-.752</td>
<td>-.125</td>
<td>.654</td>
<td>.723</td>
<td>.896</td>
<td>.716</td>
</tr>
<tr>
<td>HomeCare Use</td>
<td>-.654</td>
<td>-.745</td>
<td>-.275</td>
<td>-.756</td>
<td>-1.051</td>
<td>.174</td>
</tr>
<tr>
<td>HomeCare State</td>
<td>.181</td>
<td>.000</td>
<td>.600</td>
<td>.957†</td>
<td>1.620*</td>
<td>.068</td>
</tr>
<tr>
<td>HomeCare OoP</td>
<td>-.488</td>
<td>-.155</td>
<td>-.072</td>
<td>.479</td>
<td>1.454†</td>
<td>.765</td>
</tr>
<tr>
<td>Respite Use</td>
<td>.353</td>
<td>.698</td>
<td>.283</td>
<td>2.028†</td>
<td>-.912</td>
<td>.675</td>
</tr>
<tr>
<td>Respite State</td>
<td>.134</td>
<td>-.088</td>
<td>-.368</td>
<td>-.145†</td>
<td>.378</td>
<td>-.173</td>
</tr>
<tr>
<td>Respite OoP</td>
<td>-.648</td>
<td>.885</td>
<td>-.234</td>
<td>-1.186</td>
<td>.302</td>
<td>-.152</td>
</tr>
<tr>
<td>Residential Use</td>
<td>.458</td>
<td></td>
<td>-.542</td>
<td></td>
<td></td>
<td>-.947</td>
</tr>
<tr>
<td>Residential OoP</td>
<td>1.170</td>
<td>-1.045</td>
<td>-2.041</td>
<td>.030</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income Problems</td>
<td>-1.314**</td>
<td>-.901†</td>
<td>-1.049*</td>
<td>-1.947**</td>
<td>-1.437†</td>
<td>-.350</td>
</tr>
<tr>
<td>CarePayCosts</td>
<td>-1.727*</td>
<td>.294</td>
<td>-.570</td>
<td>-.729</td>
<td>-1.031</td>
<td>.523</td>
</tr>
<tr>
<td>CarePayHelp</td>
<td>.375</td>
<td>.911†</td>
<td>-1.165**</td>
<td>.418</td>
<td>-.780</td>
<td>-.493</td>
</tr>
<tr>
<td>Intercept</td>
<td>.909</td>
<td>.942</td>
<td>.487</td>
<td>.144</td>
<td>-.173</td>
<td>.188</td>
</tr>
</tbody>
</table>

Observations 152  137  146  120  108  135
χ² Statistic 44.907** 18.032  33.499† 30.344†  35.428** 23.647
McFadden R²  .2282  .1313  .1941  .2511  .2717  .1675
Hosmer-Lemeshow 3.49  6.77  0.00  11.31  6.07  10.19

Significance levels: †: 10%  *: 5%  **: 1%
Abbreviations in labels:
Out-of-Pocket expenditure (OoP); State funded service (State); Service covered by private insurance (Insure); Diagnosis at memory clinic (MemClinic); Individual with dementia not informed of condition (Undisclosed)
Blank coefficients: Where the explanatory variable predicts perfectly success or failure.
11.1.ii Post-estimation statistics

To examine how meaningful each model is, post-estimation tests were performed and their statistics indicate the performance of each model. Table 12 also indicates the performance of each model by calculating the overall statistical significance of each model (given by the Wald Chi Square statistics \( \chi^2 \)); the McFadden Pseudo R\(^2\) provides an indication of the model’s dispersion and each model’s goodness of fit is observed by giving the Hosmer-Lemeshow statistics.

Examining the Wald \( \chi^2 \) statistics reveals that four out of the six models are significantly explained by the covariate matrix, namely: CARE, COST, SERVICE and QUALITY.

The logistic model is linear and the McFadden Pseudo R\(^2\) is a less meaningful statistic than a conventional measure of residual dispersion. Examining this proportion of variability across the six models indicates that COST, QUALITY, CARE and SERVICE (respectively) are most accurately captured by the regression.

As a more appropriate test of non-linear models, the Hosmer-Lemeshow conducts a hypothesis test in which significant statistics indicate a lack of goodness of fit. None of the Hosmer-Lemeshow \( \chi^2 \) statistics are significant and from this it can be inferred that all the predicted values of the model are not significantly different from the observed.
11.2. Interpretation of the Regression Coefficients to Explain Perception of Care

This section makes inferences from the significant, magnitude and sign of regression coefficients on the change in likelihood of individuals having one of the six perceptions of care that have been modelled. The models are presented in order of the level of significance.

11.2.i Determinants of whether the level of elderly CARE is considered good

The most statistically significant model explains whether the level of elderly care is considered to be good in Ireland (CARE). This perception variable is a binary response (i.e. whether care is or is not perceived as good) and is significant in five explanatory variables:

IncomeProblem is a binary variable which indicates whether the individual has sufficient income to care and is significant at the 1% level, making it the most significant determinant in the model CARE. The sign of the coefficient is negative with relatively high magnitude, suggesting those individuals that indicate income problems will be less likely to perceive care in Ireland as good. This raises the point that financial circumstance is instrumental in this perception and may concur with finding of inequities in Irish health care (Smith and Normand 2010).

MemClinic relates to a diagnosis in a memory clinic and is found to be significant at a 5% confidence level. As such this is the largest positive significant effect, increasing the probability two-fold that the level of elderly care is considered to be good. This may provide evidence that in addition to the specialised diagnostic service, these services may orientate individuals into a better level of service.

UnDisclosed indicate those individuals who were not informed of their condition. This is found to be significant at the 5% level and the sign indicates not being informed decreases the likelihood that elderly care is perceived as good.
CarerPayCosts indicates whether the carer pays medical costs (including medicine) and is significant at the 5% level. The negative sign indicates that having to pay costs is significantly associated with a perception that is not good.

GP State is an indicator of people who have their access to primary care paid for by the state (generally through the medical card system). The coefficient would suggest that in this group these individual are more likely to have the perception that elderly care is good. The lack of statistical robustness (i.e. a confidence level of 10%) may be attributable to entitlement to the medical card, which was automatic in the over 65s, but means tested for others.

11.2.ii Determinants of whether COST of health care is perceived as reasonable

The second most statistically significant model captures the determinants of whether the ‘costs of health care are reasonable’ (COST). Given the statistical limitation, the McFadden Pseudo R² further suggests that, of all the models, the COST model captures the greatest proportion of variability. The changes in likelihood of perceptions of whether health care costs are reasonable are most significantly explained by the following four variables:

UnDisclosure was statistically significant at the 5% level and the sign suggests that where individuals are not informed of their condition, costs of health care are less likely to be perceived as reasonable. The first GP survey in Ireland related to dementia categorised a market where non-disclosure may be explained by low levels of recognition in primary care (Cahill et al. 2006) presenting two potential underlying correlations, either: (1) the costs of the typical out of pocket payment to see a GP would be reasonable if individuals were informed of their condition or (2) in situations where condition is not disclosed, the consumer is more likely to incur the additional cost of access to private specialised services.
Home care (either partly or fully subsidised) has the largest effect magnitude on perceptions of COST. Home care services are fully subsidised in the Cork region and are available with minimal co-payment in other regions (The Alzheimer's Society of Ireland 2010). This indicates the value of home care services to caregivers and further research may be merited in consideration of widening this service’s availability.

IncomeProblems is correlated to the view that cost of health care may not be reasonable. Summary statistics presented in Chapter 10 show that nearly half of carers were retired and of those who work, 64.79% had to reduce their working hours in order to provide care. This raises the question for further research whether, for dementia, there is equal access for equal need or is access constrained by unreasonable health care costs?

GP State (i.e. State funded GP services) are less statistically significant but the coefficients correlate to a negative view of costs of health care. As mentioned earlier, between 2001 and 2008, those aged over 65 became entitled to a medical card and those below this age must be means tested to qualify for this or the alternative GP visit medical card. When income is above a certain threshold or where age is under 70, consumers pay 100% of the market cost for GP services (between €45 and €60).

11.2.iii What predicts whether an individual perceived QUALITY of care as high?

The QUALITY model seeks to examine where individuals perceive the quality of care as high. Overall the model is significant at the 10% level, but the McFadden Pseudo R² suggests that, despite the lower significance level, a large proportion of variability is captured in the model. The greatest influence on how people view
quality levels is the provision of community support services, specifically day care and respite services.

*Insufficient income* was the most statistically significant variable; again indicating that finance may limit the quality of care available.

*Day care* is found to increases the odds that quality is very high.

*Respite* (i.e. where carer received overnight respite assistance) is significant at the 10% level and the coefficient sign suggests that respite increases the likelihood that *quality* is perceived highly (as much as 6.5 times).

There seems to be a potential interaction between overnight respite and whether this respite is state funded. Whilst the use of respite is correlated with positive perceptions of the quality of care, state funded respite is limited and therefore individuals reliant on state funded relief are associated with a lower perception of quality.

### 11.2.iv What explains whether SERVICE is perceived as sufficient

The main aim of the *SERVICE* model is to explain whether services are perceived as sufficient. Overall, the model is significant at the 10% level and would capture 19.41% of proportion of variability (allowing for the limitation of the Pseudo R²).

Three explanatory variables provide the most statistically significant changes in whether services are perceived as sufficient:

*Hospital Use* is significant at a 1% level and increases the odds that services are viewed as sufficient nearly one hundred fold. The implication of this finding is that – while the majority of care is contained in the community – access to specialist services for dementia is a quintessential part of a sufficient service.
Income Problems reduces the likelihood that service levels are perceived to be sufficient. Irish researchers have previously indicated that health inequalities in Ireland are driven by personal financial means whereby those with private health care get preferential access to services (Burke 2009).

Paying for extra help is associated with low service levels, indicating that a low perception of sufficient service may motivate out of pocket payment for additional help.

11.2.v PAYER: Determinants of whether health care services should be covered by society

The PAYER model examines whether individuals agree with the statement ‘the cost of health care and service should be covered by society’. Overall the model was not statistically significant and this maybe because of the dual statements (‘health care and services’) in the question leading to varying interpretations. Nevertheless, 16.75% of the proportion of variability is explained by the model which is in part explained by two significant explanatory variables:

1. *GP State* (i.e. state funded GP service) is significant at the 5% level and a positive coefficient suggests that perception that ‘health care cost and service should be paid by society’ is likely to be driven by individuals with medical card coverage.

2. *MemClinic* (i.e. those who receive a diagnosis in a memory clinic) are more likely to hold the perception that society should cover the costs. At the time of data collection there were nine memory clinics in Ireland (Cahill et al. 2006) and this finding should represent a good indication that the role of memory clinics in statutory services requires further investigation.
11.2.vi PUBLIC: What determines whether elderly care is public?

The PUBLIC model aims to elucidate what drives the opinion that elder care should be a public matter. This model is the least statistically significant, most likely because the statement is unclear to the respondent. However, paying for extra help has a significant positive effect, potentially indicating the burden of care might be distributed publicly. Despite the fact that the statement lacks clarity, the disproportionate burden placed on informal carers would logically lead to the interpretation that greater support is required through public statutory services.

In summary, these six logistic regression models find that outcomes are commonly explained by the individuals’ financial means, services utilised and source of diagnosis. Across the outcomes, insufficient income is implied in carer’s views suggesting that social inequalities are present across various dimensions of dementia care. Secondly, non-disclosure of the dementia to the individual is associated with several negative outcomes such as level of care and whether costs are viewed as reasonable. The use of formal and supportive services were significant predictors of positive and negative perceptions. The policy implications of these findings will be discussed in 14.1.
Chapter 12. Informal Care by Stage and Task: Time and Value

Informal care is hypothesised to increases as dementia progresses. In Section 12.1, the hours of informal care are explained using a model consisting of individual effects (demographic, employment status and current stage of dementia), functional limitations (HDL, ADL, and IADL) and behavioural problems. Section 12.2 examines the explanatory variables, quantifying how symptoms impact on informal care. Section 12.3 applies single and multiple proxies to components of informal care indicating market values of the care provided at the progressive stages.

12.1. Tobit Regression to Explain Level of Informal Care

In this first section, the results of the estimation of the number of informal hours of care provided per day are presented. This is done in two parts: in Section 12.1.i the outputs of the Tobit regression model present the regression coefficients, their level of significance and the standard error and Section 12 the results of post estimation tests are given.

12.1.i The outputs of the estimation of informal care

Regression output is presented in Table 13 displaying the results for the three sets of explanatory variables, namely:

**Individual Characteristics** are divided into Demographics, Dementia Stage, Employment;

**Functional Limitations** are divided into Household Activities of Daily Living (HDL), Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL);
Behaviour Problems categorise psychiatric symptoms of dementia of two sorts: firstly those that are most common and secondly those that are ranked by respondents as the most problematic (denoted by the symbol *).
Table 13: Regression outputs of the Tobit model estimating daily number of hours spent on informal care.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Coefficient</th>
<th>(Std Err.)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Equation 1: Informal Care Time</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demographics:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Care Recipient</td>
<td>1.151†</td>
<td>(0.606)</td>
</tr>
<tr>
<td>Recipient Lives in a Nursing Home</td>
<td>-6.619†</td>
<td>(3.433)</td>
</tr>
<tr>
<td>Carer Received Training to Care</td>
<td>-2.971†</td>
<td>(1.563)</td>
</tr>
<tr>
<td><strong>Current Stage of Dementia:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current: Early Stage</td>
<td>-3.886†</td>
<td>(2.205)</td>
</tr>
<tr>
<td>Current: Mid -Stage</td>
<td>-0.687</td>
<td>(1.174)</td>
</tr>
<tr>
<td>Current: Late Stage</td>
<td>2.709†</td>
<td>(1.563)</td>
</tr>
<tr>
<td><strong>Employment/Cohabitation Status:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-Time, Live Together</td>
<td>4.506</td>
<td>(3.948)</td>
</tr>
<tr>
<td>Full-Time, Live Apart</td>
<td>-2.710</td>
<td>(3.782)</td>
</tr>
<tr>
<td>Part-Time, Live Apart</td>
<td>0.736</td>
<td>(3.779)</td>
</tr>
<tr>
<td>Has Retired</td>
<td>8.882*</td>
<td>(3.516)</td>
</tr>
<tr>
<td>Resigned to Care</td>
<td>11.646**</td>
<td>(3.660)</td>
</tr>
<tr>
<td><strong>Problems with Household Activities of Daily Living:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleaning</td>
<td>1.780</td>
<td>(1.556)</td>
</tr>
<tr>
<td>Cooking</td>
<td>-5.015**</td>
<td>(1.848)</td>
</tr>
<tr>
<td>Shopping</td>
<td>0.452</td>
<td>(2.002)</td>
</tr>
<tr>
<td><strong>Problems with Activities of Daily Living:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dressing</td>
<td>3.449*</td>
<td>(1.385)</td>
</tr>
<tr>
<td>Bathing</td>
<td>-0.610</td>
<td>(1.494)</td>
</tr>
<tr>
<td>Eating</td>
<td>1.412</td>
<td>(1.326)</td>
</tr>
<tr>
<td><strong>Problems with Instrumental Activities of Daily Living:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Read/Write</td>
<td>2.200</td>
<td>(1.430)</td>
</tr>
<tr>
<td>Following Conversations</td>
<td>1.156</td>
<td>(1.549)</td>
</tr>
<tr>
<td>Telephone Use</td>
<td>-2.615*</td>
<td>(1.237)</td>
</tr>
<tr>
<td>Hobbies/Interests</td>
<td>0.507</td>
<td>(1.363)</td>
</tr>
<tr>
<td>Socialising</td>
<td>0.308</td>
<td>(1.545)</td>
</tr>
<tr>
<td><strong>Behavioural Problems:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>° Language</td>
<td>-2.344</td>
<td>(1.567)</td>
</tr>
<tr>
<td>° Aggression</td>
<td>4.285**</td>
<td>(1.428)</td>
</tr>
<tr>
<td>* People</td>
<td>-1.375</td>
<td>(1.527)</td>
</tr>
<tr>
<td>° Memory/Confusion</td>
<td>-1.198</td>
<td>(1.669)</td>
</tr>
<tr>
<td>Wandering</td>
<td>3.449**</td>
<td>(1.334)</td>
</tr>
<tr>
<td>Recognising People</td>
<td>1.332</td>
<td>(1.440)</td>
</tr>
<tr>
<td>Incontinence</td>
<td>-0.333</td>
<td>(1.126)</td>
</tr>
<tr>
<td>Inhibition</td>
<td>4.065**</td>
<td>(1.477)</td>
</tr>
<tr>
<td>Concentration</td>
<td>1.917</td>
<td>(1.664)</td>
</tr>
<tr>
<td>Memory/Confusion</td>
<td>-4.299†</td>
<td>(2.269)</td>
</tr>
<tr>
<td>Aggression</td>
<td>-3.142†</td>
<td>(1.623)</td>
</tr>
<tr>
<td>Mood Swings</td>
<td>-1.483</td>
<td>(1.487)</td>
</tr>
<tr>
<td>Incontinence</td>
<td>-8.788</td>
<td>(6.874)</td>
</tr>
<tr>
<td><strong>Equation 2 : Sigma</strong></td>
<td>5.593**</td>
<td>(0.455)</td>
</tr>
</tbody>
</table>

Significance level: †: 10%      * : 5%      ** : 1%      [Symbol (º) indicates top ranking problems to the carer]
12.1.ii Post-estimation test

This section describes the post-estimation test of the Tobit model, detailing the specification test, the test for heteroskedasticity and, Wald tests indicating the significant sets of explanatory variables.

Overall the model specification was significant ($p<0.0001$), had a McFadden Pseudo $R^2$ of 0.2126 and a Pregibon Link test (Pregibon 1980) found the model correctly specified ($P[g(\mu) = \mu] = 0.018$) and ($P[g(\mu)^2 = \mu] = 0.172$). From these tests, it can be concluded that the model is highly significant in explaining informal care time, capturing 21.26% of the variance, and that the conditional mean is correctly specified in the regressors.

To examine the degree of normality in the error term in the general residuals, firstly an Ordinary Least Square (OLS) regression is performed below the censoring threshold and tested using the Breusch-Pagan test for heteroskedasticity. A Wald $\chi^2$ statistic of 1.55 and $p$ value of 0.2137 implies that the variance is homogeneous below 14 hours of informal care.

To examine the overall variance in the error, Table 14 shows the calculated generalised residuals for the Tobit model.

<table>
<thead>
<tr>
<th>Dementia Stage</th>
<th>Mean</th>
<th>S.D.</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Stage</td>
<td>-.4084036</td>
<td>.775071</td>
<td>-2.052283</td>
<td>1.102631</td>
</tr>
<tr>
<td>Middle Stage</td>
<td>-.5411693</td>
<td>.8080381</td>
<td>-2.356948</td>
<td>1.058019</td>
</tr>
<tr>
<td>Late Stage</td>
<td>-.9808728</td>
<td>.8769894</td>
<td>-2.579628</td>
<td>-.0069069</td>
</tr>
<tr>
<td>No Stage</td>
<td>-.7285411</td>
<td>.7171276</td>
<td>-2.307712</td>
<td>.617860</td>
</tr>
<tr>
<td>Total</td>
<td>-.6284674</td>
<td>.7934834</td>
<td>-2.579628</td>
<td>1.102631</td>
</tr>
</tbody>
</table>
Examining the mean generalised residuals with the inclusion of the censored observations to the model, the residuals are non-zero at the mean and standard deviation. Testing whether the generalised residuals are significantly different from zero, scores are generated to use in a maximum likelihood test. Overall, normality is rejected, however, by stages, early and mid-stage, the null hypothesis stands and the divergence from normality is in late stage dementia.\textsuperscript{40}

The Wald test results of the three grouped categories of variables examine their joint significance in estimating informal hours of care. The Wald tests find the following sets of explanatory variables to be significant:

**Individual effects** are all significant *demographics features*, $p=0.0041$; *stage of dementia*, $p=0.0402$; and *work/cohabitation status*, $p<0.0001$.

**Functional limitations**: the effects are also significant for *HDL* ($p=0.0196$) and *ADL* ($p=0.0133$) but limitations often associated with earlier stage dementia such as *IADLs* lack significance ($p=0.1307$).

**Behavioural problems** are significant at the 0.05 level ($p=0.0264$).

The age and gender of the caregiver were tested in previous specifications but were found not to be significant predictors ($p = 0.5456$) and therefore are omitted in the final model.

\textsuperscript{40}This may be partly explained by the fact that the estimation procedure predicts greater than 24 hours and required that the range of predictions are limited to 24 hours.
12.2. Interpretation of Regression Coefficients to Explain Informal Care Time

This section examines the regression coefficients in more detail to make inferences on their correlation to the amount of informal care time provided daily. This will be presented in order of the three sets of explanatory variables, namely: Section 12.2.i examines the impact of various individual characteristics; Section 12.2.ii interprets the effect of functional limitations and Section 12.2.iii analyses how behavioural problems resulting from psychiatric symptoms influence the level of care.

12.2.i Individual characteristics

Informal care steadily increases as age rises; this can be associated with age-related progression of dementia or alternatively the rising likelihood of other comorbidities. Carers who receive formal training to care will provide an average of three hours less care per day indicating that training is important to ensure sustainability of this relationship. Eight respondents indicated that their recipient lived in a nursing home and were predicted to provide five hours less care per day than the average.

As would be expected, coefficients of dementia stages variables indicate that demand for care increases with stage and shows the importance of stage-related weighting in the regression. Later in this Chapter, dementia stages are utilised to estimate average daily hours of informal care at each stage and associate the proxy-good values.

In earlier specifications LivingTogether (dummy variable indicating cohabitation) is found to be highly significant and to have a driving magnitude. To fully capture this effect, the model required an enrichment of work status parameters to also indicate cohabitations. Individuals living apart from the care recipient are estimated to provide between 2 and 10 hours less care on average per day indicating competing priorities. Similarly, employment status will influence the time available for care; a
third competing priority for the caregivers’ time. Table 15 presents how cohabitating with employment status influences the predicted average hours of care provided.

Table 15: The Estimated number of hours of informal care provided dependent on work and cohabitations status

(Source: ASI, 2007).

<table>
<thead>
<tr>
<th>Live Apart</th>
<th>Hours by Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full-time</td>
</tr>
<tr>
<td>Yes</td>
<td>3.76</td>
</tr>
<tr>
<td></td>
<td>(2.54)</td>
</tr>
<tr>
<td>No</td>
<td>12.76</td>
</tr>
<tr>
<td></td>
<td>(1.64)</td>
</tr>
<tr>
<td>Total Hours</td>
<td>8.67</td>
</tr>
<tr>
<td></td>
<td>(5.91)</td>
</tr>
</tbody>
</table>

Key: Number of Hours of Care per Day (standard deviation)

Individuals living apart and working full- or part-time provide an average of 10 hours less care per day. Full-time employed carers who are living apart from their recipient will provide an average of 3.76 hours and exhibit little relative flexibility to alter their level of care (S.D 2.54). This implies individuals continuing to work while also caring will experience conflicting priorities competing for their time. This raises the research question of how carers transition from one employment status to another (e.g. full-time to part-time or part-time to resigning in order to care). This survey does not offer the opportunity to follow the individuals over time; however, this cross section does ask how caring affects their work. ASI 2007 shows that 50% reduced their hours of work, 35% resigned in order to care, leaving only 15% managing to continue working the same hours.

Carers who resign in order to care are significantly more likely to provide informal care (p=0.008), which may indicate the motivation behind resignation to care. These results find 85% of carers who resign will live with the person with dementia and
will provide an average of 9 hours more care per day than those who continue working.

Carers who are retired from work provide an average of 17 hours of care per day and living apart from the recipient only marginally changes this (reduces to 13 hours). These retired carers are most commonly aged between 65 and 74 (40%) and 75 and 84 (33%), suggesting their ability may in itself be limited by their own health status.

Future analysis should assess transition probabilities from various work statuses and how this relates to the concept of deficit hours and eliciting replacement services.

12.2.ii Functional limitations

The significance of functional limitations indicates the individual’s need for care and support with functions necessary within daily life. Problems are captured in three forms of activities of daily living: HDLs, ADLs and IADLs. The coefficients in the regression capture the influence of stated problems with each on the required level of informal care.

The first set of limitations examined is in household activities of daily living (HDL), which are highly prevalent and stated in approximately 70% of respondents. HDLs are more commonly reported where the recipient is female, indicating a deficit in domestic maintenance, which may have previously been the responsibility of the recipient. Regression coefficients indicate that Cooking is significantly correlated with less informal care reducing the level of care substantially. HDL parameters capture a loss in household activities and reflect the carer substituting for the recipient in general household duties. Later in this Chapter, proxy-good values are applied by stage, and estimates indicate that informal care relating to HDLs decrease with disease progression whilst assistance with ADLs is increasing, further
suggesting that informal care time is limited and must be prioritised in order of importance (shown later in Table 17).

The second part examined under functional limitations is instrumental activities of daily living (IADL). This domain of functional activity is associated with higher cognitive abilities such as socialising, communication and complex activities. As such decline in this set tends to be primarily associated with earlier stage dementia (Skurla et al. 1988). Therefore the lack of significance of this overall group may be associated with the lower sample number in earlier stages and individuals only starting to lose coping skills. The only problem of significance is telephone use; and two conclusions from this are possible: either it indicates a situation where care is less required given a lower level of impairment in earlier stage dementia or alternatively, the association with telephone use may indicate where carers are unable to provide more care (e.g. where working or living far away) and the problem relates to direct concern where the caregiver needs a communication to alert them of need. On analysis, telephone use becomes a significant concern in mid stage dementia, at which stage cohabitation is concurrently observed to increase compared with the early stage group. This leads to the probable conclusion that the breakdown in remote communication makes the informal carer explicitly aware that the level of care required is falling into a deficit and therefore increases the likelihood of cohabitation.

The final components are the activities of daily living (ADL) which become a more significant problem from mid stage dementia onwards. For example, individuals find that the ability to dress themselves diminishes as the dementia progresses (early stage 50%, mid stage 59% and 80% in late stage) suggesting physical disability associated with the latter stage. The regression parameters only find dressing as significant. Facilitating personal hygiene (problems with showers, baths, etc.) occurs in 76% of the sample and therefore may form more of a constant dementia care effect. Overall,
carer level where there is at least one ADL limitation increases by an average of 2.5 more hours of care per day.

Overall, predicted levels of informal care are significantly explained by activities of daily living and this analysis would confirm their importance in predicting informal demand by stage.

12.2.iii Behavioural problems

Behavioural problems caused by psychiatric symptoms of dementia are significant predictors of informal care. Aggression, wandering and inhibition are specific psychiatric symptoms of dementia, each significantly increasing the demand for informal care (p=0.003, p=0.010 and p=0.006 respectively). Aggression is found to affect 46% of people and commonly indicates that depressive symptoms may underlie the dementia (Lyketsos et al. 1999). Individuals who indicate that their recipient wanders will provide on average 5.2 hours more care per day and wandering has also previously been identified as an exacerbated effect of depression in dementia. Individuals with dementia may lose their inhibitions which may lead to undesirable behaviour and carers are observed to provide approximately 2 hours more care per day for these individuals, predominantly for those with mid stage dementia.

12.3. Stage-Related Market Value of Informal Carer

Individual effect, functional limitations and behavioural problems form the basis of demand for care. The volume of informal care is strongly correlated to the carers’ work life which may conflict with maintaining their own household or productivity. Table 16 presents estimated results of informal care time at the average, minimum
and maximum hours provided in early, mid and late stages of dementia. To these figures an aggregated replacement cost to the Irish health system is applied using the national costing framework for economic evaluations (HIQA 2010). This single proxy-agent is a ‘care assistant (intellectual disability agencies)’, which, it is assumed would provide a general alternative to the informal carer. Following the Irish health economic evaluation guidelines (HIQA 2010), an annual midpoint salary for the care assistant is taken as €31,942\(^{41}\) and calculating a total staff unit cost per hour gives the value of this formal proxy as €33.62.\(^{42}\) Table 16 applies this shadow price to the aggregated hours of informal care by stage giving mean average daily replacement values for this single proxy (multiple dementia specific proxies may provide more accurate values of dementia specific care – see Table 17).

\begin{table}[h]
\centering
\begin{tabular}{lcccc}
\hline
\textbf{Variable} & \textbf{Informal Care (Hrs/Day)} & \textbf{Replacement Cost (Euro)} \\
\hline
Early-Stage & 8.327 & 1.97 & 14.721 & 279.97 & 212.82 - 347.12 \\
Mid-Stage & 14.066 & 1.57 & 23.027 & 472.92 & 430.65 - 515.18 \\
Late-Stage & 19.274 & 1.396 & 23.784 & 648.00 & 611.92 - 684.09 \\
\hline
\end{tabular}
\caption{Estimated informal care time and the associated replacement cost (single proxy: care assistance (intellectual disabilities)) [Source ASI, 2007].}
\end{table}

This approach is an example of the ‘replacement cost’ method which, in application, assigns a single proxy cost weight. The values (above) are crude and not sensitive to the actual demand of variation in symptomology of the person with dementia. The main limitation of costing informal care in this manner is that the replacement values assume the informal carer would not exhibit any preference of whether to accept the formal agent substituting their role. In essence, the level of competency captured in this proxy may not achieve a point of indifference to agree to substitution. In fact, the


\(^{42}\) ‘Care assistant (intellectual disability agencies)’ is a modest cost and international informal care cost estimates (Koopmanschap 2008) indicate ‘community psychiatric nurse’ as the appropriate agent for behavioural problems. This would raise the total hourly staff cost to €52.08.
informal carer (who gains a level of utility from ensuring appropriate care) may experience a disutility from this substitution given that the agent may not have the competency level required by more demanding symptoms.

Nevertheless, these results suggest that dementia care in Ireland displaces substantial costs on to the informal sector. Early stage dementia consumes the equivalent of a full-time working day of care and this more than doubles by the later stages. The range of times provided by stage varies substantially and (as shown in Table 15) the lower range is often caused by conflicting priorities related to cohabitation and employment status. Comparing the patterns of informal care by stage, it should be noted that the distributions become increasingly skewed with disease progression. From the progressive volumes of care required, providing this care may necessitate resignation from work and potentially forming a cohabitation arrangement with the care recipient. Ultimately, the distribution of informal care for late stage dementia is right skewed around a median of 20.43 hours per day and a kurtosis of 8.303, which would indicate a high density around the median (95% of carers at this stage providing more than 10 hours per day). These results suggest an absence of sufficiently planned formal services, which places a growing burden on informal carers.

The first full replacement values given in Table 16 aim to highlight the financial risk associated with care burnout and associated formal costs of losing all household outputs of that individual. Whilst the full duty of care in replacing all household production is unlikely to be accepted by the state, previous research shows that consistently overburdening informal carers will result in carer burnout (Angermeyer et al. 2006, Cuijpers and Stam 2000, Yilmaz et al. 2009). Assuming that a care assistant would be the most likely single proxy for an informal carer in burnout, the replacement value total of the stated outputs per day would range from €279.97 in

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43 The skew of the distribution in early is -0.0311; in mid-stage -0.4652; and late stage -2.2078.
early stage to €648 in later stage dementia. The financial impact associable to burnout is best highlighted by the marginal effect of losing one carer. The annual cost of replacing the total household outputs provided by one informal carer would range from €66,681 in early stage to €154,872 per annum at late stage.

Accepting the financial risk associated with caregiver burnout is therefore unlikely, either from within the public finance budget or via a personal out-of-pocket payment. The valuation with respect to carer burnout or loss should serve to provide a weight to the informal carer’s time to offset against increased resource allocation to avoid carer burnout (e.g. carer interventions). Whilst an increase in the budget allocated for dementia care in Ireland is merited, spending is likely to continue to fall short of the required level (Comas-Herrera et al. 2010). To make best use of limited resources will require efficient allocation within a dementia budget. In line with this notion of increasing technical efficiency, proxy-good values for dementia specific symptoms are estimated to indicate the components of care which may be substituted by formal services.

The full proxy-good valuation method aims to examine specific tasks and to allocate to each a shadow price for the production of each task. To do this in this situation, the specific amount of time associated to each symptom is calculated and the following agents are taken as having the minimum level of competence for each:

**Care assistant** is still generally accepted as replacement for the informal carer providing the level of competency for functional limitations (HDL, ADL, IADL);

**Community psychiatric nurse** is the minimum standard within formal setting to manage *behavioural* problems as competency in this area is complex and requires specific training.

To extend the estimation of the informal cost of dementia care, the tasks are divided between specific agents and the total staff cost is applied as per the proxy-good
method (Koopmanschap et al. 2008). Table 17 presents the number of estimated hours per day devoted to the three functional limitations and behavioural problems (left); these dementia specific symptoms are summed to give a subtotal of dementia specific hours and this is subtracted from the total estimated hours per day, to give non-dementia hours of household input (diff.), which is assumed to represent general household inputs which are not part of the dementia informal cost function.

Table 17: Estimated symptom specific time devoted to the elements of dementia and forming the basis of the proxy-good valuation [Source: ASI, 2007].

<table>
<thead>
<tr>
<th>Dementia Stage</th>
<th>Stage</th>
<th>HDL</th>
<th>Proxy-goods</th>
<th>Diff. Total</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>Baseline</td>
<td>-0.51</td>
<td>1.64</td>
<td>0.46</td>
<td>2.43</td>
</tr>
<tr>
<td>Mid</td>
<td>-1.00</td>
<td>2.58</td>
<td>0.80</td>
<td>3.55</td>
<td>7.89</td>
</tr>
<tr>
<td>Late</td>
<td>-1.67</td>
<td>3.42</td>
<td>1.15</td>
<td>4.48</td>
<td>11.31</td>
</tr>
<tr>
<td>Total</td>
<td>2.51</td>
<td>-1.19</td>
<td>2.81</td>
<td>0.90</td>
<td>3.80</td>
</tr>
</tbody>
</table>

Applying a proxy value for each task produces the following results: for *behavioural* problems, 'community psychiatric nurse' (£52.08); for the estimated daily deficit in HDL, the hourly cost of a 'domestic' (£30.51); and to stage-specific constants, ADL and IADLs, the cost of 'care-assistant (intellectual disability agencies)' (£33.62). The observed difference (diff.) is associated to a distribution held in the error term which will correlate with general household output that is not associated with dementia but which changes at progressive stages. This increase in severity may be explained by two features: firstly shift in shared responsibility to perform household activities by stage and secondly increase in age care will slow the rate of work.

---

44 Informal care related to *behavioural* problems assumes that care will be for one of the three significant behavioural problems at any one time. So, the mean time spent on either wandering, lack of inhibition or aggression is used in the calculation.

45 This increase in severity may be explained by two features: firstly shift in shared responsibility to perform household activities by stage and secondly increase in age care will slow the rate of work.
In Equation (23) \( y_{is} \) is the level of informal care for individual \( i \) at dementia stage \( s \); \( \alpha_{is} \) is the stage related constant output; \( x_{is}B_k \) is the matrix of stage specific outputs (\( s \)) for individual (\( i \)) which the symptom specific coefficient (\( \beta \)) for the \( k^{th} \) dementia symptom. The error term (\( \varepsilon_{is} \)) captures the stage related distributions of regular output in the household which are not associated with dementia care.

Applying the shadow prices to the Irish public health system cited above to each dementia symptom provides the stage specific proxy-good values ranging from \( €240.96 \) in early stage, to \( €394.92 \) in mid stage to \( €570.04 \) in late stage. While these estimates do not consider preference and utility gain, applying the proxy-good approximates a competency level at which informal carers would be indifferent to accepting formal services over maintaining their duties.

The estimated costs are concurrent with observations by the World Health Organisation (Saxena et al. 2007) which find a growing gap between burden of disease and budget allocation. In Ireland, the 'growing gap' in dementia care results from an absence of statutory policy for older people which will only start to be remedied once appropriate legislation ensures community care services are made available (Cahill 2010). The implication of these findings in relation to policy will be further discussed in 14.1.
Chapter 13. Dementia in Europe: Summary Statistics from SHARE

The Survey of Health, Ageing and Retirement in Europe is a comprehensive longitudinal survey of individuals over 50 and captures a cohort of individuals who were diagnosed with dementia between 2004 and 2006. This Chapter presents summary statistics to introduce the dementia population in SHARE 2006 in two stages: Section 13.1 provides a description of the dementia population in SHARE and Section 13.2 examines specific statistics related to the research question: how is formal service utilisation influenced by depression in dementia?

13.1. Description of the Dementia Population

Dementia is a major condition developing in the elderly population and new evidence is now available through SHARE on the emergence of a dementia population. This section reviews dementia in Europe by comparing and contrasting the elements of this dementia population over four sections: Section 13.1.i examines the age profile across all countries in SHARE; Section 13.1.ii examines the correlation of age groups to income; Section 13.1.iii compares SHARE’s general age distributions with individuals with dementia; and Section 13.1.iv reviews the age profile of individuals with dementia across all countries in SHARE.
13.1.i  Age profile of individuals in fourteen European countries in SHARE

SHARE surveys individuals over 50 and their partners. Figure 1 presents the general age profile across the 14 countries in Wave 2, indicating in the Box plot the mean, median, interquartile range, standard deviation and outliers in these intervals.

![Box plot of the age distribution by country](Source: SHARE).

Figure 35 presents 14 Box plots ordered by increasing median age by country and demonstrate that median age range is essentially comparable ranging from 61 in Poland to 64 in Austria. The interquartile ranges across the sampled countries are comparable, potentially demonstrating some increase in skew toward older age as the median age increases. The standard deviation in age varies across the sample; this is
largely influenced by households with a partner aged less than 50 years old and sometimes significantly younger in age.

13.1.ii Distribution of age by log income captured in SHARE

To illustrate this phenomenon slightly further, the next figure shows the variation in age with increasing income.

Figure 36: Scatter plot on the distribution of age by logged income [Source: SHARE].
Figure 36 presents a scatter plot examining the amount of household income increasing from left to right. Up until an average household of between €10,000 and €20,000, there is little variation in the age range observed. More specifically, a strict line exists along the 50 years of age inclusion criteria, with very few partners below the age of 50. The majority of the sample has a median household income of €32,297 and, as the income increases above the median, so does the dispersion of outliers below the age of 50. This aspect of the sample is not generally meaningful when considering the dementia population but is noteworthy, given its implications for the results; such factors are controlled by introducing proxy socioeconomic class using education level.
13.1.iii A comparison of the age distribution of individuals with dementia to the non-dementia population in SHARE

It is a clearly established fact that dementia is a syndrome that effects individuals as they are. To illustrate this point, Figure 37 presents age distribution of the SHARE sample with a diagnosed dementia as compared to the full SHARE sample (excluding dementia).

![Figure 37: A comparison of the age distribution in the dementia and non-dementia population [Source: SHARE].](image)

Figure 37 provides a simple illustration of the vast difference between the general ageing population in SHARE and the subsample with dementia. The two opposing distributions are skewed in opposing directions, indicating that most people without
dementia (median value) are aged around 60, whereas the majority of people diagnosed with a dementia are somewhere around 80. Analysis of the dementia age distribution reveals a significant change in rate in the dementia population is observed after the 61 year mark. The oldest old in the dementia population is 99 whereas SHARE captures individuals up to 104 living without a diagnosed dementia. Of the people with a dementia, the average age is 78.56 and 10% are found to have ages below 65 (a situation which is often termed early onset dementia). By comparison, in the non-dementia group over 50% are aged below 65 and the average age is 64.17.

13.1.iv Age distribution of the dementia population across the fourteen European countries in SHARE

The sample of dementia varies substantially from one country to the next in SHARE. To illustrate these differences, the Box plot representation of age distributions is repeated for the dementia population. Figure 38 presents a box plot (identical to Figure 35) for the dementia group. Countries are ranked in order of median age and in contrast to Figure 35, substantial variations in the median age are found.
The lowest average age is found in Czech Republic (Czechia), a median of 74 and mean 73.21. The highest average age is found in Switzerland where the distribution is also highly skewed towards a median of 85 and mean of 79. The largest variation in the dementia population is found in Poland where ages range from 52 to 98 and where 10% of those with dementia are aged below 60 representing the highest rate of early onset dementia in all European countries. By contrast, Germany would seem to have the highest late onset of dementia with a minimum age of 68 in its sample. Several countries have several outlying cases of early onset which fall below confidence intervals of their standard deviation, namely Italy, France, the Netherlands, Spain, Belgium and (to a lesser extent) Germany.
So far this thesis has reviewed how SHARE was conceived in 2002, rigorously tested and rolled out over several European countries. The first section of this Chapter has introduced the dementia population within SHARE 2006; the next section presents statistics relevant to the analysis of this population.

13.2. Summary of the Relationships between Depression and Dementia

The final research question asks: how is formal service utilisation influenced by depression in dementia? This section specifically highlights the summary statistics taken from SHARE Waves 1 and 2 on dementia and depression. The survey provides comprehensive indicators for regression analysis including socio-demographic indicators and data regarding physical, emotional and psychosocial health and health-related behaviours.

Standard measures of depression are taken in SHARE using two instruments: Euro-D scale (Prince et al. 1999) in the CAPI over the two waves and the CES-D (Radloff 1977) into a drop-off questionnaire (only in 2004). This analysis uses measurements of depression given by the Euro-D as this is a validated scale designed for standardised, pan-European measurement of depression and indicates clinically relevant symptoms of depression by threshold scores above 3.46

Euro-D rating scales readings taken in 2006 indicate those with depression given by a score over the threshold. In a subpopulation indicated as not having dementia, 22.17% were above the depression threshold. In the dementia population (n=407), 44% of individuals were over the same depression thresholds, indicating those with dementia were nearly twice as likely to exhibit depression.

46 The CES-D questions in the drop off contained similar indicators of depression and as such were not selected for the regression analysis.
As the Euro-D was repeated in both 2004 and 2006, a panel was formed to examine how depression varied over the two waves. Table 18 compares dementia to non-dementia individuals, providing the frequency of depression in three distinct ways:

**Overall** captures the overall frequency of individuals (with dementia or not) who exhibited threshold depression pooled across the two waves;

**Between** indicates the proportion of individual who were either depressed or not in 2004 or 2006;

**Within** provides the percentage of individual who endure within the same stage (depressed or not) between waves.

<table>
<thead>
<tr>
<th>Euro-D&gt;3</th>
<th>Overall</th>
<th>Between</th>
<th>Within</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Normal</td>
<td>Dementia</td>
<td>Normal</td>
</tr>
<tr>
<td>Yes</td>
<td>22.57%</td>
<td>43.23%</td>
<td>27.72%</td>
</tr>
<tr>
<td>No</td>
<td>77.43%</td>
<td>56.77%</td>
<td>82.44%</td>
</tr>
</tbody>
</table>

Table 18: Rates of depressive symptoms overall, across or within the two waves [Source: SHARE 2004 & 2006].

In the non-dementia group *overall* an average of 22.57% had depressive symptoms above the threshold, 22.72% were either depressed in 2004 or 2006 and 81.68% who were depressed in 2004 were still depressed in 2006.

In the dementia group, *overall* an average of 43.23% were depressed in both waves, 54.79% had significant depressive symptoms in either wave and 79.38% who were depressed in 2004 were still depressed in 2006.

Comparisons of these rates indicate three key findings:
1. Overall there are nearly double the rates of depression in the dementia population over the non-dementia population.

2. Depression is significantly more likely to have occurred in dementia in one of the two points taken.

3. All states are persistent indicating certain individuals are more vulnerable to depression and other may have enduring resilience. Individuals with dementia are less likely to remain not depressed compared with the non-dementia group.

To further elaborate on this dynamics, Table 19 calculates the transitional probability of moving from state to state and again compares the dementia and non-dementia groups.

<table>
<thead>
<tr>
<th>2004</th>
<th>Euro-D &gt;3</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0.52 vs. 0.54</td>
<td>0.48 vs. 0.46</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.12 vs. 0.35</td>
<td>0.88 vs. 0.65</td>
<td></td>
</tr>
</tbody>
</table>

Table 19: Probabilities of depression state changing between 2004 and 2006. Comparison of the non-dementia population (left) to the dementia population (right). Figures indicate non-dementia vs. dementia population.

The transitional probability captures how the dementia versus non-dementia compares in their propensity to move between states. This provides two important conclusions in considering the effects of depression in dementia:

1. Comparing the probability of being depressed in 2006 given having not been depressed in 2004 suggests that individuals with dementia are
approximately *three* times as likely to become depressed compared to the general population.

2. Secondly, the probability of staying depressed is similar in both groups.

These finding raise question about the nature of depression in dementia, which are in part answered by the three stages of analysis Chapter 8. Could depression be a prodromal syndrome of dementia (Brommelhoff et al. 2009), or a form of pseudo-dementia (McAllister 1983)? Or could it be that depression is a result of developing a chronic disease (Lyketsos et al. 2000) as has been found in diabetes (Anderson et al. 2001), cancer (Massie 2004), or in heart disease?

The next Chapter presents results of the analysis of the effects of depression in dementia on health care use. The first stage captures how depression correlates to dementia through presenting and interpreting results of logistic regressions to predict depression. Thereafter an incremental effect of comorbid depression on service use is isolated through one-to-one matching and the effects of depression captured through a two stage regression.
Chapter 14. Comorbid Depression and Impacts on Dementia Health Care Utilisation

The third specific research question seeks to generate empirical results to answer the question how is formal service utilisation influenced by depression in dementia? This Chapter presents results related to this question in the three sets of analysis. Firstly, results are presented on how depression effects the prediction of having dementia (14.1). Next, the results of the matching are examined at a country level (14.2). Finally, the results of the two step regression are presented contrasting individual with dementia to control group formed through matching.

14.1. Does Depression Predict Dementia?

The aim of this first analysis is to examine how depression variables influence the logit model sensitivity to predicting dementia. The propensity for having dementia is calculated in a series of five logistic regressions, the first of which establishes a baseline by using only common predictors and no depression variables. The subsequent four are used to test the incremental effects of specifications which include depression indicators (see Table 20).
Table 20: Correlation of depression in predicting dementia over a control (Logit)

<table>
<thead>
<tr>
<th></th>
<th>Baseline (1)</th>
<th>Threshold (2)</th>
<th>EuroD06 (3)</th>
<th>EuroD04 (4)</th>
<th>Combined (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>.402**</td>
<td>.586**</td>
<td>.426**</td>
<td>.459**</td>
<td>.534**</td>
</tr>
<tr>
<td>Age²</td>
<td>-.003**</td>
<td>-.004**</td>
<td>-.003**</td>
<td>-.003**</td>
<td>-.003**</td>
</tr>
<tr>
<td>ISCED-97(1-2)</td>
<td>.528**</td>
<td>.701*</td>
<td>.759**</td>
<td>.387</td>
<td>.631†</td>
</tr>
<tr>
<td>ISCED-97(3-4)</td>
<td>.882**</td>
<td>1.191**</td>
<td>1.232**</td>
<td>.864†</td>
<td>1.244**</td>
</tr>
<tr>
<td>ISCED-97(5-6)</td>
<td>1.114**</td>
<td>1.510**</td>
<td>1.581**</td>
<td>1.071†</td>
<td>1.469**</td>
</tr>
<tr>
<td>ADL</td>
<td>-.105*</td>
<td>-.223*</td>
<td>-.167*</td>
<td>-.109</td>
<td>-.215*</td>
</tr>
<tr>
<td>IADL</td>
<td>.769**</td>
<td>.724**</td>
<td>.715**</td>
<td>.766**</td>
<td>.701**</td>
</tr>
<tr>
<td>IADL²</td>
<td>-.050**</td>
<td>-.050*</td>
<td>-.052**</td>
<td>-.055**</td>
<td>-.057*</td>
</tr>
<tr>
<td>Recall first</td>
<td>-.145**</td>
<td>-.184**</td>
<td>-.120*</td>
<td>-.205**</td>
<td>-.269**</td>
</tr>
<tr>
<td>Recall delayed(O4)</td>
<td>-.210**</td>
<td>-.245**</td>
<td>-.219**</td>
<td>-.234**</td>
<td>-.230**</td>
</tr>
<tr>
<td>Verbal fluency</td>
<td>-.037**</td>
<td>-.038*</td>
<td>-.038*</td>
<td>-.033†</td>
<td>-.034†</td>
</tr>
<tr>
<td>Orientation</td>
<td>-.649**</td>
<td>-.705**</td>
<td>-.684**</td>
<td>-.665†</td>
<td>-.678**</td>
</tr>
<tr>
<td>Numeracy(O4)</td>
<td>.337**</td>
<td>.292**</td>
<td>.304**</td>
<td>.221*</td>
<td>.200*</td>
</tr>
<tr>
<td>Numeracy</td>
<td>-.164†</td>
<td>-.180†</td>
<td>-.156</td>
<td>-.147</td>
<td>-.126</td>
</tr>
<tr>
<td>Euro-D &gt;3(O4)</td>
<td>.107</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Euro-D &gt;3(O6)</td>
<td>.966**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Euro-D &gt;3(O4&amp;O6)</td>
<td>-0.497</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression(O4)</td>
<td>.196</td>
<td></td>
<td>-.213</td>
<td>-.095</td>
<td></td>
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<tr>
<td>Depression</td>
<td>.196</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pessimism(O4)</td>
<td>.673**</td>
<td></td>
<td>-.805**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pessimism</td>
<td>.673**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suicidality(O4)</td>
<td>-.050</td>
<td></td>
<td>-.469</td>
<td>-.596†</td>
<td>-.043</td>
</tr>
<tr>
<td>Suicidality</td>
<td>-.050</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guilt(O4)</td>
<td>.814*</td>
<td></td>
<td>.898*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guilt</td>
<td>.814*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep(O4)</td>
<td>.042</td>
<td></td>
<td>.042</td>
<td>-.040</td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td>.042</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interest(O4)</td>
<td>.422</td>
<td></td>
<td>.217</td>
<td>-.034</td>
<td></td>
</tr>
<tr>
<td>Interest</td>
<td>.422</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irritability(O4)</td>
<td>-.284</td>
<td></td>
<td>.281†</td>
<td>-.126</td>
<td></td>
</tr>
<tr>
<td>Irritability</td>
<td>-.284</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appetite(O4)</td>
<td>.237</td>
<td></td>
<td>-.424†</td>
<td>-.453†</td>
<td>-.070</td>
</tr>
<tr>
<td>Appetite</td>
<td>.237</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue(O4)</td>
<td>.089</td>
<td></td>
<td>.007</td>
<td>.970</td>
<td>.233</td>
</tr>
<tr>
<td>Fatigue</td>
<td>.089</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concentration(O4)</td>
<td>.400**</td>
<td></td>
<td>.438*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concentration</td>
<td>.400**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enjoyment(O4)</td>
<td>.050</td>
<td></td>
<td>-.092</td>
<td>.337</td>
<td>-.321</td>
</tr>
<tr>
<td>Enjoyment</td>
<td>.050</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tearfulness(O4)</td>
<td>-.183</td>
<td></td>
<td>.337</td>
<td>.321</td>
<td>.233</td>
</tr>
<tr>
<td>Tearfulness</td>
<td>-.183</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Model Statistics

<table>
<thead>
<tr>
<th>Statistic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>33321</td>
</tr>
<tr>
<td>χ² statistic</td>
<td>1522.356</td>
</tr>
<tr>
<td>McFadden R²</td>
<td>.458</td>
</tr>
<tr>
<td>AIC</td>
<td>2330.501</td>
</tr>
<tr>
<td>BIC</td>
<td>2476.71</td>
</tr>
<tr>
<td>Hosmer-Lemeshow χ²</td>
<td>0.5815</td>
</tr>
<tr>
<td>Sensitivity(Pr</td>
<td>27.66%</td>
</tr>
</tbody>
</table>

Given inconsistency between SHARE Wave 1 and 2, sample size in these regressions vary; caution is advised in comparing across individual regression output (see Chapter 9 - Limitations).
The baseline equation explained 45.8% of the variability of the model (McFadden Pseudo $R^2$). In terms of goodness of fit, the Hosmer-Lemeshow test rejects lack of fit and therefore observed dementia is comparable to expected outcomes of the logit model. The Wald test indicates that overall and for each individual parameter, the model is significant. In terms of coefficients, age, education (all categories of ISCED), instrumental activities of daily living (IADL) and numeracy in 2004 are positively predictive of dementia. As a result, out of the sample of 33,322, this equation accurately predicts 27.66% of all individuals with dementia. From this the following inferences are possible:

1. The probability of dementia increases with age (categorically the coefficients suggest the risk doubling every five years after 65);
2. The greater the educational level attained, the larger the reference for any decrease in cognition;
3. The greater the loss of the ability to live independently in the community (as indicated by IADL), the more chance of the diagnosis;
4. Numeracy problems two years prior to diagnosis may strongly signal dementia.

The second equation (Threshold) adds whether the individual had a Euro-D score greater than three either at the time, two years before or both. This is indicative of the nebulous nature of the two syndromes. The three threshold indicators reduce the efficiency of the model finding, Pseudo $R^2$ is reduced and there is a decrease in model accuracy in predicting dementia (the model’s sensitivity for prediction dementia dropping to 18.87%). This reduction in model efficiency is most significantly correlated to current depression (Euro-D $>3$) and given that depression is correlated to dementia, but does not contribute to model accuracy, this suggests
significant coexistence. To explore specifically which symptoms coexist, each question is examined individually in the final three equations.

The third equation (EuroD06) includes symptoms measured by the Euro-D (Depression to Tearfulness, see Table 20 above). A substantial reduction in sensitivity and model efficiency occurs where difficulty with concentration is indicated. One clear weakness in differentiating dementia from depression is the overlap of cognitive impairment, most specifically indicated by loss of concentration. When concentration is removed from the equation, sensitivity reduces to 15.36% with irritability (another overlap) becoming significant. The stepwise process can continue by removing fatigue (increasing sensitivity to 17.1%), depressed last month (18.75%), tearfulness (19.64%), interest (18.48%), guilt (19.3%), suicidality (20.69%), pessimism (20.69%) and so on. Overall, the addition of any depression indicator reduces model sensitivity by an average of 7% (ranging from fatigue, reducing by 9% to concentration 1%).

In equation four (EuroD04), symptoms of depression experienced two years previously are examined for significance in predictions of dementia (given individual’s with dementia were actively excluded in this phase). This has been indicated by model statistics showing a gain in Pseudo $R^2$ and sensitivity. To test the validity of the improvement, a balanced panel is formed to observe similar numbers in the baselines and show over a reduced sample number of individuals with dementia (n=251), that baselines would continue to be relatively superior to EuroD04 equation (sensitivity 33.73% versus 30.49%, respectively). Two specific symptoms are positively predictive of dementia, guilt and concentration (the latter is already explained and the statistical significance of guilt may raise some interest to clinicians). Furthermore, suicidality and appetite have negative coefficients indicating differential qualities between depression and dementia and hence, the
positive model performance may also be attributed to the avoidance of false positive predictions.

The final model (*Combined*) includes covariate of both *EuroD06* and *EuroD04* and provides dynamic features of depression over time. Whilst a symptom of depression in 2004 will be correlated to a symptom in 2006, the datasets are independent. Therefore, this final equation suggests on balance the importance of symptoms at the particular point in time for predicting dementia. Overall, the model benefits from the efficiency of the 2004 symptoms but model statistics are still relatively poor (sensitivity 20.13%). *Concentration* at both time points is a significant predictor, followed by guilt in 2004. The emergence of *irritability* (2004) presents particular interest to the research question as this is a common feature of depression within dementia.

In conclusion, it is safe to say that depression (whilst having some apparent interaction with dementia) does not offer any increase in the propensity to predict dementia. However, the existence of some dynamic interactions over time, such as prodromal depression and pseudo dementia are demonstrated in this first stage of analysis. As such, this analysis aims to be repeated as future waves of SHARE become available and panels can control for fixed and random effects.

14.2. How Does Dementia Service Usage Vary Across Fourteen European Countries Compared to Matched Individuals?

The last section established that the covariate matrix in the *baseline* equation optimally predicts dementia. In this section, these covariates are used to match individuals with dementia to individuals with similar propensity scores to form a control group.
This provides a treatment effect on how having been diagnosed with dementia shows how health care use varies. Health care utilisation over the total sample is compared with the dementia group and the control group formed by matching.

The process of matching is performed on a one-to-one basis within each of the included countries and the results are presented in Table 21 (below). By the process of one-to-one matching within each country, this analysis obtains for each individual with dementia an individual with a similar propensity score based on the logistic regression, baseline equation. The matching process is undertaken at random, controlling individuals’ heterogeneity and allowing for comparison between groups. One limitation of the country level comparison is that numbers of individuals with dementia varies considerably and in two countries (Ireland and Switzerland), sample size of dementia falls to 10. Furthermore, no country accrues greater than 50 individuals with dementia by 2006 and therefore country level interpretations must accept this limitation (further details provided in Chapter 9).
Table 21: European comparison of health care utilisation: compares (1) full sample; (2) sample with dementia; and (3) control group resulting from matching, to the right of the table. Furthermore summarises the health care spend (% GDP); whether the country has a gatekeeping system; the country payment mechanism; and the physician density in the country (per 10,000).

<table>
<thead>
<tr>
<th>Country</th>
<th>Full Sample Rate</th>
<th>Dementia Rate</th>
<th>Control Rate</th>
<th>R²</th>
<th>χ²</th>
<th>Sens.</th>
<th>Spend %GDP</th>
<th>Gate-keep</th>
<th>Payment Mechanism</th>
<th>Physician Density</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>8.96</td>
<td>1.268</td>
<td>18.06</td>
<td>18</td>
<td>15.17</td>
<td>18</td>
<td>0.4027</td>
<td>76.29**</td>
<td>33.33</td>
<td>Yes</td>
</tr>
<tr>
<td>Belgium</td>
<td>8.36</td>
<td>3.057</td>
<td>20.42</td>
<td>33</td>
<td>16.30</td>
<td>33</td>
<td>0.4865</td>
<td>177.70**</td>
<td>39.39</td>
<td>No</td>
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<tr>
<td>Czechia</td>
<td>8.32</td>
<td>2.447</td>
<td>12.12</td>
<td>17</td>
<td>12.71</td>
<td>17</td>
<td>0.3713</td>
<td>75.40**</td>
<td>11.74</td>
<td>Yes</td>
</tr>
<tr>
<td>Denmark</td>
<td>4.22</td>
<td>2.516</td>
<td>2.78</td>
<td>18</td>
<td>4.33</td>
<td>18</td>
<td>0.5792</td>
<td>123.85**</td>
<td>51.11</td>
<td>Yes</td>
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<tr>
<td>France</td>
<td>7.02</td>
<td>2.773</td>
<td>9.73</td>
<td>38</td>
<td>15.11</td>
<td>38</td>
<td>0.5164</td>
<td>207.84**</td>
<td>42.11</td>
<td>No</td>
</tr>
<tr>
<td>Germany</td>
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<td>2.461</td>
<td>14.97</td>
<td>37</td>
<td>13.38</td>
<td>37</td>
<td>0.7119</td>
<td>274.21**</td>
<td>72.97</td>
<td>No</td>
</tr>
<tr>
<td>Greece</td>
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<td>2.593</td>
<td>15.60</td>
<td>15</td>
<td>10.27</td>
<td>15</td>
<td>0.5359</td>
<td>88.95**</td>
<td>33.33</td>
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</tr>
<tr>
<td>Ireland</td>
<td>4.78</td>
<td>1.268</td>
<td>6.09</td>
<td>6</td>
<td>7.67</td>
<td>6</td>
<td>0.7135</td>
<td>51.39**</td>
<td>65.67</td>
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<tr>
<td>Italy</td>
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<td>2.741</td>
<td>14.33</td>
<td>33</td>
<td>20.64</td>
<td>33</td>
<td>0.4218</td>
<td>150.72**</td>
<td>21.21</td>
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<td>Netherlands</td>
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<td>2.521</td>
<td>12.76</td>
<td>21</td>
<td>9.38</td>
<td>21</td>
<td>0.4185</td>
<td>100.64**</td>
<td>33.33</td>
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<tr>
<td>Poland</td>
<td>7.28</td>
<td>2.375</td>
<td>11.25</td>
<td>40</td>
<td>6.60</td>
<td>40</td>
<td>0.4026</td>
<td>164.00**</td>
<td>22.50</td>
<td>Yes</td>
</tr>
<tr>
<td>Spain</td>
<td>8.62</td>
<td>1.683</td>
<td>19.19</td>
<td>47</td>
<td>14.85</td>
<td>47</td>
<td>0.5005</td>
<td>215.97**</td>
<td>27.66</td>
<td>Yes</td>
</tr>
<tr>
<td>Sweden</td>
<td>3.12</td>
<td>2.605</td>
<td>8.44</td>
<td>34</td>
<td>9.26</td>
<td>34</td>
<td>0.5924</td>
<td>215.32**</td>
<td>50.00</td>
<td>Yes</td>
</tr>
<tr>
<td>Switzerland</td>
<td>4.41</td>
<td>1.259</td>
<td>9.00</td>
<td>8</td>
<td>8.375</td>
<td>8</td>
<td>0.4891</td>
<td>47.44**</td>
<td>37.50</td>
<td>No</td>
</tr>
</tbody>
</table>

Total 6.54 32,733 13.43 365 12.72 365 0.4383 1800.74** .2603

Spend: Health Care expenditure as a percentage of GDP (OECD, 2006)
Gatekeep: Whether access to specialist care must be via a primary care physician (Sole-Aurn, 2011).
Payment Mechanism: Fee for Service (FFS); Capitation (CAP), Salary. (Bago and Jones, 2009)
Physician Density per 10,000 (The Annie Respiratory Infection Atlas)
Significance level: *p < 0.1%, **p < 0.5%, ***p < 1%
Across the full sample of SHARE 2006 (n=32,733), the average health care use is 6.54 and is found to range from 3.12 in Sweden to 9.54 in Italy. Across all countries, the average health care use for individuals with dementia was 13.43 (n=365) and ranged from 2.78 in Denmark to 20.42 in Belgium. In the control group, health care use is on average 12.72 (comparable to Dementia despite each country being matched individually) and ranges from 4.33 in Denmark to 20.64 in Italy. Comparing Dementia to control, the largest increase in health care use was found in Spain (from 14.85 to 19.19), four countries showed no statistical difference between the two (Germany, Switzerland, Sweden and Czech Republic) and three countries indicate reduced health care use when an individual is diagnosed with dementia (France, Denmark and Italy).

Extracting rates of access to services per country from the raw data finds comparable statistics between the dementia arm (94.5% overall access in all countries, ranging from 79.4% in Sweden to full access in Belgium, Czech Republic, Germany, Greece, Ireland and Switzerland) and the control arm (93.4% overall access, ranging from Poland with 82.5% to full access in Czech Republic, Germany, Greece, Ireland, Netherlands and Switzerland). Given that the two arms were homogenised by propensity scoring for predicting dementia, access within these experimental conditions were significantly higher than the full SHARE sample (86.5 %, n=33,721, ranging from 80.0% in Netherlands to 94.8% in France).

It could be hypothesised that this country level variation is exogenous, explained by local health system characteristics such as spending, primary care gatekeeping, payment mechanisms and the density of physicians. Alternatively, perhaps variation is endogenous and depression may determine the extent of use. The final phase presents characteristics for each country and uses idiosyncrasies to control for country level variation in estimating health care use; the nature and effect of idiosyncratic differences will be discussed further in Chapter 17.2.
14.3. How Does Depression Influence Health Care Utilisation in Dementia?

This final result uses regression analysis to capture an effect of depression in dementia on health care use. Prior to considering the control versus dementia, note there is considerable differences in contact rates between the full SHARE sample (median 4, mean 6.48, S.D. 9.17), those with dementia not indicating depression (median 6, mean 11.19, S.D. 15.56) and dementia with depression (median 10, mean 13.31, S.D. 15.96). Figure 39 illustrates the choice of econometric techniques applied to estimate health care utilisation, firstly let us inspect the features of health care usage and how it varies when divided by dementia and depression status.
Figure 39: The annual rates of health care divided by dementia and depression status [Source: SHARE 2006].
The first observation is that health care utilisation in all subgroups exhibits the classic characteristics of a positively skewed distribution (where the majority of individuals will have a contact rate with services less than 20 times a year) and a long right tail (correlating to a smaller proportion of users of services exhibiting substantial costs of service).

There are a substantial number of individuals using no services, suggesting that average use across the population will be influenced by a mass of zeros. While these characteristics are generally consistent for the four subgroups, it is observed that dementia and/or depression (EuroD >3) causes the distribution to shift right as greater services are required. As would be expected, this causes a decrease in the density of zero users for both dementia and depression.

To explain the causes of these shifts and to account for the zero mass, left skew and long right tail, the distribution of zeros and the positive portion of the distribution are fitted with the two-step procedure with the first step selecting positive users with the logic and the second examining the conditional use where use is positive with a GLM model.

Health care utilisation varies substantially across Europe, (both generally and in response to dementia), which may be partly influenced by local health system characteristics. The average usage rates vary considerably given specific diagnosis of dementia, showing double the demand compared to the general population. However, this increase is not uniformly observed, with certain countries displaying static or reduced rates. Substantial differences in rates of access to services across countries are observed and may influence these overall rates. This final phase of analysis controls for these two levels of variability (health system and individual effects) and using the quasi-experimental condition, depression is demonstrated to have a substantial influence on the health care use. Table 22 presents the two stage regression outputs, grouped into dementia or control.
Table 22: Parameter estimates of service usage in dementia population versus the matched control divided into two stages: a. whether any services are used in a given year (AnyUse) and b. given that usage is positive, the quantity of use over the year (PositiveUse).

<table>
<thead>
<tr>
<th>Depression Indicators</th>
<th>Control AnyUse</th>
<th>Control PositiveUse</th>
<th>Dementia AnyUse</th>
<th>Dementia PositiveUse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>.176</td>
<td>.241*</td>
<td>-.773</td>
<td>-.037</td>
</tr>
<tr>
<td>Pessimism</td>
<td>.166</td>
<td>-.057</td>
<td>.313</td>
<td>.086</td>
</tr>
<tr>
<td>Suicidality</td>
<td>-1.226</td>
<td>-.327*</td>
<td>-2.735**</td>
<td>.001</td>
</tr>
<tr>
<td>Guilt</td>
<td>-2.022</td>
<td>-.060</td>
<td>-2.436</td>
<td>-.023</td>
</tr>
<tr>
<td>Sleep</td>
<td>.216</td>
<td>-.030</td>
<td>.735</td>
<td>-.373*</td>
</tr>
<tr>
<td>Interest</td>
<td>.419</td>
<td>.063</td>
<td>.137</td>
<td>.276*</td>
</tr>
<tr>
<td>Irritability</td>
<td>-.430</td>
<td>.217</td>
<td>.066</td>
<td>-.250*</td>
</tr>
<tr>
<td>Appetite</td>
<td>s</td>
<td>s</td>
<td>s</td>
<td>s</td>
</tr>
<tr>
<td>Fatigue</td>
<td>.268</td>
<td>.143</td>
<td>-.273</td>
<td>-.186</td>
</tr>
<tr>
<td>Concentration</td>
<td>-.866</td>
<td>.154</td>
<td>-.122</td>
<td>-.118</td>
</tr>
<tr>
<td>Enjoyment</td>
<td>s</td>
<td>s</td>
<td>s</td>
<td>s</td>
</tr>
<tr>
<td>Tearfulness</td>
<td>s</td>
<td>s</td>
<td>s</td>
<td>s</td>
</tr>
<tr>
<td>Euro-D&gt;3</td>
<td>-2.403*</td>
<td>.771*</td>
<td>-1.773†</td>
<td>1.021**</td>
</tr>
<tr>
<td>Healthcare Use(04)/Euro-D&gt;3</td>
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<td>-.204*</td>
<td>2.045*</td>
<td>-.113</td>
</tr>
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<td>Demand Variables</td>
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<td></td>
<td></td>
<td></td>
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<td>Healthcare Use(04)</td>
<td>-.169</td>
<td>.390**</td>
<td>.840</td>
<td>.392**</td>
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<tr>
<td>NumbChronic2</td>
<td>.137**</td>
<td>-.0005</td>
<td>.089*</td>
<td>.008*</td>
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<tr>
<td>Specialist</td>
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<td>.275**</td>
<td></td>
<td>.546**</td>
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<td>Country Variables</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Expenditure(%GDP)</td>
<td>.319</td>
<td>.025</td>
<td>-2.579*</td>
<td>.037</td>
</tr>
<tr>
<td>GateKeep</td>
<td>-1.503*</td>
<td>.155</td>
<td>-5.606*</td>
<td>.157</td>
</tr>
<tr>
<td>FecForServ</td>
<td>-2.013*</td>
<td>.182</td>
<td>.169</td>
<td>.118</td>
</tr>
<tr>
<td>Capitation</td>
<td>-.965</td>
<td>.359</td>
<td>-.816</td>
<td>.094</td>
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<tr>
<td>PhysicianDensity</td>
<td>.035</td>
<td>.019*</td>
<td>.692**</td>
<td>.005</td>
</tr>
<tr>
<td>Constant</td>
<td>.825</td>
<td>-.374</td>
<td>7.596</td>
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</tr>
<tr>
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<td></td>
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</tr>
<tr>
<td>n</td>
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<td>271</td>
<td>254</td>
<td>238</td>
</tr>
<tr>
<td>Wald $\chi^2$</td>
<td>66.879**</td>
<td>125.668**</td>
<td>54.204**</td>
<td>183.67**</td>
</tr>
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<td>156.663</td>
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<td>Hosmer-Lemeshow $\chi^2$</td>
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</tr>
<tr>
<td>Specificity(Pr(y=0 D=0))</td>
<td>13.33%</td>
<td>50.00%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Significance levels: †: 10% ●: 5% ●●: 1%  
Label: Suppressed Variable (s)
Firstly, comparison of the specificity from the diagnostic test of the equation Any Use finds that the dementia equation predicts 50% of individuals who will not use services, compared with 13.33% in the control group. Clinical depression (Euro-D>3) significantly reduces the likelihood of access in both the dementia and control group. This suggests that some characteristic of having depression lower the chances of having positive use of services. In dementia, the depressive symptom suicidality is particularly significant, whereas the control group show no specific symptom as significant. Individual’s previous health care utilisation (in 2004) given that they are depressed (Healthcare Use(04)| Euro-D>3) is significant. Under Demand Variables, the unconditional Healthcare Use (04) (without depression) is not significantly predictive of access. A similar profile is observed in the control group, however magnitude of effect for Healthcare Use(04)| Euro-D>3 is half dementia (1.273 versus 2.045, respectively).

Increasing national health expenditure (as a percentage of GDP) and the presence of gate keeping in a country both significantly decrease the likelihood of an individual with dementia accessing services, while increasing national physician density (which is a national measure of the number of physician per 10,000 of population) increases access. Similarly, the presence of gatekeeping reduces the likelihood of access in the control group and a fee for service payment mechanism is found to significantly predict none-use.

Next, the level of conditional use (given health care use >0) is examined and associated parameters are explored. Overall, the predicted mean health care utilisation is 11.74 for dementia and 10.52 for the control group. This indicates that (having formed the matched groups) overall the two equations predict on average similar health utilisation.

Examining the marginal effects at the mean of the clinical depression indicator (Euro-D>3) significantly predicts more use in the dementia arm than in the control group; the marginal effect at the mean finds that depression (Euro-D>3) would increase service use by 10.54 visits per year (p= 0.002) in comparison with the marginal increase in the control of 7.57 (p=0.105), representing a 39% difference in effect.

Significant specific symptoms of depression affecting dementia usage were sleep (reducing average use by 4.30), loss of interest (increasing use by 3.56) and irritability (lowering average contact by 2.83). This significant profile is very different in the control group, where being depressed in the last month increases use by 2.59 visits and suicidal feelings reduces contact by an average of 3.13.
A second significant observation for individuals with dementia is the marginal effect of an individual using *specialist* services which shows an average increase in health care utilisation of 6.37 per annum versus 2.59 in the control group. No local health service characteristics seem to significantly change health care use in dementia; however, physician density is found to have some moderate effect in the control group.

In conclusion, depression in dementia is influential at both stages of health care utilisation; the likelihood of access to services is lowered by depression and depression increases the average service usage in dementia by 39%.
PART V
DISCUSSIONS
Part V – Overview

PART V presents the formal discussion of the results of the three analyses into perception of care, value of informal care and the level of formal service utilisation.

Chapter 15 discusses the findings on what determines perceptions of care focusing on the influence of point of diagnosis, the impact of disclosure, the consumer-provider relationships and how financial mechanisms influence care.

Chapter 16 examines how much informal care is provided at progressive stages of dementia and discusses the implications of the stages related valuation of care.

Chapter 17 debates the findings on depression in dementia and its impact on health care utilisation. Firstly, conclusions are offered as to whether the incidence of depression predicts or confounds dementia. Secondly, average treatment effects (ATE) obtained through propensity score matching are discussed with respects to health care utilisation. Finally, the determinants of access to care and the level of health care use are discussed, drawing specific conclusions on the incremental effects of depression in dementia.

Chapter 18 offers conclusions related to the three areas of analysis. Each section then offers recommendations for policy and for further research. A dissemination strategy is also detailed for each set of findings.
Chapter 15. What Determines Individuals’ Perceptions of Care

This Chapter discusses the results of what determines perceptions of care in Ireland. The aim for the first research question was to examine what determines dementia care and the cost of dementia care in Ireland, using a series of logistic regressions. Results suggest that perceptions of care are explained by four sets of explanatory variables: how dementia was diagnosed (15.1), whether the individual was informed (15.2), access to specific services (15.3) and financing mechanisms (15.4).

15.1. The Influence of the Diagnosis of Dementia

The results related to access to a specialist at diagnosis (e.g. hospital or memory clinic) suggest that where individuals are diagnosed is influential on long-term outcomes of care. This discussion elucidates whether the point of diagnosis orientates user into a more integrated care pathway. Two specific points are discussed: Section 0 examine the relationship with hospital services and Section 0 the impact of memory clinics.

Hospital services

One in fourteen people were found to have had accessed specialist hospital services, indicating limitations of a service highly correlated with good quality service. ASI 2007 finds that access has regional variation, with highest rates of access in Dublin and Connaught (accepting the survey limitations presented in Chapter 9). This effect may be attributable to proximity to major teaching hospitals, and designers of optimal integrated care pathways for dementia should consider this in future service designs.
The OECD (2009) presented that Ireland has the third highest per capita production of the qualification of medical students across the OECD region. For macroeconomic reasons related to Ireland’s budget deficit, and because of specific institutional factors, Ireland is currently experiencing shortfalls in medical staff between house officer and specialist registrar level.\textsuperscript{47} Therefore, integrated approaches taken to reform dementia should also consider the fact that academic training may face limitations that are system-wide. To address this requires a strong governance structure, which includes the financial commitment to improve the post-graduate medical rotation in services related to dementia care.

**Memory clinics**

The elementary economic assumption of a ‘rational utility maximiser’ should be reconsidered for people with dementia. If individuals with dementia lose the cognitive ability to rationally seek out services that will increase that health related utility, a welfare system should accept the duty of orientating those individuals toward accessing the correct services.

For a diagnosis that occurs in a *memory clinic*, users have positive perceptions of *level of care* and exhibit greater confidence in the [tax-based] payment for public services. A diagnosis in a memory clinic is an indicator that dementia-specific services are initiated from the earliest possible stage. Greater opportunity to access memory clinics may become economically viable where such services are supported by local and international evidence. Irish research suggests, that the majority of patients visiting a memory clinic are satisfied with the explanations and information received and despite the diagnosis, generally feel more positive following the service (Cahill et al. 2006). Early intervention has been shown to improve carer well-being,

which in turn was associated with risk of a breakdown in carer dynamics (Moniz-Cook et al. 1998).

In addition to greater accuracy in diagnosis, this indicates memory clinics have a longer term effect on service outcomes. Memory clinics increase the detection rate and recipients have a better quality of life, as well as improved behavioural and psychological symptoms of dementia (Banerjee et al. 2007).

The direction of causality on memory clinics should, however, be questioned here. For example, is it that memory clinics orientate the person towards better services or does the presence of better services precede the presence of memory clinics? At present, many memory clinics are based in tertiary referral centres (e.g. St. James Hospital, Dublin) or in academic institutions (e.g. Memory Works, Dublin City University); therefore this may support the latter. Irrespective of the direction of causality, enhancing the conceptual symbiosis of academic interest and service provision would indicate that investment in research may directly improve quality of service.

Further research is required in order to ensure that sufficient points of early intervention (most likely memory clinics) meet regional demand.

15.2. The Impact of an Appropriate Disclosure

ASI 2007 suggests that 50% of individuals with dementia are not informed of their condition and this non-disclosure is significantly correlated with poor perceptions of the levels of care and the view that the costs of services are not reasonable. It is unclear as to why the level of disclosure is so low, although anecdotal evidence (derived from expert opinion) would indicate a reluctance to provide the diagnosis given the lack of availability of resources to support the individual following
diagnosis. The non-disclosure finding is a clear call for a drive for a legal framework to provide accountability for elderly care needs to be embedded in a national dementia strategy. At the service level, such a framework needs to include clear governance of what availability of care should be the minimum standard of practice. In practice structured interviews should be prerequisites in at-risk individuals and patient information should be visible to ensure efficient use of resources. At implementation, objectives need to be specific in dictating the outcome measures and how this effects provider reimbursement. A case in point: physician disclosure rates could be submitted as part of a prospective payment mechanism with fidelity to clinical guidelines dictating case-based payment.

Disclosing dementia is often difficult, and may represent a process rather than an event (Woods et al. 2003). In reviewing national dementia strategies (Chapter 1), it was pointed out that the national service framework agreed that appropriate services should ensure that an explanation of the diagnosis is provided to older persons and any carers. Given that only one in two were informed in the survey that this study uses, combined with the negative effects on perceptions of care and cost, suggests that greater transparency is required with regards to patient rights to be adopted in Ireland.

15.3. Relationships between Formal Service Providers and Consumers

Perceptions of care provide useful information on whether the end-users’ needs are being met. This section reviews two important relationships captured in the analysis of ASI 2007: Section 0 examines the impact of hospital access and Section0 examines access to community support service.
Hospital access

Access to hospital care is found to have an enormous effect on the consumers’ feelings as to whether the service is sufficient for their needs, even though only 7.04% of the 270 people surveyed in ASI 2007 had accessed hospital services (Summary Statistics, Chapter 10). Whilst the extent to which hospital services were needed has not been observed in the data, this analysis provides good indication that the contact with specialist services is important to the feeling of well-being and satisfaction.

Accepting that ASI 2007 has limitations in the scope of its national coverage (see Chapter 9 for more details), some interesting regional variations are nevertheless observed (Chapter 10). Whilst individuals captured in Dublin represent only 14% of the total in the ASI 2007 sample, 10.81% of these individuals stated that they had accessed hospital services. By contrast, Munster captures 39% of the ASI 2007 sample, but only 7.14% of the sample claimed to have accessed similar hospital services. This raises an important question: is supply of service highest where demand is at its lowest?

Further research is required in order to ensure supply meets demand; however, such research needs to investigate, and potentially control for, supplier induced demand.

Community support services

It was observed that quality of service was significantly explained by three variables in community support services: day care, home care and respite services. These observations may be in part explained by the relationship between carer and recipient: 43.5% were married to the recipient and 45.0% caring for a parent, of whom 64.8% would indicate spending 16 or more hours per day caring for the person. Given the level of the total care requirement, these findings indicate that
community support services are a critical component of high quality dementia care, particularly when a carer’s perspective is considered. Whilst there is a paucity of robust evidence to confirm the effectiveness of community care interventions such as respite, this analysis indicates that perceptions of quality do improve under the influence of community care, and future pragmatic evaluations should include multi-attribute utility measure to obtain changes in quality of life.
15.4. Relationships between Dementia and Financing Mechanisms

Dementia is a condition occurring in late life. Various forms of health insurance exist in Ireland to ensure that individuals have pooled finances over their earlier life to avoid the risk of being exposed to the full financial costs of health care in later life. This section examines evidence that suggests perceptions of care are influenced by either personal financial circumstance (Section 0) or the method of payment (Section 0).

Dementia and personal financial circumstance

Personal financial problems are found to significantly explain five of the six perceptions of care analysed. In order of magnitude, income problems most greatly affect individual perceptions of quality, level and views on cost. Having to pay medical costs is associated with the perception that the level of care is low and having to pay for additional help is correlated with the perception that service is not sufficient.

These findings provide strong and important evidence that dementia care is potentially not received equally across the population. An important question arises whether Ireland has a systematic grouping of people, who may already be socially disadvantaged, to receive poorer care, and if so does this exacerbate the problems associated with dementia?

Proposed reforms to health insurance in Ireland are underway and state a commitment to *Equal Access for Equal Need*. To implement this will require measurable, transparent service outputs which should be periodically evaluated by independent researchers. Potential policy and legal changes need to be evaluated with the intention of improving the statutory rights of the elderly to community care.
Dementia and methods of payment

Three main methods of payment exist in Ireland: payment under the medical card system (where service costs are fully covered); private health insurance (with the usual schedules of co-payment and deductibles); and out of pocket (individual costs of care are paid personally). The results of this analysis show that in several situations the method of payment often explains perceptions of care.

Whilst invariably interrelated with the earlier suggestion of personal finance, this finding also raises concerns of unequal access to services. If controls for insufficient income to provide care are introduced, the restriction on access to formal and community services reduce. This is in-line with health policy research in Ireland, which indicates that two tiers of access exist in Ireland (Burke 2009, Wren 2003). Specifically, this raises an important question: to what extent does payment method affect access to dementia specific services?

To break down this question of access to dementia specific services would require three initial stages: 1. diagnosis of the dementia 2. disclosure of dementia, indicating the need for the dementia specific service 3. the referral to said specific services. This research has so far indicated that 1. and 2. may be remedied by increasing patient access to medical staff with the required competence to make the diagnosis and disclosure. Previous Irish research suggests that only 20% of GPs feel confident of diagnosing dementia (Cahill et al. 2006).

In summary, inquiries into what determines perceptions of care in Ireland find that the nature of diagnosis, disclosure, relationships between supply and demand and finances are significant. This suggests that dementia suffers from system-wide problems and these should be incorporated into planned reforms of the system.
Chapter 16. Dementia Stage and Informal Costs of Care

This Chapter discusses the second research question: how much informal care is provided in Ireland at progressive stages of dementia and what is the value of this care? The results are discussed over two sections: Section 16.1 explains the level of informal care and Section 16.2 discusses the informal costs of dementia care calculated by applying a proxy-good valuation.

16.1. Explanations of the Level of Informal Care

International evidence suggests that the majority of people with dementia live between 2.5 and 7.6 years and those with younger onset live for up to 10.7 years (Xie et al. 2008). ASI 2007 finds that 85% of informal carers in Ireland are providing 10 or more hours of care per day. But how does this vary with dementia progression? And controlling for stage-related effects, what else determines the level of care?

This section discusses the three sets of results used to explain levels of informal care: Section 16.1.i presents individual characteristics, Section 16.1.ii examines the role of functional limitations and Section 16.1.iii inspects the impact of the psychiatrics symptoms of dementia.

16.1.i Individual characteristics

Individual characteristics are the first set of explanatory variables and capture four significant characteristics that predict hours of informal care, namely: (1) stages of dementia (2) training the carer (3) residing in a nursing home (4) work-cohabitation status all significantly explain the level of informal care provided each day.

(1) Stage of Dementia

The stage of dementia has a central role in this research question and the outcomes provide important information for service planning and policy. The most important observation is that demand for informal care time is not constant across stages of dementia. Individuals that accept the duty of care will become increasingly consumed by the role and acknowledgement of this fact in policy should aim to provide mechanisms to protect individuals from accepting excessive hours.
As would be expected, the coefficient for early stage is correlated with decreased care and late stage with an increase in care but mid stage results are not significant, indicating some underlying heterogeneity in this subgroup. Referring back to Chapter 10, Figure 34, which presented the number of reported symptoms by stage, may provide some indication of why mid stage does not appear significant; unlike early and late stage dementia, the number of reported symptoms in mid stage dementia range from the minimum in early stage to the maximum in late stage. On surveying GPs, Cahill (2006) found a lack of confidence in diagnosis and in following this observation, the origin of the level of variation in the group classified as mid stage dementia should also be clarified. Specifically, the question for future research may be: how does the stage of dementia reported by a physician compare to the stage calculated using a structured diagnostic instrument?

(2) Training

The results on training informal carers for this role suggest that the average level of informal care may be reduced by around three hours per day. The nature of the type of training received by the informal carer is unidentified and may vary quite substantially. Nevertheless, this finding would suggest that training, in whatever form, will reduce the amount of informal care and therefore will help assist the carer to maintain their role over progressive stages. More importantly, this raises questions about the counterfactual: by how much are the untrained informal carers overproviding care? And, what is the maximum level of care that training should advise?

To answer these questions, whether informal care is a complement to or a substitute for formal care must be established. Bonsang (2009) finds that informal care is interchangeable with formal services akin to either paid domestic help or nursing care. More specifically, informal care will only be an effective substitute for long-term care while the level of disability is low and thus in most situations should only serve as a complement to formal services. The analysis of the proxy-goods underlying the total hours of informal care provides evidence that informal carers may be substituting a level of formal provider competency.
(3) Nursing Home

Living in a nursing home controls for the change in burden when an individual transitions into long-term care. The analysis suggest that the effects are significant despite the low number of respondents actually residing in such a setting (n=8) and therefore caution is advised when reading the following inference.

The estimation would suggest that informal carers’ time is reduced on average by around five hours per day by nursing home care. This would suggest that the role of the informal carer is not substituted by admission to such facilities. Of the eight carers, most were a spouse (n=6) with the remainder carers of a parent (n=2). Only spouses were found to report the level of informal care per day, with two reporting less than 2 hours per day and the remainder reporting over 14 hours.

No inference can be made on nursing homes. However, future research should consider the relationship between ‘deficit hours’, which may exert a disutility (as proposed in Chapter 1), and the need for transition to nursing homes in Ireland.

(4) Work and Cohabitation

Cohabitation and employment variables are found to be jointly significant in explaining the levels of informal care (see Chapter 12, Table 15). This dynamic illustrates conflicting and competing priorities that may arise through informal care. These findings provide important information for opportunity cost and friction cost arguments (however, survey limitations prevent any formal attempt to calculate such costs). The main conclusion is that sharing the same household is indicated to increase the level of care and may decreases hours of labour force participation.

Bolin (2008b) examines the willingness to supply informal care and finds that it adversely affects labour-market outcomes. He examined the hours of informal care, the probability of employment, hours worked, and the income obtained. This analysis concludes that informal care has significant adverse effects on labour force participation. Bolin (2008a) further analyses informal care and suggests a concept of intergenerational care. Examining where carers are either adult children or adult grandchildren the results illustrate changes in the traditional domestic division of labour and a concurrently developing marginal group which could equally be the caregiver or care recipient.
Work and cohabitations are no doubt intertwined with providing care. Previous research would suggest that adverse effects on labour force participation are likely, the domestic role has changed and care may be delivered by individuals who themselves may require care. The results presented in this thesis on work-cohabitation raise the policy question: in the context of a changing workforce, what is the socially optimal arrangement?

16.1.ii Functional limitations

Three forms of functional limitation have been studies (HDL, ADL and IADLS) and their relationship to predicting informal time requires brief discussion.

HDLs are the set of variables indicating the individual’s ability to maintain the home. With the exception of cooking this category is not significant. This would suggest that household inputs are less important motivators to provide informal care. This is illustrated in the estimation of contribution of HDL at each dementia stage where it is observed to decrease from one and half hours per day in early stages to thirty minutes in late stage. This raises two potential conclusions: firstly, informal care is has more complicated limitations and secondly, informal carers would not seem to have the time to supply the basic domestic help (which is generally assumed to be their primary responsibility).

ADL are general activities of daily living and are significant as a group (predominantly explained by the ability of the individual with dementia to get dressed). These activities are associated with more progressive stages of dementia where disability becomes more prominent. ADLs indicate that informal care will be required to provide physical help associated with care and a proxy of a care assistant (specific for intellectual disability) is assumed. However, this raises the question whether the informal carer will possess the same competency or physical ability of this formal proxy.

IADL is the final set and is associated with higher cognitive abilities such as socialising, communication and complex activities. Therefore the significance in this set in predicting informal care primarily relates to the effect of reduced cognitive ability. Informal carers seem to be motivated to provide contact in this situation because of impaired ability to effectively communicate and socially interact. This
would suggest that whilst no physical role may be elicited by IADLs, there may in fact be a substantial emotional burden and (as shown in Chapter 1) previous research has demonstrated that there may be a correlation to carer burnout.

16.1.iii Psychiatric symptoms

At each stage of dementia, psychiatric symptoms are estimated to explain the largest proportion of informal care time, particularly in early stage where such symptoms are associated with more than half of the dementia specific time (see Table 17). Undoubtedly, behavioural changes from such symptoms are distressing and complicated to manage; but it is questionable whether an informal carer could actually receive training to appropriately cope with such changes. A central theme of this thesis is psychiatric symptoms of dementia (such as depression) and the third question aims to indicate incremental changes in health care from depression. Future research should further elaborate on the role of psychiatric symptoms in dementia.

16.2. Stage-Related Valuation of Informal Care

In economic evaluations the inclusion of informal care implies a societal perspective and is intended to aid policy makers in resource allocation decisions. The application of a cost weight to informal care time at progressive stages of dementia aims to provide tangible evidence of the value of care provided.

The decision on assigning costs for the stage specific valuation of informal care draws on the proxy-good method over the standard opportunity cost methods for several reasons. Firstly, as was illustrated in the previous section, proxy-goods such as activities of daily living and psychiatric symptoms significantly explain the level of dementia specific informal care. Secondly, from a policy perspective, proxy-goods provide a tangible formal cost which has been offset by informal care. Finally, as a value of the outputs of care, the proxy-good valuation weights overall cost of dementia care for an equitable comparison to other disease groups (e.g. cancer, stroke or heart disease).

The value of informal care reflects the shadow price to the public health system in contrast to the opportunity cost (the transitional method from economic theory) as it
captures a value of the next best use of the carer’s time. A theoretical comparison of the two approaches was provided in Chapter 3 and, in the review of related research, clearly indicated that informal costs of care generated by these two methods will vary considerably in their cost (van den Berg 2006).

Whilst a similar comparison is not possible using ASI 2007 data (as presented in Appendix 3), the figures presented in Chapter 7 can be reliably assumed to be also substantially higher than those that would be generated through the opportunity cost; the estimated hours of informal care there have several impact reasons why this is the case. Firstly, stage related changes in informal care are reflected in the units of time provided as the dementia progresses. Secondly, the intensity of care required is a reflection of the training level which would be a prerequisite to handle complicated demands of dementia. And finally, the valuation presented in this thesis adopts the total staff cost as prescribed by the economic evaluations guidelines of the Irish health regulatory authority, HIQA (2010). The total staff cost inflates as none-salary cost (PRSI and 40% overhead) reflect a production cost of the outputs of care.

Arguably, the proxy-good method can also agree with the standard economic theory of an opportunity cost. This is best illustrated by assuming that an individual could hypothetically be assigned to one of two disease states, for example mid stage dementia versus stage III cancer. If the cost of producing the observed care in the stage III cancer is less than €394.92 per day (the cost of mid stage dementia, Chapter 12), the opportunity cost of assigning the individual to dementia would create a greater producer surplus (from a health budget perspective). However, the quantity and emotional intensity of dementia care reflected in the figure of €394.92 indicates a reduction in the informal carer’s overall welfare (or consumer surplus).

In summary, stage related costs estimated using the proxy-good method indicates that significant formal costs are offset. In Chapter 18 these figure will be used to draw conclusions and make recommendations for future dementia policy in Ireland.
Chapter 17. Demand Associated With Depression in Dementia

This Chapter discusses the results of the three phases of analysis used to answer the question: how is formal service utilisation influenced by depression in dementia? Section 17.1 examines whether the results of the first regression indicate depressive symptoms to predict or confound a diagnosis of dementia. Section 17.2 discusses the results of matching average treatment effects of a diagnosis of dementia on the observed level of health care use. Section 17.3 concludes by discussing the results of the two stage estimation of health care use and the incremental effects of depression in dementia.

17.1. Depressive Symptoms: Predictor or Confounder of Dementia?

An important preliminary question is to what extent are depression and dementia mutually exclusive. It is important to consider the results of these dynamics and whether the evidence suggests that depression significantly predicts dementia.

The first analysis established a baseline equation confirming that accepted risk factors of dementia are indeed predictive of dementia within SHARE. The probability that the baseline equation correctly predicts dementia is 27%, which suggests the estimation method is efficient with respect to detecting positive cases of dementia. At the same time, 73% of individuals detected in the estimation will have been diagnosed with dementia and provide the control group for the matching experiment.

The three main risk factors are age, activities of daily living and cognitive function. Firstly, findings on age confirm previous research which has suggested that dementia rates double every five years after the age of 65. Secondly, concurring with the proxy-good analysis, IADLs significantly predict dementia. Finally, significant reductions in cognitive function are associated with an increase in the likelihood that the individual will be diagnosed with dementia.

Differentiation of depression from dementia is well established in the psychiatric literature and was reviewed extensively in Chapter 4. To uncover economic
implications of this psychiatric comorbidity in dementia, this analysis establishes three important interactions of depression and dementia.

Firstly, concurrence depression (as indicated by a score Euro-D(06)>3 in the Threshold equation) is significant in the model but reduces model sensitivity from 27.7% to 18.9%. This indicates that threshold depression co-occurring with dementia may confound a diagnosis. Individuals with depression are therefore at risk of being labelled as having dementia but the symptoms of depression are reversible confirming the potential for pseudo-dementia (McAllister, 1983).

Secondly, to examine why the explanatory variation Euro-D(06) is significant but reduces sensitivity and confounds the prediction of dementia, the third equation EuroD06 measures the specific symptoms underlying the level of depression measured in the Euro-D structured interview. Only the variable concentration is found to significantly influence the likelihood of predicting dementia and by disaggregating the threshold readings, the sensitivity is roughly maintained. This suggests that the reason that the aggregated Euro-D scores confound a diagnosis of dementia is primarily caused by concentration, a synonymous symptom of the two syndromes. Importantly to ascertain the incremental effect of depression in dementia, this analysis implies that the regression must control for specific symptoms to observe the effect of Euro-D(06) on health care utilisation.

The final conclusion is that the symptoms of depression measured in SHARE 2004 improve the predictive power of dementia in SHARE 2006. In the equation EuroD04 (where depressive symptoms captured by the Euro-D scales in 2004 are analysed), the sensitivity reaches 31.4% compared to 27.7% in the Baseline equation. These findings provide evidence that depression may be prodromal to dementia\(^{48}\) and concur with research discussed earlier (Brommelhoff 2009).

In summary, the results provide confidence that a matched population based on the common risk factors of dementia (represented in the Baseline equation) and co-

\(^{48}\) This conclusion on prodromal depression is inferred partly by comparing the sensitivities from the Baseline and EuroD04 equations; it should be noted that (by using results taken from the two waves) sample numbers are significantly different and therefore, comparisons are likely to provide spurious information. According to results from within the equation EuroD04 the significance of specific coefficients still hold.
occurring depression are mutually exclusive but analysis must control for specific symptoms of depression (particularly concentration) to avoid confounding effects.

17.2. Average Treatment Effect of a Dementia Diagnosis on Health Care Use

Average treatment effects (ATE) are obtained for dementia through propensity score matching. This procedure also provides the basis to compare dementia with a comparable population not diagnosed with dementia, discussed in the last section (17.3) of this Chapter. This section discusses the level of health care utilisation and infers the ATE attributable to a diagnosis of dementia at two levels: aggregated across all European countries in SHARE and at the individual country level.49

At an aggregate level across all 14 European countries in SHARE, little difference is found between the average annual service utilisation in the control (12.72) and dementia groups (13.42). The ATE for a diagnosis of dementia in usage level is 0.7 visits per year following diagnosis of dementia. Individuals with dementia can on average be assumed to have similar utilisation _ex-ante_ and _ex-post_ of a diagnosis.

The level of health service use may be attributable more to characteristics represented in the propensity score matching’s covariate matrix than the diagnosis. As such, the effect of a diagnosis only marginally increases the average health care use and certain circumstances may decrease the likelihood of service contact; inspection of country level variation provides grounded theory to this hypothesis.

Comparison of health care utilisation across the 14 countries indicates substantial variation may exist and, whilst not observable in this analysis, is assumed to be explained by idiosyncratic country-level features which are therefore controlled for in the final regression analysis. To provide a basis for the discussion of the two stage regression, several potential country-level idiosyncrasies are discussed in relation to the observed country level ATEs.

Firstly examining maximum and minimum health care utilisation for those with dementia, Denmark has the lowest rate of utilisation (4.33 visits per annum) and Belgium has the highest health care utilisation (20.42). The full SHARE sample suggests that Denmark generally has very low rates of usage. Idiosyncratic

49 Country level sample size is statistically low to make strong inference on ATE (as discussed in Chapter 9 – Limitations of the Data and Findings).
characteristics include spending of 9.6% GDP on health care, a GP gatekeeping system, payment by fee for service and a high average density of physicians (36 versus European average of 35.29). On the other hand, Belgium (where dementia health care utilisation is highest) is also observed to have higher than average service use. Belgians spend 10% GDP on health care, access to specialists are not restricted by gatekeeping, also has a fee-for-service payment system and has an above average density of physicians (42 versus average 35.29). These two findings, at the extreme, suggest that health care utilisation in dementia may be predetermined by exogenous factors of the health system, affirming that country factors can control for a country level fixed effect and individual level of health care use should be controlled for.

The largest ATE (i.e. difference in the health care use between the dementia and control group) are found in Greece (5.33), Poland (4.65) and Spain (4.34). The interesting point is that Greece and Spain are the only two countries where physicians are typically salaried (Poland pays on a capitation basis). Furthermore, Greece has the lowest density of physicians of all the countries in this wave of SHARE (1 physician for every 200 in the population). This provides indication that the payment mechanisms and physician density need to be controlled for and may be influential on a dementia specific change in dementia specific service utilisation.

In Italy, France, Ireland, Denmark, Sweden and the Czech Republic, it would seem that individuals receiving a diagnosis of dementia are likely to have a reduced contact rate. Whilst potentially unrelated, the frequency of dementia in each of these countries tends to be lower than the average (1.16%), with the lowest diagnosis rate found in Ireland (0.47%) and Czech Republic (0.69%). Again, this provides evidence that where diagnosis is low, the health care use is also reduced. Of these countries, the majority operate on a capitation payment basis (67%) as compared with a minority of countries (25%) are capitation based where the ATE is positive.

In summary discussion in this section helps provides evidence why country-level effects are controlled for in the final analysis. However, these controls are fixed and therefore do not provide large amounts of information on their influence. Future research is required to ascertain whether the level of health care use in dementia has an influence by country level features such as national health budgets, methods of provider payment or supplier controlled demand.
17.3. Depression in Dementia: Access to Service and Level of Use

Having used propensity scores to match individuals with dementia to a control group, the final stage of analysis performs a two-step model of health care usage. The primary aim of the regression analysis is to examine and compare coefficients to indicate the role of depression that coexists with dementia and the magnitude of their influence on service use (controlling depressive symptoms and country level effects).

The distribution of health care use observed in SHARE has the common hallmarks of being left skewed, having a long right tail and a significant number of individuals that access no services (indicated as zeros). In Chapter 14.3, Figure 39 presented a preliminary visual inspection and indicated that both depression and dementia cause the skew to change and indicate that the average service use increases. Furthermore, in combination depression and dementia further shift the distribution from skew towards normality indicating that increased service use can be explained by considering these comorbid syndromes.

In the two-stage regression, the first stage examines what explains service access and the second stage the level of health care use conditional on service use being positions. Having controlled for potentially confounding symptoms of depression and country level characteristics, two sets of interesting results on depression in dementia emerge as meriting discussion.

Firstly, the AnyUse equation for the dementia group positively predicts 50% of people who do not access services, as compared with 13% in the control group.\(^{50}\) This provides evidence that (based on the covariate matrix) people with dementia may be at greater risk of not engaging correctly with health providers and that being clinically depressed significantly reduces the likelihood of accessing any services. Specifically, suicidal symptoms are most significantly predictive of access, which agrees with previous research of depression in the elderly (Kaplan et al. 1999, Bartels et al. 2004). These results call for a more coordinated approach to ensuring dementia services are accessed and affirm the need to measure outcomes (such as standardised scales of depression and dementia) are used to ensure appropriate services are being used.

\(^{50}\) In Table 22: the positive prediction of no health care use is indicated by Sensitivity (Pr(\(^{\hat{y}} = 0 |D = 0\)) where \(^{\hat{y}} = 0\) indicates the level of health care use is expected to be zero and D=0 indicates that SHARE observes health care use to be zero.
accessed. Basing itself on the number of individuals identified with dementia in SHARE 2006, future research should aim to examine country level barriers to access in dementia.

The second finding was the marginal effect of depression on the dementia increases the average annual service use to 39% over those depressed without dementia (control groups). This confirms that depression significantly contributes towards intensifying health care utilisation in individuals with dementia. Further research is required to accurately detect depression in dementia and to develop appropriate interventions.

In summary, depression is a common additional complication of many chronic diseases and will increase the burden of disease. The unique feature of depression in dementia is that the two syndromes are nebulous in nature. At a service level, differentiating such disorders requires specialist services (e.g. psychiatrists, geriatricians, neurologists or the experienced staff in memory clinics). Dementia and depression coexist in up to 40% of all dementias (Lyketsos et al. 2002) and the evidence presented indicates a significantly large increase in health care demand meriting specific service planning.

51 It should be noted that a third example with similar capacity to cause confusion is delirium (sometimes regarded as acute confusion). Delirium may also merit consideration but falls outside the scope of this thesis.
Chapter 18. Conclusions: Informing Future Dementia Care

This thesis has aimed to investigate the determinants of dementia care as they pertain to perception of care, value of informal care and the level of formal service utilisation. This Chapter concludes by making three sets of evidence-based recommendations: Section 18.1 summarises what new information has been presented on perceptions of care and how it relates to future dementia care; Section 18.2 explains what has been learned about informal care and makes suggestions to improve overall welfare; Section 18.3 highlights the importance of depression in dementia and makes recommendations for future service planning.

18.1. Perceptions of Care: Conclusion and Recommendations

Perceptions of care are potentially the most informative form of information as to how well the care available meets the needs of individuals with dementia. This first analysis provided new evidence that experience of diagnosis and of disclosure affect long-terms perceptions of care, about how well services received meet end-user requirements and how financial circumstances influence care.

A central health policy in Ireland is Quality and Fairness for All and the analyses of perceptions of care indicate that these pillars of health services are not being delivered.

Significant, recent academic effort has gone into providing an outline of a blueprint for dementia care in Ireland (O'Shea and O'Reilly 1999). To drive implementation, further consideration has been given to clinical and economic factors (O'Shea 2007). The evidence explaining end-users’ perceptions of care suggests that much work is still required to improve elderly care available in dementia.

Most importantly, the analysis suggests that access is not equal amongst all individuals with dementia. Dementia specific barriers exist through poor diagnosis of dementia and, following a diagnosis, whether individuals are even informed of their condition. Social determinants (Marmot 2006) clearly work systematically to ensure individuals receive poorer health outcomes and such individuals are be further disadvantaged by the method of payment required (Braveman and Gruskin 2003).
The World Health Organisation would characterise health inequities as, “affecting groups without political, social or economic power”; these findings further indicate the presence of such a situation. For this reason, remedies tend to require systematic changes in legal, economic or social dimensions (Kawachi and Kennedy 1997, 'WHO | Equity'). Legally, the elderly in Ireland currently lack statutory rights to community care (Cahill 2010), so these results illustrating poor perceptions of the state’s performance of its duty of care are not surprising.

Given that resource allocation is limited, Ireland needs to move towards measuring the outcome of services provided, if the system is to aim to optimise the efficiency of resource use. Dementia specific outcomes measures are required and should form a method for provider payment by results. The following potential outcomes measures are patient centred and may assist in improving perceptions of care:

1. Individuals registered with dementia should receive a Care Plan that measures personal and social needs, making the shared arrangement (or contract) between formal and informal services explicit.
2. Functional limitations need to be documented to indicate demand for service and ensure a needs-based provision.
3. The number of people explicitly receiving their diagnosis should be measured as a percentage of the population.
4. Persons with dementia who exhibit non-cognitive symptoms (e.g. depression) should be tracked and challenging behaviour should receive access to specialist services.
5. A case manager should overview this process ensuring that each plan is tailored to individual needs.

The Irish health care market requires regulatory intervention to ensure that individuals access service on the basis of health need. An outcome based regulatory framework should aim to enhance quality of service and demonstrate improvement in individuals’ perceptions of care. Individuals who have paid a substantial proportion of their income to insure their health should not be denied a good

52http://www.alzheimer-europe.org/FR/Research/European-Collaboration-on-Dementia/Psychosocial-interventions/Potential-quality-indicators
standard of elderly care. From a societal point of view, Ireland needs to reaffirm its commitment to Equal Access for Equal Need.

**Policy Implication:** The government manifesto to implement universal health insurance provides an opportunity to implement prospective payment mechanisms which will improve quality of services and improve perceptions of care. A mixture of diagnostic related groups (DRGs) and community based payment formulae are required to ensure health care providers are correctly incentivised to follow future dementia guidelines.

**Further Research:** Health economic research and decision analysis should be undertaken to ensure that decision makers make better use of limited resources and perceptions of care should assess the utility gains of patients and their carers.

**Dissemination Strategy:** results of the perception of care have been presented at the Irish Society for New Economists (ISNE, 2010) and a related article has been submitted to a health policy journal.
18.2. Informal Costs of Dementia Care: New Information and the Implications

Maintaining a person with dementia in the community can offset the cost of long-term care and the shift of individuals from institutional care has represented a substantial achievement for those with mental and learning difficulties (Morrissey and Goldman 1984). Concomitant with this reform, the demand for care has shifted from formal services to informal carer, developing a gap between budget allocations and burden of disease (Saxena et al. 2007). The analysis has served to illustrate the extent to which burden is placed on informal care and valued that displacement in terms of its formal market substitutes.

The daily value of the care provided informally has been calculated to range from €240.96 in early stage to €394.92 in mid stage and reaches up to €570.04 in late stage. This represents a substantial averted cost to the health budget resulting from the current level of reliance on informal care. Irish people with dementia are suggested to have available to them only half the OECD average level of care and this shortfall in formal services is undoubtedly linked to the levels of informal care observed. The main objective of estimating informal costs of dementia care is to highlight the true market value of the care provided and motivate policy to support informal carers.

The theoretical framework underlying this study suggests that informal care may only reasonably be sustained until the carer’s individual welfare starts to diminish. This threshold (where welfare is diminishing) will be attributable to various circumstantial factors. This study has highlighted that the intensity of care increases with each dementia stage and that individuals are likely to have to make life changing decision to maintain their duty of care.

Only 15% of informal carers surveyed were able to continue working the same hours and the remainder either reduced their hours worked or resigned in order to care. With the combination of the stress associated with functional or behavioural problems and the reduced income, individuals will inevitably experience a reduction in welfare, typified in the research literature as emotional exhaustion and burnout (Yilmaz et al. 2009).
In 1970, Amartya Sen defined informal care as “the dutiful act of basic concern given an *anticipatable* lower yield of personal welfare than other options also available to the individual” (Sen 1997). Whether this is still an acceptable notion in today’s society could be drawn into question.

The data suggest that females continue to be most likely to assume the role of informal carer. In 1973, Ireland removed legislative restrictions on female workforce participation (Deane 1992). Since that time, the average age of first marriage has increased by six years. This suggests a change, which may influence the dutiful act of informal care, specifically an increase in career responsibility and later life starts in having children. Conflicting priorities within the overall construct of dementia care reinforce the need to acknowledge the true market value of care provided informally.

From the formal budget perspective, informal carers should be regarded as a credence good consumed by individuals with dementia. The proxy-good valuation provides information on the value of this good to the formal sector and provides justification for supporting carers through appropriate interventions. In the analysis, training of carers implied a substantial reduction in the level of burden placed on carers and provides evidence for explicit investment in this area. This is in line with international recommendations for dementia that resources for dementia be primarily directed to support the informal sector (WHO 2008). Pinquart and Sörensen (2006) find that combinations of training, respite services and regular counselling optimally reduce burden, increase welfare and reduce the risk of institutionalisation. Such carer interventions may be cost-effective by reducing the amount of care required related to behavioural problems (Gaugler et al. 2003) and by savings accrued in reduced long-term bed use (Donaldson and Gregson 1989).

International dementia strategies have explicitly recognised informal input, and there is national agreement on a providing a minimum standard of support to such informal carers (e.g. training, respite). An Irish dementia strategy should primarily aim to increase funds available for dementia to bring the budget in-line with international levels. To demonstrate the value of implementation (Fenwick et al. 2008), economic evaluations should incorporate the proxy-good valuation method.
thereby ensuring resource allocation considers a perspective of optimising social welfare.

**Policy Implication:** The informal cost of dementia care is estimated to be substantial and represents a loss in consumer surplus in providing care which should ordinarily be provided through elderly care services. Greater attention should be given to ensuring that informal carers are not overburdened and receive appropriate training to cope with their duty of care.

**Further Research:** The ability to uniformly associate proxy value or shadow prices to specific units came into effect when the HIQA economic guidelines adopted the RIA guidelines (HIQA 2010). The estimation of informal costs of dementia care by proxy-good valuation is intended to serve as a blueprint for inter-disease group comparisons. In contrast to the opportunity cost method (which can be viewed as a measure of input by forgoing input into some competing prospect) proxy-good values the level of output and provides disease specific costs.

Valuation by proxy-good provides an important and complementary alternative to the opportunity cost method and should be incorporated into health economics evaluations to inform efficient resource allocations between disease related groups. Future policy research is required to ensure that resources are focused on the core care providers: informal carers.

**Dissemination Strategy:** The paper, ‘Informal Cost of Dementia Care. A proxy-good valuation in Ireland’, was published in the *Economic and Social Review* (Trépel 2011). The paper was also presented at the Irish Economic Association (IEA) in April 2011; it has been accepted for presentation at the Irish Gerontological Society (Aviva Stadium, 9th–10th September 2011) and the CARDI’s ‘Ageing Globally – Ageing Locally’ Conference (Croke Park, Dublin, 2–3 November 2011).
18.3. The Importance of Depression in Dementia and Implications for Service Planning

Depression and dementia have different economic profiles and consequences; depression’s high prevalence imposes a burden on the health system and society, whilst dementia requires intense care and demands informal care. The potential for misdiagnosis is highlighted in this analysis, drawing into question the level of overlap in cost of illness studies in elderly populations. The coexistence of depression may occur in nearly half of all dementia and increases service use by 39%. In terms of inclusion or exclusion criteria of costing studies, these findings may have significant implications for projected global costs (Wimo and Prince 2010).

Depression does not predict dementia when controlling for other common indicators. Nevertheless, individuals with dementia are three times more likely to have become clinically depressed than the general population, with an overall rate of depression of 43.23% (double the rate of the general population over 50). The clinician must make a decision based on the available information, whether the person is depressed, has a dementia or a combination of both. The first set of results would suggest that individuals with both dementia and depression will be at risk of inaccurate diagnosis of dementia and indicating the importance of specialised services.

Once diagnosed with dementia, data from SHARE suggests that services use doubles compared with the general population. However, the extent that this increase is attributable to dementia requires an acknowledgement that the dementia population are different from the general population. For example, the average age of individuals with a dementia is 17 years higher than the general population (83 versus 66). Propensity score matching homogenises this and allows us to measure the effect of a diagnosis of dementia on service use.

Age, education level (a proxy for socioeconomic status), physical disability and cognitive impairments reliably predict dementia. These indicators explain 45.8% of variance related to diagnosis of dementia, positively predicting 27.7% (given prevalence of 1% out of the sample of 33,322) and explain approximately 10% of the linear variance in predicting health care utilisation.
The average treatment effect of a diagnosed dementia (aggregated across the 14 European countries) displays only marginal difference compared with the control (13.43 versus 12.72), but substantial differences may exist within individual countries. As the control group were randomly selected using propensity score matching for each individual country (from samples ranging from 1,259 to 2,778), the results are not likely to occur solely by chance.

Causal relationships between depression and health care utilisation were examined and depression is found to significantly reduce the likelihood of accessing services. This pattern has previously been documented and previous recommendations have called for greater integration of care (Kaplan et al. 1999, Bartels et al. 2004). Individuals with dementia and a comorbid depression are likely to be physically aggressive, have more frequent serious wandering (Lyketsos et al. 1999) and 4% report a 'wish to die' (Hoogendijk et al. 1999). Barriers to accessing appropriate services are therefore a substantial risk factor which may place a substantial burden on informal care and therefore require a policy focus.

A reduced likelihood of accessing services may also result from negative externalities. Health system inputs (as indicated by health expenditure) and gatekeeping are also observed to have an impact on access, specifically for those diagnosed with dementia. This provides further evidence to support the World Health Organisation notion of a growing gap between burden of disease and budget allocation (Saxena et al. 2007). Should resource allocation indeed not be meeting the disease burden caused by dementia, situations such as comorbid depression necessitate measures to ensure enhanced access is elicited for the enhanced need.

Assuming the hurdle of accessing services is overcome, depression is found to significantly increases the level of care consumed correlating to an incremental gain of 39% compared with the control group. The evidence suggests depression coexisting with dementia has a multiplicative effect. Comorbid depression is shown to exacerbate cognitive and functional impairment (Lyketsos and Lee 2004) and these results show a direct impact on formal services use. Therefore, improving screening and treating depression in dementia is likely to enhance patient care, improve health outcomes and ultimately reduce expenditure.
In summary, the associated effect of depression in dementia on health care utilisation indicates that screening for depression should form part of routine dementia care whilst improved management of depression may help rationalise growing expenditure on dementia care.

**Policy Implication:** Comorbid depression affects half of all people with dementia and once service is accessed, increases services usage. Identifying depression in dementia should form part of routine management and active follow-up is required in individuals with depression.

**Dissemination Strategy:** The working paper entitled ‘Depression in dementia and the effects on health care utilisation: Evidence from SHARE’ has been submitted for peer review to a leading health economics journal. The paper has also been submitted for discussion by the Health Economists Study Group and the annual meeting of the International Centre for Mental Health Policy and Economics.

**Further Research:** Depression in dementia is a severe complication which is found to significantly reduce the likelihood of accessing appropriate services and the existence of which suggests the desirability of screening for depression in dementia.
Bibliography


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Appendices
Appendix 1: A Carer’s Survey – The Questionnaire
Alzheimer's Disease Research Questions
Draft Questionnaire 21 January 2006

Please complete this questionnaire using black ink and by ticking the box(es) for each question or writing in where appropriate. Some questions require just one answer or tick, for others you can give more than one answer.

Carer Information

Q1. Which gender are you?
Male □
Female □

Q2. In which of the following age groups do you belong? Please tick one box only.
Under 35 years old □
35 – 44 years old □
45 – 54 years old □
55 – 64 years old □
65 – 74 years old □
75 – 84 years old □
85 or over □

Q3. What region of Ireland do you live in?
Dublin □
Leinster (outside Dublin) □
Munster □
Connaught / Ulster □

Q4. What is the relationship of the person with Alzheimer’s disease / dementia to you? Please tick one box only.
Spouse/partner □
Father/mother □
Father in law/mother in law □
Spouse/partner □
Friend □
Other relative □
Other, please write in …………………………………….

I am a professional carer □

Q5. What is your employment status? Please tick one box only.
Working in paid employment full-time □
Working in paid employment part-time □
Retired/not working □
Not working owing to carer role □
Not in paid employment for another reason □
Other, please write in …………………………………….

Q6. Do you feel you have sufficient income to look after the person with Alzheimer’s disease or not?
Yes – definitely □
Yes – probably □
No – probably not □
No definitely not □
Don’t know □
Q7. Approximately how many hours per day do you spend caring for the person with Alzheimer’s disease / dementia? Please tick one box only.

- Less than 2 hours per day
- Between 2 and less than 4 hours per day
- Between 4 and less than 6 hours per day
- Between 6 and less than 8 hours per day
- Between 8 and less than 10 hours per day
- Between 10 and less than 12 hours per day
- Between 12 and less than 14 hours per day
- 14 hours per day or more

Q8. Have you received any kind of training or education on to how to care for someone with Alzheimer’s disease dementia?

- Yes
- No

Q9. If yes, where did you get this training or education?

- Hospital
- Nurse/Public Health Nurse
- HSE Home Help Service
- Carers Organisations
- GP/doctor
- Alzheimer Society
- Friend/family member
- Other carers
- Books/Internet/reading
- Other (Please specify) ………………………………………..

Q10. Would you like to receive training or education?

- Yes
- No

Patient Information

Q11. Which gender is the person with Alzheimer’s disease / dementia?

- Male
- Female

Q12. In which age group does the person with Alzheimer’s disease / dementia belong? Please tick one box only.

- Under 35 years old
- 35 – 44 years old
- 45 – 54 years old
- 55 – 64 years old
- 65–74 years old
- 75–84 years old
- 85 or over
Q13. Has the person been informed about his/her condition?

Yes ☐ No ☐

Q14. By whom has the person been informed? Please tick one box only.

- You yourself ☐
- GP/Primary care physician ☐
- Hospital doctor ☐
- Neurologist ☐
- Family member ☐
- Geriatrician ☐
- Old age Psychiatrist ☐
- Psychiatrist ☐
- Psychiatric nurse ☐
- I don’t know ☐
- Other, please write in ………………

Q15. Where does the person with Alzheimer’s disease / dementia generally live? Please tick one box only.

- At home ☐
- In a nursing/residential home ☐
- Other, please write in …………………………………

Q16. Do you live with this person?

Yes ☐ No ☐

Q17. Has the person you care for ever been in a hospital or nursing home with issues related to their Alzheimer’s disease / dementia?

Yes ☐ No ☐

If yes, how long did they spend in hospital? ……………………………

Q18. Has the person you care for ever been in hospital or nursing home because of issues related to caring such as?

- Carer unwell ☐
- Carer requires break/holiday ☐
- Other ☐

Q19. Would you consider long-term care in a nursing home for this person?

- Definitely would consider ☐
- Probably would consider ☐
- Might or might not consider ☐
- Probably would not consider ☐
- Definitely would not consider ☐
- Don’t know ☐
Patient Information – when first diagnosed

Q20. What first prompted you or the person with Alzheimer’s disease / dementia to seek help?
Please tick all that apply.

( Difficulties with household activities and daily tasks)
- Cleaning
- Cooking
- Dressing
- Shopping
- Getting to the toilet
- Showering/bath/wash
- Incontinence
- Eating/ drinking
- Loss of appetite
- Sleeping
- Finding belongings
- Being left alone
- Financial activities

( Difficulties with memory/attention/mood)
- Wandering/restlessness
- Memory/confusion
- Concentration/attention
- Orientation/getting lost
- Lack of energy/apathy
- Depression
- Irritability
- Inhibition/poor self control
- Personality changes/mood swings
- Agitation/aggression

( Difficulties with mobility (physical and mechanical))
- Standing up
- Moving in general
- Travelling outside home
- Driving a vehicle

( Difficulties with communication/speech/social activities)
- Comprehension of language
- Speaking
- Following conversation
- Writing/reading
- Group activities
- Hobbies/interests
- Social withdrawal
- Recognising people
- Using the telephone

Q21. Where was the person with Alzheimer’s disease / dementia first diagnosed?
Please tick one box only.

- GP/primary care practice
- Hospital
- Memory Clinic
- Private Clinic
- Other
- I don’t know
Q22. Who first made the diagnosis of dementia? Please tick one box only.

Neurologist
Geriatrician
Old age psychiatrist
Psychiatrist
Psychiatric nurse
Hospital doctor
Other, please write in: ..............................................

I don’t know
GP/primary care physician

Q23. Did you get a referral from a GP/primary care physician to see this person?

No
Yes

Q24. How long was the time from the first visit to the GP/primary care physician to the actual meeting with the person that made the diagnosis? Please tick one box only.

1 week or less
Between 1 week and less than 4 weeks
Between 4 weeks and less than 2 months
Between 2 months and less than 6 months
Between 6 months and less than 1 year
1 year or more
I don’t know

Q25. At the time of diagnosis, which stage or severity of Alzheimer’s disease/dementia did the doctor say the person was experiencing? Please tick one box only.

Early stage/mild
Middle stage/moderate
Late stage/severe
No stage/severity was mentioned
I don’t know

Q26. What length of time has passed since the person with Alzheimer’s disease/dementia was diagnosed with the condition? Please tick one box only.

1 month or less
Between 1 month and less than 6 months
Between 6 months and less than 1 year
Between 1 year and less than 2 years
Between 2 years and less than 4 years
4 years or more
I don’t know

Q27. What information, if any, did you, the caregiver, receive about the condition upon diagnosis? Please tick all that apply.

Information about:
Alzheimer’s
Dementia
Disease progression
Drug treatments
Alzheimer Society of Ireland
Other help/support groups available

Legal rights and issues
Services available
Advance planning
Driving
None/nothing
Other, please write in: .........................
Q28. Are you generally satisfied or dissatisfied with the information you received about Alzheimer’s disease / dementia following the diagnosis? Please tick only one box.

- Very satisfied
- Fairly satisfied
- Neither satisfied nor dissatisfied
- Fairly dissatisfied
- Very dissatisfied
- I did not receive any information

Q29. How, if at all, could the information be improved? Please tick all that apply

- More practical information on help/services
- More medical information
- Less technical information
- To be easier to understand
- More comprehensive information
- Less information (as information overload)
- Other, please write in ……..

Q30. What information would you have liked that you did not receive? Please tick all that apply.

Information about:
- Alzheimer’s
- Dementia
- Disease progression
- Drug treatments
- Alzheimer Society of Ireland
- Services available
- Advance planning
- Driving
- None/nothing
- Other help/support groups available
- Other, please write in:……………………
- Legal rights and issues

Patient Information – Current condition

Q31. Which stage or severity of Alzheimer’s disease / dementia has the doctor indicated the person is currently experiencing? Please tick one box only.

- Early stage/mild
- Middle stage/moderate
- Late stage/severe
- No stage/severity was mentioned
- I don’t know/ can’t remember
Q32. Which symptoms is the person with Alzheimer’s disease / dementia currently demonstrating/experiencing? Please tick all that apply.

<table>
<thead>
<tr>
<th>(Difficulties with household activities and daily tasks)</th>
<th>(Difficulties with mobility (physical and mechanical))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleaning</td>
<td>Standing up</td>
</tr>
<tr>
<td>Cooking</td>
<td>Moving in general</td>
</tr>
<tr>
<td>Dressing</td>
<td>Travelling outside home</td>
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<tr>
<td>Shopping</td>
<td></td>
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<tr>
<td>Getting to the toilet</td>
<td></td>
</tr>
<tr>
<td>Showering/bath/wash</td>
<td>Driving a vehicle</td>
</tr>
<tr>
<td>Incontinence</td>
<td></td>
</tr>
<tr>
<td>Eating/ drinking</td>
<td>(Difficulties with communication/speech/social activities)</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>Comprehension of language</td>
</tr>
<tr>
<td>Sleeping</td>
<td>Speaking</td>
</tr>
<tr>
<td>Finding belongings</td>
<td>Following conversation</td>
</tr>
<tr>
<td>Being left alone</td>
<td>Writing/reading</td>
</tr>
<tr>
<td>Financial activities</td>
<td>Group activities</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>(Difficulties with memory/attention/mood))</td>
<td></td>
</tr>
<tr>
<td>Wandering/restlessness</td>
<td></td>
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<tr>
<td>Memory/confusion</td>
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<tr>
<td>Concentration/attention</td>
<td></td>
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<tr>
<td>Orientation/getting lost</td>
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<tr>
<td>Lack of energy/apathy</td>
<td></td>
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<tr>
<td>Depression</td>
<td></td>
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<tr>
<td>Irritability</td>
<td></td>
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<tr>
<td>Inhibition/poor self control</td>
<td></td>
</tr>
<tr>
<td>Personality changes/mood swings</td>
<td></td>
</tr>
<tr>
<td>Agitation/aggression</td>
<td></td>
</tr>
</tbody>
</table>

Q33. Which five symptoms of the list below are the most problematic for you? Please tick FIVE symptoms ONLY from the whole list.

<table>
<thead>
<tr>
<th>(Difficulties with household activities and daily tasks)</th>
<th>(Difficulties with mobility (physical and mechanical))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleaning</td>
<td>Standing up</td>
</tr>
<tr>
<td>Cooking</td>
<td>Moving in general</td>
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<tr>
<td>Dressing</td>
<td>Travelling outside home</td>
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<tr>
<td>Shopping</td>
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<tr>
<td>Getting to the toilet</td>
<td></td>
</tr>
<tr>
<td>Showering/bath/wash</td>
<td>Driving a vehicle</td>
</tr>
<tr>
<td>Incontinence</td>
<td>(Difficulties with communication/speech/social activities)</td>
</tr>
<tr>
<td>Eating/ drinking</td>
<td>Comprehension of language</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>Speaking</td>
</tr>
<tr>
<td>Sleeping</td>
<td>Following conversation</td>
</tr>
<tr>
<td>Finding belongings</td>
<td>Writing/reading</td>
</tr>
<tr>
<td>Being left alone</td>
<td>Group activities</td>
</tr>
<tr>
<td>Financial activities</td>
<td></td>
</tr>
<tr>
<td>(Difficulties with memory/attention/mood))</td>
<td></td>
</tr>
<tr>
<td>Agitation/aggression</td>
<td></td>
</tr>
<tr>
<td>Wandering/restlessness</td>
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<tr>
<td>Memory/confusion</td>
<td></td>
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<tr>
<td>Concentration/attention</td>
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<tr>
<td>Orientation/getting lost</td>
<td></td>
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<tr>
<td>Lack of energy/apathy</td>
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<tr>
<td>Depression</td>
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<tr>
<td>Irritability</td>
<td></td>
</tr>
<tr>
<td>Inhibition/poor self control</td>
<td></td>
</tr>
<tr>
<td>Personality changes/mood swings</td>
<td></td>
</tr>
</tbody>
</table>
Patient Information – Treatments and techniques

Q34. Which, if any, anti-Alzheimer’s/dementia medicine was the person with the condition first prescribed? Please tick all that apply.

- Aricept/donepezil
- Ebixa/memantine
- Exelon/rivastigmine
- Reminyl/galantamine
- Other, please write in ……………………
- No medicine prescribed
- I don’t know

Q35. How long after diagnosis was an anti-Alzheimer’s medicine prescribed? Please tick one box only.

- At the time of diagnosis
- Within a week
- Within a month
- Within three months
- Within six months
- Within a year
- Over a year
- I don’t know

Q 36a. Is the person currently taking an anti-Alzheimer’s/dementia medicine? Everyone please answer this question.

- Yes
- No
- I Don’t know

Go to Q36b

Q36b. If yes, which type?

- Aricept/donepezil
- Ebixa/memantine
- Exelon/rivastigmine
- Reminyl/galantamine
- I don’t know

- Other, please write in ……………………
Q37. If anti-Alzheimer’s/dementia medicine is being used, which symptoms, if any, have improved or stabilised? Please tick all that apply.

- **(Difficulties with household activities and daily tasks)**
  - Cleaning
  - Cooking
  - Dressing
  - Shopping
  - Getting to the toilet
  - Showering/bath/wash
  - Incontinence
  - Eating/ drinking
  - Loss of appetite
  - Sleeping
  - Finding belongings
  - Being left alone
  - Financial activities

- **(Difficulties with memory/attention/mood)**
  - Wandering/restlessness
  - Memory/confusion
  - Concentration/attention
  - Orientation/getting lost
  - Lack of energy/apathy
  - Depression
  - Irritability
  - Inhibition/poor self control
  - Personality changes/mood swings
  - Agitation/aggression

- **(Difficulties with mobility (physical and mechanical))**
  - Standing up
  - Moving in general
  - Travelling outside home
  - Driving a vehicle

- **(Difficulties with communication/speech/social activities)**
  - Comprehension of language
  - Speaking
  - Following conversation
  - Writing/reading
  - Group activities
  - Hobbies/ interests
  - Social withdrawal
  - Recognising people
  - Using the telephone

Q38. Have any of the following methods helped alleviate some of the symptoms of Alzheimer’s disease/dementia?

- Involving person in favourite activities
- Distraction techniques
- Music
- Social contact
- Memory aids
- Reminiscing
- Exercise
- Other (please comment) ____________________________________________
### Q39a. Which of the services listed below are available to you, and which services do you use? Please tick all that apply.

<table>
<thead>
<tr>
<th>List of services</th>
<th>Services available</th>
<th>Services Used</th>
<th>ASI</th>
<th>HSE</th>
<th>Carers Orgs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mutual or peer group support</td>
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<tr>
<td>Befriending</td>
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<tr>
<td>Information and emotional support</td>
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<tr>
<td>Counselling</td>
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<tr>
<td>Training for carers</td>
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<tr>
<td>Supported holidays</td>
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<tr>
<td>Day care</td>
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<tr>
<td>Home support</td>
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<tr>
<td>Respite care</td>
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<tr>
<td>Carer support groups</td>
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<tr>
<td>Residential/nursing home care</td>
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<tr>
<td>Hospital care</td>
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<tr>
<td>GP/doctor</td>
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<tr>
<td>Hospice care</td>
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</tbody>
</table>
Q40. Who is paying for these services? Please tick all that apply.

<table>
<thead>
<tr>
<th>List of services</th>
<th>The patient</th>
<th>You, the carer</th>
<th>Insurance</th>
<th>Publicly funded</th>
<th>Family/friend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mutual or peer group support</td>
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<tr>
<td>Befriending</td>
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<td>Information and emotional support</td>
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<td>Counselling</td>
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<td>Training for family carers</td>
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<td>Supported holidays</td>
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<td>Day care</td>
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<td>Hospital care</td>
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<td>GP/doctor visits</td>
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<tr>
<td>Hospice care</td>
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</tr>
</tbody>
</table>

Q41. What, if any, sources of information do you use to keep up to date with issues relating to Alzheimer’s disease /dementia. Please tick all that apply.

<table>
<thead>
<tr>
<th>Source of information</th>
<th>The Internet</th>
<th>TV/radio</th>
<th>Newspaper/journals/magazines</th>
<th>Specific dementia literature</th>
<th>Other, please write in…………………………</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP/ primary care physician</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Neurologist</td>
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<tr>
<td>Geriatrician</td>
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<tr>
<td>Old age psychiatrist</td>
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<tr>
<td>Psychiatrist/</td>
<td></td>
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<tr>
<td>psychiatric nurse</td>
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</tbody>
</table>
Q42. In the table below, please indicate any/all of the statements that you feel apply to you by ticking the relevant boxes. Please tick all that apply.

<table>
<thead>
<tr>
<th>Statement</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I have had to pay medical costs (including medication) for the person with Alzheimer’s disease / dementia</td>
<td>□</td>
</tr>
<tr>
<td>I have had to pay for additional help to care for the person with Alzheimer’s disease / dementia (e.g. cleaner, solicitor etc)</td>
<td>□</td>
</tr>
<tr>
<td>I have managed to continue working the same number of hours and care for the person with Alzheimer’s disease / dementia</td>
<td>□</td>
</tr>
<tr>
<td>I have had to reduce the number of hours I work to care for the person with Alzheimer’s disease / dementia:</td>
<td></td>
</tr>
<tr>
<td>I now work less than 10 hours per week</td>
<td>□</td>
</tr>
<tr>
<td>I now work between 10 and 19 hours per week</td>
<td>□</td>
</tr>
<tr>
<td>I now work between 20 and 29 hours per week</td>
<td>□</td>
</tr>
<tr>
<td>I now work between 30 and 39 hours per week</td>
<td>□</td>
</tr>
<tr>
<td>I now work 40 or more</td>
<td></td>
</tr>
<tr>
<td>I have had to stop work to care for the person with Alzheimer’s disease / dementia</td>
<td>□</td>
</tr>
<tr>
<td>I do not work anymore/ retired</td>
<td>□</td>
</tr>
</tbody>
</table>

Q43. Please indicate how much you agree or disagree with the statements below, by ticking the relevant boxes.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The level of care for the elderly is good in Ireland</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Caring for the elderly is a public matter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Services available are sufficient for my needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The quality of services available is very high</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The cost of health care is reasonable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The cost of health care and services should be covered by society</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Thank you very much for taking the time to complete this questionnaire. Your views are very important to us.

If you would like a copy of the report of the research results sent directly to you, please complete the information required below.

This information will be held in confidence in the Alzheimer Society of Ireland National Office and will not be shared with any outside sources.

Name: ____________________________________________
Address: __________________________________________

________________________________________
Appendix 2: Calculation of the Proxy Market Value

Provided below is the calculation of the cost to replace one informal carer with a formal care assistant provided by the HSE. The approach used to obtain the replacement cost is as defined in the Guidelines for the Economic Evaluation of Health Technologies in Ireland, 2010.\textsuperscript{53}

Calculation:

**Care Assistance Salary:** A care assistant (intellectual disability agencies) has a pay scale ranging from: €26,590 to €36,680 as indicated in Pay-scales for public sector\textsuperscript{54} (Jan 2010). The midpoint on the scale (sixth of eleven on the scale) is taken as the consolidated salary:

\[ \text{€31,942 Per Annum} \]

Non-pay costs are calculated in accordance with the approach outlined in Regulatory Impact Analysis (RIA) guidelines.\textsuperscript{55}

**Direct salary cost:** Direct cost calculates the midpoint salary inclusive of PRSI contribution:

\[ \text{€31,942 + 10.75\% (31,942) = €35,375.765} \]

\textsuperscript{53} Guidelines for the Economic Evaluation of Health Technologies in Ireland, 2010. Available at www.hiqa.ie
**Total Salary Cost:** Total salary is direct salary plus imputed pension cost (based on salary midpoint):

- Direct Salary + Employer PRSI
- $35,375.765 + 13.1\% \ (31,942)$
- $35,375.765 + 4,184.402$
- $39,560.167$

**Total Staff Cost:** Total staff cost is total salary cost plus overheads (e.g. rent, light and heat, office facilities, telephone, general supplies), which is calculated at 40% of salary:

- Total Salary Cost + Overheads (40% of Salary)
- $39,560.167 + 40\% \ (31,942)$
- $39,560.167 + 12,776.8$
- €52,336.967 per annum

So the cost of employing an additional care assistant per year is **€52,336.967**

**Daily rate:** Assumes general employment of 242 days per year minus leave (RIA):

- Annual Staff cost/(249 – annual leave entitlement)
- $52,336.967/(249 – 25*)$
- $52,336.967/224$
- €233.65 per day

**Hourly rate:** Assumes 6.95 hours in the working day (RIA):

- Annual Staff cost/(249 – annual leave entitlement) x 6.95
- $52,336.967/224 \times 6.95$
- $52,336.967/1,556.8$
- €33.62 per hour
Appendix 3: Analysis of the Opportunity Cost of Informal Care

This thesis calculates the informal costs of dementia care using a proxy-good method. Ideally, for completeness, this research thesis should have also calculated the opportunity cost associated with providing informal care. This method would value the hours of foregone earnings.

To calculate foregone earnings, ASI 2007 contained the following questions:

The first two options relate to paying costs related to care whilst the remaining options would be ideal for calculating an opportunity cost at the individual level. However, Q42 is essentially related to two forms of financial impact (outgoing and income). In the section related to employment, the term ‘working’ is used and may therefore relate to employment or other perceived forms of work (e.g. housework or informal care).

The following table presents results from answers to Q42 cross referenced with employment status (as stated in Q5) producing 225 responses with potential for calculating an opportunity cost of informal care.
To a great extent these results demonstrate that there is agreement between whether the individual was in employment (Q5) and Q42 inferring that each question is consistently answered. However, constructing an opportunity cost based on the data available will require several assumptions:

**Assumption 1:** The first major assumption is that the term ‘work’ solely relates to labour force participation. Referring to the earlier discussion, women married before 1973 would have been encouraged to resign to raise a family and therefore ‘work’ for these individuals will naturally have a very different interpretation.

**Assumption 2:** As Q5 only collects current working status, the employment status prior to starting informal care would require the assumption of being the same as the current status in Q5. On this assumption, all those individuals stating full employment worked 40 hours per week and likewise part-timers work 25 hours per week.

If the data is broken down further into by all employment categories in Q5 (see table A3.2 below), the need for further assumptions become apparent. Specifically, two problems must be considered. Firstly, does the part-time group indicate a reduction in hours of work to part-time time from full time or further reduction in part-time employment? Secondly, of the resigned group 36 indicate stopping working to care and 19 indicate resignation to retirement; this raises a further question of whether resigning in order to care is consistent across all groups.
Table A3.2: Frequency of work related change by stated employment status

<table>
<thead>
<tr>
<th></th>
<th>Full-Time</th>
<th>Part-Time</th>
<th>Retired</th>
<th>Resigned</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stopped work to care</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>36</td>
<td>40</td>
</tr>
<tr>
<td>Retired</td>
<td>1</td>
<td>0</td>
<td>89</td>
<td>19</td>
<td>109</td>
</tr>
<tr>
<td>Same number of hours</td>
<td>12</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>19</td>
</tr>
<tr>
<td>Now work less than 10h</td>
<td>0</td>
<td>6</td>
<td>1</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Now work between 10 and 19h</td>
<td>2</td>
<td>14</td>
<td>1</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>Now work between 20 and 29h</td>
<td>2</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Now work between 30 and 39h</td>
<td>7</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Now work 40 or more hours</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>31</strong></td>
<td><strong>33</strong></td>
<td><strong>97</strong></td>
<td><strong>63</strong></td>
<td><strong>224</strong></td>
</tr>
</tbody>
</table>

This analysis justifies the use of symptom-based proxies to explain informal care time and the above examples explain the complexities in employment status and the need for the employment-cohabitation interaction terms.

**Assumption 3:** Finally, should meaningful data be taken on the change in employment from ASI 2007 as no data was collected on the nature of employment? This therefore calls for more routine assumptions of individual wage rate. Various arguments can be made about which cost weight should be applied and given the randomisation of individuals within a cost-effectiveness analysis; it is generally acceptable to apply a minimum or average wage rate. However, these types of assumptions are likely to provide minimal values for informal care and may not capture the true opportunity cost of the individual’s time.

It was therefore concluded that a formal analysis of opportunity cost was not feasible using the ASI 2007 data for reasons of comparison with the informal cost by proxy-good.
Appendix 4: Table of Health Expenditure (OECD 2008)

Table A4.1: Health expenditure data used in Figure 2 [Source: OECD 2008].

<table>
<thead>
<tr>
<th>Country</th>
<th>Public</th>
<th>Private</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>7.544</td>
<td>8.856</td>
<td>16.4</td>
</tr>
<tr>
<td>France</td>
<td>8.6247</td>
<td>2.4753</td>
<td>11.1</td>
</tr>
<tr>
<td>Germany</td>
<td>8.1962</td>
<td>2.5038</td>
<td>10.7</td>
</tr>
<tr>
<td>Switzerland</td>
<td>6.3665</td>
<td>4.3335</td>
<td>10.7</td>
</tr>
<tr>
<td>Austria</td>
<td>8.0288</td>
<td>2.3712</td>
<td>10.4</td>
</tr>
<tr>
<td>Canada</td>
<td>7.2615</td>
<td>3.0385</td>
<td>10.3</td>
</tr>
<tr>
<td>Denmark</td>
<td>8.7241</td>
<td>1.5759</td>
<td>10.3</td>
</tr>
<tr>
<td>Belgium</td>
<td>7.575</td>
<td>2.525</td>
<td>10.1</td>
</tr>
<tr>
<td>Portugal</td>
<td>6.5751</td>
<td>3.5249</td>
<td>10.1</td>
</tr>
<tr>
<td>Netherlands</td>
<td>6.1875</td>
<td>3.7125</td>
<td>9.9</td>
</tr>
<tr>
<td>New Zealand</td>
<td>7.7088</td>
<td>1.8912</td>
<td>9.6</td>
</tr>
<tr>
<td>Sweden</td>
<td>7.498</td>
<td>1.702</td>
<td>9.2</td>
</tr>
<tr>
<td>Iceland</td>
<td>7.5166</td>
<td>1.5834</td>
<td>9.1</td>
</tr>
<tr>
<td>Italy</td>
<td>6.975</td>
<td>2.025</td>
<td>9</td>
</tr>
<tr>
<td>Spain</td>
<td>6.534</td>
<td>2.466</td>
<td>9</td>
</tr>
<tr>
<td>OECD Average</td>
<td>6.44436</td>
<td>2.55564</td>
<td>9</td>
</tr>
<tr>
<td>Ireland</td>
<td>6.7496</td>
<td>2.0504</td>
<td>8.8</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>7.2512</td>
<td>1.5488</td>
<td>8.8</td>
</tr>
<tr>
<td>Australia</td>
<td>5.916</td>
<td>2.784</td>
<td>8.7</td>
</tr>
<tr>
<td>Norway</td>
<td>7.2498</td>
<td>1.3502</td>
<td>8.6</td>
</tr>
<tr>
<td>Japan</td>
<td>6.868</td>
<td>1.632</td>
<td>8.5</td>
</tr>
<tr>
<td>Finland</td>
<td>6.2496</td>
<td>2.1504</td>
<td>8.4</td>
</tr>
<tr>
<td>Slovenia</td>
<td>6.1656</td>
<td>2.2344</td>
<td>8.4</td>
</tr>
<tr>
<td>Slovak Republic</td>
<td>5.424</td>
<td>2.576</td>
<td>8</td>
</tr>
<tr>
<td>Israel</td>
<td>4.4968</td>
<td>3.2032</td>
<td>7.7</td>
</tr>
<tr>
<td>Chile</td>
<td>3.3</td>
<td>4.2</td>
<td>7.5</td>
</tr>
<tr>
<td>Hungary</td>
<td>5.112</td>
<td>2.088</td>
<td>7.2</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>5.8575</td>
<td>1.2425</td>
<td>7.1</td>
</tr>
<tr>
<td>Poland</td>
<td>5.054</td>
<td>1.946</td>
<td>7</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>5.7188</td>
<td>1.0812</td>
<td>6.8</td>
</tr>
<tr>
<td>Korea</td>
<td>3.6335</td>
<td>2.8665</td>
<td>6.5</td>
</tr>
<tr>
<td>Estonia</td>
<td>4.7458</td>
<td>1.3542</td>
<td>6.1</td>
</tr>
<tr>
<td>Turkey</td>
<td>4.453</td>
<td>1.647</td>
<td>6.1</td>
</tr>
<tr>
<td>Mexico</td>
<td>2.7202</td>
<td>3.0798</td>
<td>5.8</td>
</tr>
<tr>
<td><strong>OECD Average</strong></td>
<td><strong>6.315457647</strong></td>
<td><strong>2.534542353</strong></td>
<td><strong>8.85</strong></td>
</tr>
</tbody>
</table>