# Developing approaches to measure dependency across different domains of need in later life: an exploration of the relationship between need and care receipt using the English Longitudinal Study of Ageing

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# List of Abbreviations

AoN	Array of Need
AoN-ADL	ELSA-derived AoN ADL domain
AoN-MHW	ELSA-derived AoN MHW domain
AoN-PC	ELSA-derived AoN PC domain
ADL	activities of daily living
BHPS	British Household Panel Survey
BIC	Bayes Information Criteria
CANE	Camberwell Assessment of Need for the Elderly
CES-D	Center for Epidemiologic Studies Depression Scale
CFAS	Cognitive Function and Ageing Studies
CHS	Continuous Household Survey
CI	confidence intervals
DAMES	Data Management through e-Social Science
DoH	Department of Health
EDA	exploratory data analysis
ELSA	English Longitudinal Study of Ageing
ELSA-IoRN	IoRN framework applied to ELSA
ESRC	Economic and Social Research Council
GHS	General Household Survey
GP	general practitioner
HAGIS	Healthy Ageing in Scotland study
HSE	Health Survey for England
IADL	instrumental activities of daily living
IoRN	Indicator of Relative Need
IoRN-ADL	IoRN-specified collective grouping of ADL needs
IoRN-BM	IoRN-specified collective grouping of dependency in bowel management
IoRN-MHW	IoRN-specified collective grouping of mental health and wellbeing needs
IoRN-PC	IoRN-specified collective grouping of personal care needs
ISD	Information Services Division (NHS Scotland)
JIT	Joint Improvement Team
JFG	Joint Future Group
КМО	Kaiser-Meyer-Olkin
LA	local authority
MHW	mental health and Wellbeing domain
Mobility	functional mobility difficulty items
NICOLA	the Northern Ireland Cohort for Longitudinal Study of Ageing
NHS	National Health Service
ONS	Office for National Statistics
OR	odds ratios
NSSEC	National Statistics Socio-economic Classification
PCA	principal components analysis
RRR	relative risk ratio
RUM	Resource Use Measure
SHARE	Survey of Health, Ageing and Retirement in Europe (study)
SE	standard errors
SES	socio-economic status
SSA	single shared assessment
TILDA	the Irish Longitudinal Study on Ageing
VIF	variance inflation factor

# Abstract

This thesis explores the relationship between the needs people experience in later life and the types of care they receive. The thesis provides evidence on the role of different types of care in supporting the needs of people aged 60+ in England using the English Longitudinal Study of Ageing (ELSA). The research presented adopts a number of new approaches to capturing the multi-dimensional nature of dependency by utilising a range of binary indicators of difficulty performing 10 actions related to upper and lower body mobility, 6 activities of daily living (ADL) and 7 instrumental activities of daily living (IADL). The thesis provides a detailed analysis of the prevalence of these items when considered independently and collectively in combination. A central aim of the research is to develop a more nuanced understanding of dependency to allow for the dimensionality of the needs experienced by older people living in their own homes to be considered. The thesis utilizes a number of different approaches, including simple binary and count-based indicators of need and more complex measures reflecting dependency across different domains of need. These approaches allow a more dynamic picture of dependency in later life to be considered.

Using these measures, the research explores the role of different types of care in meeting different types of need. Of these, a unique application of an existing assessment tool is presented, the Indicator of Relative Need (IoRN), which is used as a framework to derive an equivalent measure – the Array of Need (AoN). Given the aim of the study is to investigate the multi-dimensional nature of dependency, various data reduction approaches are used including principal components analysis. Finally, research from similar studies is acknowledged and work from the Survey of Health, Ageing and Retirement in Europe (SHARE) study is reproduced using ELSA. The thesis suggests that when considering the dependency needs experienced by older people living in the community, it is important to be aware that this group includes both less and more dependent older people. As such, developing a better understanding of the dynamic relationship between dependency and the receipt of informal and formal care may require more suitable measurements of dependency.

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Use of the English Longitudinal Study of Ageing (Marmot et al, 2014) data:-

The data were made available through the UK Data Archive. ELSA was developed by a team of researchers based at the NatCen Social Research, University College London and the Institute for Fiscal Studies. The data were collected by NatCen Social Research. The funding is provided by the National Institute of Aging in the United States, and a consortium of UK government departments co-ordinated by the Office for National Statistics. The developers and funders of ELSA and the Archive do not bear any responsibility for the analyses or interpretations presented here.

# Chapter 1 1. <u>Introducing the research project and research design</u>

## **1.1. Introduction to the research**

This thesis explores the relationship between the needs people experience in later life and the types of care they receive. The thesis provides evidence on the role of different types of care in supporting the needs of people aged 60+ in England using the English Longitudinal Study of Ageing (ELSA). The research presented adopts a number of new approaches to capturing the multi-dimensional nature of dependency, utilising a range of binary indicators of difficulty performing 10 actions related to upper and lower body mobility, 6 activities of daily living (ADL) and 7 instrumental activities of daily living (IADL). The thesis provides a detailed analysis of the prevalence of this range of items, considered both individually and together in combination. A central aim of the research is to develop a more nuanced understanding of dependency, allowing for the dimensionality of dependency experienced by older people living in their own homes to be considered. The thesis utilizes 8 different approaches to consider the dimensionality of need, moving from binary and count-based indicators, to the construction of more complex measures allowing for dependency across a range of domains to be taken into account simultaneously, providing a more dynamic construct of need. This chapter begins by providing an outline of the background to the research providing the research context, research aims and an overview of the thesis, before presenting a review of literature relating to elder care in the UK.

### 1.1.1. Research context

Estimates of the UK population show that, over the last 50 years there has been a marked increase in the proportion of older people in the UK, associated with gains in life expectancy. Current population projections suggest that, as these trends continue 'by 2034, 23 per cent of the population is projected to be aged 65 and over compared to 18 per cent aged under 16' (ONS, 2010). The population pyramids in Figure 1 show the changing age structure for the UK population from 1971 to 2001, and population projections for 2031 (ONS, 2014).

Figure 1. Age structure for the UK population in 1971, 2001 and population projections for 2031 (based on 2011 census)



Source: Reproduced from ONS, 2014

Figure 1 shows that the number of people aged 65+ is projected to continue expanding over the next 20 years as people live longer, with a significant increase in the number of people aged 80+. Most significantly, as the UK population continues to age, the proportion of people aged 85+ is projected to expand dramatically. Often referred to as the 'oldest old', this group is projected to increase from '1.4 million in 2009 ... [to] 3.5 million [by 2034,] ... accounting for 5 per cent of the total population' (ONS, 2010). The associated growth in life expectancy sees 1 in 3 babies born in 2013 expected to live to age 100 (ONS, 2013). Projections of future demand for elderly care suggest that the number of dependent older people living at home will rise from 2.1 million in 1996 to 3.4 million by 2031, based on the age-dependency rates remaining static (Pickard et al, 2000). In the context of this shift, the impact of providing care for a greater number of frail elderly is likely to increase the burden placed on the provision of both unpaid support and professionally provided care services. Figure 2 shows that over the last 5 years the number of people aged 65+ receiving community-based care declined consistently.

The numbers in Figure 2 suggest that, although more people aged 65+ use these services, as the total numbers using services fall the proportion of people aged 65+ using the services declines (from around 66% of all users of these services in 2008-09 to less than 64% in 2013-14). Further, over the last 3 years the number of people receiving planned contact hours for less than 10

Figure 2. Number of clients receiving community-based services during the financial year, by age group



#### England, 2008-09 to 2013-14

Source: Reproduced from Health and Social Care Information Centre (HSCIC) (2014:44)

hours per week has fallen, while the number of people receiving 10+ hours of home care per week increased (HSCIC, 2014). This reflects a longer-term trend since the early 1990s towards targeting resources towards those people with the highest dependency needs (HoL, 2013:12; Vlachantoni et al, 2011). As formal services become focused towards fewer individuals with relatively high levels of need, there is likely to be an expanding number of older people with less critical needs who are unable to access formal care services.

Data from 2006–08 shows the disability-free life expectancy of someone aged 65 in England was 10.5 years for men and 10.9 years for women (ONS, 2010), highlighting a need to understand the impact that less severe disability and dependency has on the eldest in society when formal services are unavailable or directed elsewhere. For example, the development of age-specific conditions such, as dementia which affects more than 700,000 people in the UK, of which only around 2% are aged below 65 (Bowers et al, 2009:17), places an increased pressure on providers

of unpaid care. In turn, those providing informal care are likely to have their own needs, and this is a particular concern for the very old who provide unpaid care to a dependent partner.

The increasing demand for health and care services in the context of declines in the provision of community-based care services may place burdens on other aspects of care. For example, between the 1980s and 2000s the proportion of people aged 85+ attending an outpatient clinic in the UK doubled (Tomassini, 2006). Altogether, concerns about the current and future care needs of an older UK population in the recent economic climate has seen the demand for care become routinely characterized in public discourse as a potentially unmanageable tax-burden on increasingly limited public funds as greater numbers of dependent older people rely on a smaller number of the working population. However, it has been argued that using the standard agedependency ratio, that is the ratio of working age (16-64) to retirement age (65+) people, reveals little about dependency in and of itself, and more constructive methods might consider the ratio of employed to non-working, regardless of chronological age (Spijker and MacInnes, 2013). However, it is accepted that current arrangements for funding long-term care in England and Wales are unsustainable, and there is consensus on the fact that the system requires reform (Collins, 2009; Dilnot Commission, 2011). Since the ongoing provision of formal care services is highly dependent on the ongoing supply of unpaid care, understanding how the needs of older people are met by formal and informal care becomes important. In particular, it is of interest to consider how the many older people with less critical needs are able to manage and support those needs at home.

#### 1.1.2. Research objectives

The pressures on the future administration and provision of formal care to meet the needs of an ageing UK population is intertwined with the ongoing provision of unpaid care, representing the main and often only source of support for the majority of older people. Understanding the wider continuum of care, therefore, requires acknowledging the interplay between all forms of care, whether these are provided by formal state-funded care services, informally by unpaid help from

family or friends, or by services provided by the voluntary or private sectors. The way in which older people make use of different types of care is fundamentally in response to their needs. As such, a fully informed understanding of how the continuum of care that exists for older people works to support their needs can provide an understanding of how different needs are met by particular types of care. In turn, this can help identify those most at risk of formal care receipt in later life. Developing approaches to understand differences in the types of dependency experienced by older people will enable a better understanding of the dynamics of the wider continuum of care. With this in mind, the research presented in this thesis aims to unpick the multidimensional aspects of dependency as it occurs in later life – focusing specifically on people aged 60-and-older – to better understand how informal, formal and private care respond to different needs differently.

From this starting point, the research has three main but closely interconnected aims:

1. To develop approaches to illustrate and control for the multidimensionality of dependency, providing more nuanced measures with which to explore the relationship between need and care in later life;

2. To explore how different types of need influence the likelihood of receiving different types of care;

3. To focus on the dynamics of different types of care within the wider continuum of care for older people, particularly focusing on the role of informal care as the predominate source of care for older people, to identify whether unpaid, private and formal care are complementary or substitute for each another.

By seeking to account for the dimensionality of need, the research is unique in taking a more holistic approach to capturing both a broader range of needs and the links to a wider range of care, employing various methodological approaches to investigate these aims.

A primary aim of the research is to develop indicators of dependency allowing for the multidimensional nature of need to be captured. Initially aiming to understand the differences between particular difficulties experienced in old age, the thesis uses the English Longitudinal

Study of Ageing (ELSA) to provide a detailed exploratory analysis of the characteristics of different types of need. The 3 key 'domains' of need considered cover: activities of daily living (ADL), instrumental activities of daily living (IADL), and functional mobility difficulties (referred to as 'Mobility' throughout). Descriptive analysis of the prevalence of different difficulties – individually and collectively – identifies that attempting to understand dependency requires being able to summarize common characteristics shared by particular needs while retaining the individual characteristics which differentiate particular difficulties from one another. This exploratory analysis provides grounding for adopting approaches to investigate the relationship between needs and care receipt, which enable the multi-dimensional nature of needs to be considered.

The thesis continues by considering the benefits and limitations of different approaches to operationalizing dependency. These approaches include multiple binary indicators reflecting individual difficulties, and continuous and categorical approaches to measure relative complexity of needs across different domains. These are used to unpick the ways in which different types of dependency are met by care from different sources, showing how care from unpaid, formal and private sources vary in the types of support they provide. The analysis suggests that relying on simplified measures of the existence of needs, for example classifying need where a single ADL or IADL difficulty is reported, provides a limited understanding of how care operates in the home. Rather, this analysis confirms that at the interface between dependency and care, not all needs are equal and particular difficulties can have a far greater impact on what care is received than others. Further, the research expands the scope for measuring dependency using a tool developed to compliment the single shared assessment (SSA) process in Scotland – the Indicator of Relative Need (IoRN). The thesis is innovative in uniquely applying the methodology of the IORN framework to the ELSA data, allowing the analysis to simultaneously control for varying levels of need across different domains, and applying a formal assessment tool to understand the needs and care arrangements of older people living at home.

Exploring the relationship between the *need for* and *receipt of* care, the research expands existing research in this area by differentiating between different sources of unpaid care and different types of professional paid care. Making distinctions between dimensions of dependency and the receipt of different types of care, the research aims to provide a picture of the relationship between need and care in later life as *dynamic*. The thesis utilizes the longitudinal nature of ELSA to explicitly model how care is initially received in response to changes in dependency from specific difficulties.

Throughout the thesis, the research takes into account demographic and socio-economic status (SES) factors, including gender, age, household composition, and education. The thesis also presents new methodological approaches to exploring the substitution between formal and informal care, a highly relevant area of research in light of the decline in the number of older people receiving formal care at home (HSCIC, 2014). The analysis of substitution extends on other research in this area, usefully differentiating between commonly conflated state-funded and privately paid professional care services. The research finds that not differentiating between formal and informal care.

#### 1.1.3. Overview of the thesis

The next section begins by defining terms relating to care in the context of this study, providing an overview of existing arrangements for the provision of formal care in the UK, and discusses differences in the assessment and provision of care services across the UK. The chapter then discusses the continuing importance of informal care within existing arrangements for older people, reviewing existing approaches to exploring patterns of care utilisation in later life, and focusing predominately on the relationship between informal and formal care use. The chapter continues by looking at how needs are operationalized in other research, ending with a discussion of the limitations of the existing field of research exploring the relationship between need and care receipt for older people.

Chapter 2 outlines the research aims of the thesis, discusses conceptual frameworks that will be adopted for the analysis presented in the thesis, and considers the range of secondary data sources that are available which could potentially be used to conduct the proposed study. This discussion identifies the English Longitudinal Study of Ageing as the most appropriate data source to conduct the research, presenting descriptive statistics for the key dependent and independent variables that are used in this study. The chapter ends with discussion of methodological approaches and diagnostic methods to be applied when conducting the analysis. Chapter 3 begins with an introduction to the ELSA study, and presents a summary of previous studies relevant to this research, including other studies utilising ELSA to explore aspects of dependency and care for older people. The chapter continues by introducing the key variables — binary indicators of ADL, IADL and Mobility difficulty — that are used to generate measures of dependency throughout this thesis. The chapter continues with in-depth univariate and bivariate descriptive analysis of the characteristics of dependency from ADL, IADL and Mobility difficulties, illustrating key differences in the patterns of prevalence for specific ADL, IADL and Mobility needs as age and dependency increase.

Chapter 4 builds on the descriptive analysis of chapter 3, presenting logistic regression analysis exploring the relationship between dependency and care using the key ADL, IADL, and Mobility measures in different constructions of dependency, comparing the descriptive and analytic benefits and limitations of adopting each approach. The approaches include a full model, exploring the effects of individual difficulties on receipt of different types of care, a metric approach capturing the *degree* of dependency, and a domain-based approach controlling for both the type and level of dependency. The chapter closes with an exploration of transitions in dependency resulting from specific needs, exploring how changes in particular difficulties may affect first receipt of care.

Chapter 5 introduces the Indicator of Relative Need (IoRN), a social care assessment tool used within the social care system in Scotland, as a potential framework for measuring needs across

different domains of need simultaneously. The chapter outlines the development of a new equivalent – the Array of Need (AoN) – following the structure of the IoRN.

Chapter 6 presents logistic regression analysis exploring receipt of care in response to type and level of dependency, using the new IoRN-based AoN measure. The limitations of the AoN measure are discussed, and an expanded multi-domain approach to considering dependency is proposed, using principal components analysis (PCA). PCA methods are then used to test and derive summary measures of relative need in 3 alternative domains – Physical, Cognitive and Mobility dependency – which are then entered in logistic regression modelling.

Chapter 7 focuses on the substitutionary/complementary relationship between informal, formal and private care. The chapter begins with descriptive analysis using the IoRN-based AoN measure, to examine how level of dependency is reflected in concurrent care from multiple sources. The chapter introduces an approach to considering concurrent care, and presents logistic regression analysis exploring how receipt of care from one source affects the likelihood that care will be received from other sources. The chapter continues with an alternate approach to unpicking the relationship between informal and formal care, replicating analysis from a study by Litwin and Attias-Donfut (2009) that used data drawn from the Survey of Health, Ageing and Retirement in Europe (SHARE) study. The similarities between ELSA and the SHARE study provide grounds for a close replication using data from the UK.

Finally, chapter 8 summarises key findings from the preceding chapters, drawing the analysis across the study together, and identifying the contribution the research makes to the field of research. The chapter ends with discussion of the limitations of the research, and considers possible areas where future research could build upon the groundwork established by this thesis in exploring the relationship between dependency and care in later life.

## **1.2.** Care in the UK

This chapter defines the meaning of care in the context of this study, and outlines the arrangements for providing care for older people within the UK. The chapter discusses alternative approaches that have been adopted to meet the needs of older people in the UK, the roles of 2 different aspects of formal care provision – health and social care services – and the impact that a lack of integration has on service users. The chapter continues by examining the role of informal care in current arrangements of care in the UK, discusses how previous research has considered the relationship between informal and formal care, and reviews how previous approaches have attempted to measure need and dependency.

#### 1.2.1. Defining care

This thesis explores how the types of difficulties people experience in later life affect the type of care they receive. The focus of the analysis is older people aged 60+ living at home, who may rely on care from a number of different sources to provide support with their needs. Discussion of how older people use the care available to them must begin with an understanding of how older people are able to access and engage with different types of care. This necessarily requires a clear understanding of what the term care means in the context of this thesis. Care at the most basic level involves the provision of support to those with needs. Within official discourse surrounding future arrangements for caring for older people in England and Wales, the fundamental principles of care are identified as a system to protect the vulnerable, to promote well-being and to maintain dignity in order to allow continued participation in society in later life (Dilnot Commission, 2011). The principle of continued participation in society reflects the importance of independence in maintaining a good quality of life in old age. For example, 'being able to walk and having good mobility ... to continue to be able to do things for themselves, such as shopping and household tasks' (Gabriel and Bowling, 2004:687). The role of care as a system of support for those with continuing care needs may relate to a range of services and systems, provided formally, informally and privately, which are accessible through a number of different channels. For the purposes of this study, the term 'care' refers to the provision of help with common tasks and activities that are likely to be performed on a day-to-day basis.

It is important to note that how need is defined is contested, since needs may exist within the boundary between subjective and objective needs (Asadi-Lari, Packham and Gray, 2003; Bradshaw, 2003). Defining care for the purposes of this thesis therefore necessitates that care be defined as a response to measurable and classifiable needs. Needs considered in this thesis are defined by difficulties with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and mobility impairments. ADLs are core activities that everyone performs 'habitually and universally' (Katz et al, 1963:94) such as eating, using the toilet and taking a bath or shower. IADLs are activities requiring a combination of physical and cognitive capacity that a person could be expected to be able to perform in order to live independently in their own home, such as shopping for groceries, preparing food, and taking medication (Lawton and Brodie, 1969). Mobility impairments relate to upper and lower limb functioning.

In terms of the types of difficulties described, care received to meet these needs may be provided informally, formally, or via self-financed private care and a person may potentially receive care from more than one of these sources at the same time. Some needs experienced by older people fall outside those described, and may require more specialised care from nursing and medical care services. As the focus of this thesis is on care as it is received by older people within their own homes, forms of professional medical care provided by doctors and other medical staff within institutional settings are not considered.

In this thesis, Formal care will refer to any care provided by a local authority (LA), health department or other state-funded source to someone living at home, including registered National Health Service (NHS) nursing, and may cover both personal and/or nursing care. Informal care will refer to any unpaid care provided by family (partners, children, and other family) or friends, most commonly involving help with routine tasks. Private care will refer to any professional care that is paid for by an individual, and may potentially include personal and/or nursing care. To summarise, throughout this thesis the term care refers to any help or support received, provided informally, formally or privately, covering a range of care activities classified as being personal care or nursing care, and delivered to older people living at home. The next

section outlines current arrangements for supplying and funding care for older people within the UK.

### **1.3.** Formal care in the UK

In order to consider the broader context in which different types of care may be received, this section introduces and outlines the current arrangements for providing formal care services for older people in the UK. Contemporary care services for those without chronic-conditions requiring institutional medical care and support are currently focused on providing domiciliary support and services in the home (HSCIC, 2014:53), arrangements for care which commonly rely upon the availability of informal support provided by family and friends (Bell and Bowes, 2006). Such arrangements centred on care in domiciliary settings reflect an attempt to limit the costs of providing care to older people by moving towards a community-care model of care services. The adoption of nationally implemented care-in-the-home policies has been criticised for failing to consider the needs of specific groups of the older population, including people in minority ethnic groups, disabled people, and those with specific conditions such as dementia (Bell et al, 2006:13). Concerns have also been raised that an emphasis on non-institutional care arrangements may lead to traditional forms of long-term care having less emphasis, yet there has been both an increased demand for formal personal care services (Bell et al, 2006), and a decline in the number of older people accessing community-based care services in England (HSCIC, 2014:44). These issues draw attention to the potential disparity between individuals' need for support and their ability to access care resources to meet their own particular needs, whether this is unpaid care, paid domestic help, or formally-provided services such as meals-onwheels. In particular, accessing formal care services may be dependent on local arrangements for the provision of particular services. Regional differences affecting formal service provision may include how needs are assessed, how eligibility criteria for particular services are defined, and in the financial contribution people are required to make towards the care that they receive.

#### 1.3.1. Assessment and eligibility for care services

A key dimension of understanding care for older people is how individuals are able to access formal services since the processes associated with assessment for care services are central to both equity in access to care services and the financial cost of providing formal services. As suggested, current care services in the UK are framed around protecting the most vulnerable and allowing older people to maintain participation in the wider community. However, there is currently regional variation in the administrative, departmental arrangement, financing and availability of formal care provision, both within and between the component countries of the UK, which ultimately affects the degree to which services support such equity (Glendinning et al, 2004). For example, key differences exist between Scotland and the rest of the UK when considering the assessment and eligibility for care services. Within England, there is currently no cohesive system for identifying how individuals' eligibility for care services should be assessed. LAs within England follow a national guideline – the Fair Access to Care Services (FACS) eligibility criteria - to assess level of need according to 4 bands: 'Critical', 'Substantial', 'Moderate', and 'Low' (Social Care Institute for Excellence (SCIE), 2013:8-9). The criteria include an assessment of the degree to which an individual may represent a danger to themselves, and whether they are able to carry out common personal care activities and domestic tasks. However, the criteria do not explicitly define the boundaries between, for example, moderate needs ('inability to carry out several personal care or domestic routines') and substantial needs ('inability to carry out the majority of personal care or domestic routines') (SCIE, 2013:8-9). Currently, LAs are likely to provide care services to support only those with the relatively high needs (e.g. critical or substantial needs), although decisions regarding whether a particular level of need should be met is determined at the LA level.

This identifies a potential source of variation in the way in which needs are structurally prioritised and formal services are provided. Official guidelines on interpreting the national assessment criteria for determining needs confirms a key difference between the potential range of needs which an individual may have ("presenting needs") and the range of needs for

which a given authority's available services may be designed to meet ("eligible needs") (Department of Health (DoH), 2010). In this way, if an individual experiences particular needs which are not 'eligible' then these needs will remain unmet by formal services. This arrangement has resulted in variation in both the assessment process and eligibility criteria by which care services are provided, a framework which has recently been criticised for 'lack[ing] transparency, consistency and clarity' (Dilnot Commission, 2011:15).

This identifies a key factor potentially creating a divergence in equitable access to care services across England, caused by differences in the definitions and processes used to define and assess eligibility criteria. In comparison to the English framework for assessment and eligibility for care services, Scotland provides a more clearly defined framework for the assessment of eligibility for personal care services. Following the recommendation of the Joint Future Group (JFG) in 2002, as part of the implementation of free personal care Scotland introduced a single shared assessment (SSA) process, aiming to adopt a more joined-up approach to delivering the range of health care, social care and housing services in Scotland.

As part of the SSA, a Resource Use Measure (RUM) was developed and implemented, providing a framework for standardising the assessment process and defining eligibility criteria for formal services to support the introduction of the free personal care policy. The RUM has since been superseded by the Indicator of Relative Need (IoRN) tool, which has been implemented within certain LAs across Scotland, including Dumfries and Galloway, Fife and Inverclyde (Joint Improvement Team (JIT), 2012). The IoRN is a tool for assessing dependency in older people, which can be used to evaluate any individuals' degree of dependence, and thus relative need for care, based on explicitly defined criteria. The development and implementation of a nationally standardised framework for assessing need should enable older people across Scotland to be assessed according to the same criteria, regardless of their locality. As such, this approach aims to overcome the potential divergence in service provision due to variation in assessment

procedures resulting from systems such as the FACS eligibility criteria used in the English system. The IoRN may therefore provide greater equity in access to care services in Scotland.<sup>1</sup>

Additionally, there are differences in the ways individuals may be expected to contribute to the cost of any formal care they receive. The next section discusses the current arrangements for funding formal care for older people. This study focuses only on care received by older people living at home, and as such, care to older people living in residential care homes is not relevant to this study and is not discussed.

#### 1.3.2. Nursing care

Nursing and medical care is provided free for all residents living in the UK, including England, Wales, Scotland and Northern Ireland, as part of the NHS health care system. The universally provided NHS system aims to provide equity in access to necessary nursing and medical care services for all people, regardless of age, whether they have critical and intensive health care needs or require less intensive nursing support. As such, there are currently no charges placed on individuals receiving medical or nursing care from NHS-registered staff, and this includes after-care services, intermediate care services, NHS services arranged through a primary care trust or general practitioner (GP), and NHS continuing healthcare received both domestically or residentially (AgeUK, 2014). Since these services are provided free at the point of need for all, the costs associated with providing nursing and medical care services are met entirely by the DoH, and financial resources allocated for these services are determined by centrally determined DoH budgets.

#### 1.3.3. Personal care

While nursing and medical care is free for all older people, there are currently differences between the administrative arrangements and systems for funding personal care services across the component countries of the UK. Following the recommendation of the Royal Commission for Long-term Care (1999), the costs of personal care have been free to people aged 65+ in Scotland

<sup>&</sup>lt;sup>1</sup> It is for this reason that the IoRN is used in this research with ELSA, as it has never been operationalised in such a way before

since 2002, whether in domiciliary, residential or institutional settings, irrespective of individuals' personal financial resources or their potential ability to pay in the absence of such provision. However, elsewhere in the UK the costs charged to service users for personal care services, including home care or day centre access, are determined at a LA level. This creates potential disparity in the expectation for service users to pay for similar services within and between the borders of England, Wales and Northern Ireland. Where charges may be levied on service users, individuals are subject to means testing to determine their liability to pay financially towards the costs of services.

Determining liability to pay for personal care services in England involves the assessment of individuals' financial resources. Income from disability benefits, accumulated financial savings and capital are used to determine their liability to pay, with a lower limit – currently set at £14,250 – beneath which people are not expected to contribute to the costs of their care (AgeUK, 2014). Since decisions about charges and liability to pay for care are made at the LA level, the process of determining charges outside of Scotland is complicated, and has been criticised for being unfair due to inconsistent criteria in determining liability for care charges (Dilnot Commission, 2011:45).

# 1.3.4. Alternative arrangements for supplying formal care

In the context of the current provision of formal care, predominantly focused on providing direct practical support to people living at home, other arrangements for supplying have aimed to enable service users to maintain greater control in accessing support services. Such alternative models include the introduction of cash payments in the form of *direct payments* and individual budgets. These transfer the responsibility for purchasing health care and support services directly to the individual service user. The take up of direct payments and individual budgets has been lowest amongst the very old (Bowers et al, 2009:9), which has been attributed to 'restrictions on the use of the payments, the administrative burden of becoming an employer, lack of effective support schemes for users and reluctance of LA to promote direct payments'

(Comas-Herrera, Wittenberg and Pickard, 2010:381). These barriers suggest that access to such services do not accommodate the specific characteristics and needs of older people. While the adoption of policies such as direct payments and individual budgets may not necessarily meet the needs of all older people, they reflect attempts to provide access to more user-centred services. However, a drive towards cost-effectiveness in state-financed care places limits on the degree to which alternative care arrangements are adopted. In the context of the financial effectiveness and sustainability of current arrangements of care, there has been increasing debate about alternate models for funding care.

#### 1.3.5. Alternate models for financing long-term care

Proposed changes to future arrangements for funding long-term care for older people (Dilnot Commission, 2011) must overcome a general lack of understanding and awareness about individual liability for making contributions towards the cost of care in later life (Parker and Clarke, 1997; Bowers et al, 2009; Deeming and Keen, 2002). This is particularly important for older people on lower incomes, who are less able to pay for support and rely on unpaid care for support not covered by formal services (Deeming and Keen, 2002). The belief that state-funded services will provide care to meet the needs of older people (Parker and Clarke, 1997; Deeming and Keen, 2002) helps explain a widespread lack of financial preparation and planning for care in later life. Financial insecurity is likely to be a greater problem for pensioners living alone, particularly for women, and while this may affect some older people throughout later life, for others it may arise only in the later years of their old age when 'savings prove insufficient to meet the costs of care' (Phillipson, 1998). Issues with the current funding model have led to an alternative model for funding long-term care being proposed, whereby people will make meanstested contributions towards the costs of their own care across their lifetime with a ceiling at which all future care costs would be provided free (Dilnot Commission, 2011).

### 1.4. Private Care

Outside of formal care services, older people may be able to access support from the private sector. In 2009-10, around 400,000 people in England aged 65+ received privately-funded home care services, compared to around 610,000 receiving formally provided care services (Dilnot Commission, 2011). Paid professional care services in the home represent one avenue for some older people to manage their needs, commonly involving the scheduled provision of help with specific tasks such as cleaning, shopping and aspects of personal care. Private care may be used by older people who are not otherwise eligible for formal services, due to their needs falling below LA-determined criteria, or because their financial resources are assessed as above the boundary to receive state-funded care.

The role of private in the study of the relationship between dependency and care is commonly secondary to consideration of the interrelationship between formal and informal care. However, the role of private care in alleviating the burden of caring for another, for example a dependent parent, requires attention when considering how the wider range of available care resources operate together. Breeze and Stafford (2010) found private care more common among older people living alone without a partner or child, suggesting private care acts as a replacement for care more commonly provided informally, although they identify more than half of those receiving private care additionally receive unpaid care. Their analysis assumes an ordinal hierarchical structure to receipt of informal, formal and private care, whereby informal care is subsumed within private care, which is likewise subsumed within formal care (Breeze and Stafford, 2010). As such, their analysis does not actually differentiate those receiving combinations of private and informal care from those that receive only private care. It is likely that those relying on more complex care arrangements, involving care from multiple sources, may be characteristically different to those relying only on private care. As such, their analysis is restricted in how it helps to unpick the roles of different types of care.

Vlachantoni et al (2011) conducted bivariate analysis of care in response to ADL difficulties, using equivalent ADL measures collected in 3 large-scale surveys (ELSA, the General Household Survey

(GHS), and the British Household Panel Survey (BHPS)). Their analysis considered how 2 specific ADL difficulties, experienced individually or in combination, are associated with receipt of informal, formal and private care, with a focus on unmet need as identified by the absence of any care, finding ADL needs more important in respect to formal care than private care (Vlachantoni et al, 2011). Vlachantoni et al (2015) illustrated the impact of different ADL and IADL needs on care receipt, finding private care supporting IADL activities such as doing shopping and housework (Vlachantoni et al, 2015:322).

Several studies using the Survey of Health Ageing and Retirement in Europe (SHARE) consider private care receipt in different European countries. A common methodological approach adopted in these studies is the conflation of private and formal care to a single category of professional care (Bonsang, 2009; Bolin, Lindgren and Lundborg, 2008; Gannon and Davin, 2010). As such, the analysis of the roles of informal and professional care in meeting needs does not allow for consideration of the way formal care and private care may respond differently in the presence or absence of informal care. In considering the relationship between dependency and the receipt of care, informal care remains the primary source of care for the majority of older people, and the next section introduces and discusses informal care in more detail.

## 1.5. Informal care

Informal care relates to the unpaid help and support people receive from 'one's own household, or from members of other households' (Foster and Fender, 2013), and may include help from partners, children, and other family and friends in the community. Informal care plays a crucial role in the provision of care to older people. There are 'twice as many unpaid carers in the UK nearly 6.4 million—as there are paid staff in the health and social care systems combined' (House of Lords (HoL), 2013:82), with more than a tenth of the population in England providing unpaid care in 2011 (White, 2013). Around 86% of people aged 65+ with functional difficulties receive some form of informal care (Comas-Herrera, Wittenberg and Pickard, 2010), and around half of UK adults receiving care are aged 70+ (Foster and Fender, 2013). Although the number of

people receiving unpaid care has remained relatively stable between 2000 and 2010, the number of hours of unpaid care being received has increased dramatically. For example, the proportion of people receiving informal care on a full-time continuous basis increased in this period from 27% to 35% (Foster and Fender, 2013), with 1.4 million people providing unpaid care for more than 50 hours per week in 2011 (White, 2013).

#### 1.5.1. Informal care from within the household

The majority of unpaid care comes from people living in the same household (Finch, 1989), and 1.2% of people in the UK in 1999 provided unpaid care to an older relative living within the same household (Rodrigues and Schmidt, 2010). Care is commonly provided by one person (Sláinte, Sóisialta and Poiblí, 2001), particularly children who are single (Finch, 1989), while older people are more likely to choose to care for a dependent co-resident than younger people (Mentzakis, McNamee and Ryan, 2009). The amount of care provided to a dependent within the household may be intense (Murphy et al, 1997). Over half of those providing care to someone they live with do so for more than 20 hours per week (Hirst, 2005), with more than 1 in 5 caring for 100+ hours per week (Beesley, 2006:4). In the context of the large amount of unpaid care, recent estimates – based on the cost to buy equivalent hours of professional care – suggest the value of unpaid care tripled to £61.7 billion between 1995 and 2010 (Foster and Fender, 2013). The focusing of formal care services on meeting only the most critical needs places a greater demand on informal networks of partners, children and others to meet the needs of dependent older people.

#### 1.5.2. Responsibility for providing unpaid care

In attempting to understand the ongoing provision of unpaid care, the characteristics of those providing care are important. In later life, the responsibility for providing care most commonly falls to the partner. More than a third of unpaid care provided to people aged 65+ is provided by people who are themselves aged 65+ (Arber and Ginn, 1990). Outside of the partner-to-partner caring relationship, the burden of care most often falls to children as the second tier of unpaid support, where this care is most likely to be provided by daughters (Finch, 1989:28-29). For

daughters, caring for a parent is shown to negatively affect opportunities for employment, and women who both work and provide unpaid care are likely to work fewer hours and receive lower wages than women who do not (Carmichael et al, 2008). Further, being outside the job market due to caring for an elderly parent can affect access to both state and occupational pensions, potentially influencing individuals' current and future reliance on state benefits (Glendinning, Schunk and McLaughlin, 1997). For those continuing to both work and care for a dependent, the investment of time required to provide care may inhibit time otherwise spent participating in their own pursuits (Finch, 1989), and the impact of caring for a very dependent older person can have negative consequences for a carer's mental wellbeing (André et al, 2014).

The assumption of responsibility for caring for a parent is likely to develop from interactions between kin across an extended period of time, often seeing daughters assume a 'natural' role as carer (Finch and Mason, 1990:64-67). This reflects the deeply gendered nature of care and the caring roles people inhabit. The division of caring roles by gender continue later in life, with women being more likely than men to have provided care in post-retirement (McMunn et al, 2008). Although women are more likely to provide care overall, at ages 75+ a greater proportion of men provide care than women (Arber and Ginn, 1990).

Informal care is predominately provided by a partner, child or combination of both (Arber and Ginn, 1990; Pickard, 2008), and the impact of increasing numbers of the very old is likely to lead to a greater reliance on children for support. Projections suggest that, were the distribution of functional difficulties amongst the older population to remain stable, there will need to be a massive increase in the number of children providing unpaid care to meet the demands (Pickard et al, 2007), with a shortfall in the supply of intergenerational child-to-parent care occurring and expanding from 2017 onwards (Pickard, 2015). A shortfall in care from children will then place pressure on other forms of care to meet older people's needs, be that a greater burden on partners or reliance on formal care services. It is therefore necessary to understand how different types of care currently operate together, and to consider the dynamics of the wider continuum of care.

## **1.6.** The relationship between informal and formal care

Understanding and unpicking how informal and formal care operate together to meet older people's needs is a central concern of the current thesis. For example, although the majority of people aged 65+ with ADL and IADL difficulties receive informal care, the likelihood of receiving care from formal sources becomes much more likely much later, particularly for those aged 85+ (Breeze and Lang, 2008; Breeze and Stafford, 2010; Thompson et al, 2014). An important aspect of studies focusing on the informal-formal care relationship has been analysis of the substitution between these different types of care. The substitution thesis understands the informal-formal care relationship as reactive. That is, an increase in the amount of formal care service provision, perhaps resulting from policies introduced to alleviate the burden of unpaid care, will see the supply of informal care retract in response (Pickard, 2012). The inverse may also be occur, whereby as formal care service are reduced, for example, as has occurred in the UK in response to continuing austerity measures, there is an associated increase in the supply of informal care to replace absent formal care services.

The informal-formal care relationship has been examined in a range of different countries using data from the SHARE study. For example, several studies find a substitution effect evidenced by greater hours of informal care being associated with lower use of low-skilled professional care services (Bolin, Lindgren and Lundborg, 2008; Bonsang, 2009; Gannon and Davin, 2010; Van Houtven and Norton, 2004). Other findings suggest informal care is complementary to rather than a substitute for other types of care, specifically high-skilled and technical medical support such as outpatient care (Litwin and Attias-Donfut, 2009), GP visits and hospital nights (Bolin, Lindgren and Lundborg, 2008) and professional or paid nursing care (Bonsang, 2009). In a study of older people in Norway, formal care is shown to complement informal care, although the measurement of frequency of care used, 'more than once a week', was acknowledged as an imprecise way to gauge the relationship (Dale et al, 2008). Albert et al (1998) studied dementia patients in the US and found that formal care increased in response to disease severity, but there was no substitution effect between informal and formal care.
A feature of many of the studies is that they use cross-sectional data to verify a substitution effect (e.g. Agree and Freedman, 2000; Bolin, Lindgren and Lundborg, 2008, Bonsang, 2009). The cross-sectional approach of such research restricts the degree to which causation is identified, since it is unclear whether any substitution effect is due to the increase or decrease in the provision of the care in question. Pickard (2012) addressed the question of substitution in her analysis of GHS data on intense care received by people, compared to the number of older people in long-term residential care across 4 times points (1985 to 2000). Her analysis showed that until 1995, increases in residential care occurred as the number of older people receiving very intense care declined, but the situation has since reversed (Pickard, 2012). As such, without longitudinal data the analysis of substitution provides only a static picture of a dynamic process that is likely to shift across time. It is therefore of interest to consider the dynamics of need and care longitudinally.

Further, when there is a no direct equivalence between the types of support commonly provided by informal and formal sources, the concept of substitution itself becomes problematic. That receipt of one type of care affects another is clearly demonstrated, however framing this relationship in terms of substitution suggests a direct replacement of care from one source by care from another. However, informal-formal care substitution is unlikely to reflect a true likefor-like replacement of help since there are aspects of informal care which formal care cannot meet, due to the organisational demands of providing routinized services (Litwak, 1985). The tasks-specific model of substitution proposed by Litwak, suggests that 'a group can optimally manage those tasks that match it in structure' (Litwak, 1985:28). This model considers a person's needs in terms of distinct tasks, where the most suitable source of care is that which most closely reflects the same key structural factors, including the need for proximity, frequency of contact and time-investment.

Similarly, Stansfield (2006) frames informal care across the dimensions of availability of support (number of contacts and frequency of contact), and the types of care they are able to provide (instrumental or emotional). Considering informal care along these lines provides a framework

for understanding how formal care varies according to the supply of informal care. For example, those receiving unpaid care from a child are less likely to receive formal care than those receiving care from a friend (Barrett and Lynch, 1999). This highlights how unpaid care can vary in the support it provides, with the effect of informal care on other types of care dependent on who the unpaid carer is and their relationship to the person being cared for, over and above the needs they have.

This draws attention to the question of whether informal care can be entirely substituted by formal care, or whether needs would remain unmet for those relying on formal care alone. In terms of the substitutability of different tasks, help with domestic chores is low-skilled and easily transferable between individuals, regardless of the relationship between care giver and receiver. Personal care may involve help with intimate activities, and substituting care commonly provided by a partner or child with that provided by formal service may be less than ideal. The intimate nature of such care means it is most likely to be provided by those sharing close ties, while medical care is highly specialised and can only be provided by qualified staff (Arber, Gilbert and Evandrou, 1988:159).

Tennstedt, Crawford and McKinlay (1993) consider the direct substitution between formal and informal care longitudinally, exploring whether informal care becomes redirected to other tasks as formal care substitutes for specific tasks. However, they find this was not the case and formal care only directly substitutes for particular tasks without informal care being directed elsewhere. In particular, the task with the greatest degree of substitutability – arranging services – appeared to have a direct outcome on service substitution by other services, such as personal care and housekeeping (Tennstedt, Crawford and McKinlay, 1993).

Other aspects of care not generally considered in such studies are the social and emotional support provided by the carer – 'providing company and 'keeping an eye' on the older person, particularly if cognitively impaired' (Beesley, 2006:4). In terms of the substitution of emotional support, formal care may assume an informal quality as the relationship between the dependent and their carer develops over time, particularly for those without strong family and friendship

networks (Allen and Ciambrone, 2003:222). This suggests that a need for emotional support may potentially place already vulnerable older people at further risk if the boundary between informal and formal care is blurred. Further, this emphasises the role of care in providing more than purely instrumental help. In some situations, the provision of care from child to parent may be reciprocal in nature, with exchanges of 'practical, material or emotional help to each other and to their children and grandchildren' (Arber and Ginn, 1990:434). This suggests that understanding the nature of dependency involves being aware that need is likely to be more nuanced than the measures commonly relied on in studies such as this are able to capture.

### 1.6.1. Definitions of informal and formal care in research

A central aspect of analysing the relationship between informal and formal care is how each is specified. Definitions vary between studies and this can have important ramifications for how the relationship is unpicked. For example, informal care has been defined as assistance from any person living outside the home (Gannon and Davin, 2010), a non-resident, a child or a child's family (Bolin, Lindgren and Lundborg, 2008; Bonsang, 2009; Van Houtven and Norton, 2004), a person providing the majority of care and support non-professionally (Nordberg et al, 2005), and care provided to a dependent parent by a married child or step-child (Henz, 2009). Additionally, informal care may distinguish between care provided by a co-resident partner or child and non-professional care provided by other non-residents (Litwin and Attias-Donfut, 2009). Informal care has been measured as the number of hours of care received, but measurements vary between studies from hours of assistance provided per day (Nordberg et al, 2005), per week (Henz, 2009), per month (Bonsang, 2009; Van Houtven and Norton, 2004), or per year (Bolin, Lindgren and Lundborg, 2008; Gannon and Davin, 2010). Alternatively, the unit of measurement may be less metric, focusing on the particular combination of informal and formal care received (Litwin and Attias-Donfut, 2009).

# **1.6.2.** Endogeneity bias when capturing informal and formal care receipt Studies exploring the relationship between informal and formal care must consider the potential bias in a child's decision to care for a dependent parent. Ettner (1996) outlines conditions under

which the amount of care provided by children to a parent care can be considered exogenous, as follows

'The parent is assumed to require a certain amount of care, based on her health. Some care is provided informally by the spouse, depending on the marital status of the parent with disabilities. The children are expected to provide the remainder of the necessary care ... [where the allocation of care giving] does not depend on endogenous characteristics of the children (for example, employment status); the family does not allow the parent with disabilities to experience unmet needs; and there is no possibility of substitution of formal for informal care' (Ettner, 1996:190).

Endogeneity bias arises due to factors such as employment status, where a child chooses to forgo other opportunities, including income from employment, in order to undertake care for a parent. In deciding against providing care for a parent, the burden of care is placed elsewhere, either informally or more formally (Van Houtven and Norton, 2004). As such, the choice a child makes in undertaking a caring role will have a direct effect on their own circumstances as well as feed directly into the receipt of care from other sources. For example, a child may choose to pay for professional care for a dependent parent, particularly where the financial cost of providing care, that is forgone employment income, is greater than the cost of paying for it directly (Ettner, 1996). Elsewhere, studies consider endogeneity bias in labour market participation, where poor health may be used as justification for being out of work, particularly for those receiving out of work benefits (Akashi et al, 2011; Baker, Stabile and Deri, 2004; Benitez-Silva, 2004).

Analysis of formal care utilisation has controlled for endogeneity bias using an instrumental variable approach (Bolin, Lindgren and Lundborg, 2008; Bonsang, 2009; Gannon and Davin, 2010; Van Houtven and Norton, 2004). These studies restrict analysis to older people living alone, in order to extricate the decision making process of children in choosing whether to care from the conditions that implicate an obligation to care (residence with an elderly parent). The instruments relate to characteristics of children known to affect decisions regarding care, such as the number, gender and proximity of children to the parent. However, while it is well established

that older people living alone are more likely to receive both informal and formal care, the focus exclusively on lone parents in these studies excludes consideration of care as it is received by a larger part of the population who live with a partner. Indeed, the ongoing availability of partners as primary carers fundamentally determines the balance between unpaid and state-funded care.

# 1.6.3. Conflating formal and private care

A further limitation of studies exploring care arrangements, particularly those exploring the interrelationship between informal and formal care using SHARE data, is a common non-distinction between professional care – care referred to as 'formal' in this thesis – and paid-for care – termed 'private' in this thesis (e.g. Bolin, Lindgren and Lundborg, 2008; Bonsang, 2009; Gannon and Davin, 2010; Litwin and Attias-Donfut, 2009). Conflating privately purchased care with state-funded formal care in this way does not identify how private care and formal care may differ in regards to the substitution of informal care.

# 1.6.4. Household adaptations and the use of mobility equipment

Finally, the use of equipment such as canes and household adaptations can provide increased mobility at home. They have been shown to lower the number of hours of unpaid care received (Agree et al, 2005), reduce the number of formal care hours (Allen, Foster and Berg, 2001), and notably provide support with tasks where the privacy of the individual is important, such as using the toilet (Agree and Freedman, 2000). Although this thesis does not consider equipment and adaptation, it is important to keep in mind that relatively simple changes can have a beneficial impact and enable older people to be more independent in their own homes.

In summary, a fundamental factor in understanding how different types of care interact relies on the identification, classification and measurement of the needs people experience, since the fundamental aims of the formal care system is maintaining people's dignity while enabling them to participate in society in later life (Dilnot Commission, 2011). As such, a key focus of research is to improve the understanding of dependency in later life, and to explore the way in which older people's needs are met. The next section discusses approaches to defining and constructing a measure of need.

# **1.7.** The need for care

The existence of need is a fundamental factor determining whether someone receives care. Yet, the definition of need is not fixed, and its precise meaning is dependent upon the particular context in which it is defined (Asadi-Lari, Packham, and Gray, 2003). In exploring the relationship between dependency and care throughout this thesis, it becomes necessary to define need in terms of the particular perspective through which it will be considered. For the purposes of this thesis, needs can be understood as aspects of dependency that can be met by commonly available care *services*, whether such care is supplied by unpaid help, by formal services, or supplied by privately-funded professional care services.

Bradshaw (2003) summarizes the key perspectives through which needs are defined. Need is initially internalised by individuals ('felt'), then externalized in the activity of seeking help ('expressed'), at which point need becomes defined by a third party in the process of evaluation against criteria specified by healthcare professionals ('normative'), operating within a wider healthcare system which prioritizes particular needs above others ('comparative') (Bradshaw, 2003). This taxonomy is helpful to understand the framing of subjective and objective needs, and identifies a potential disparity between the subjective need of individuals and the specification of need as defined within the health care system.

As discussed previously, within the current English care system needs are classified on a scale of relativity from 'low' to 'critical', where 'low' or 'moderate' needs are unlikely to be met by formal care services. This identifies that normative need, the criteria by which a qualifying person's needs are assessed to be of a level which should be met by formal care services, are not stable but respond to the circumstances in which they defined and applied (Bradshaw, 1994). As a result, needs as determined by the availability of care resources may result in the divergence of assessment and eligibility criteria between LAs in England (Dilnot Commission, 2011). The Needs Assessment Decree (NAD), introduced in the Netherlands to attempt to maintain objectivity in the assessment of individuals, regardless of the availability of resources to supply care, was shown to remain subject to the interpretation of regulations and reliant on consistency

among independent assessors (Algera et al, 2003:240). More recently, the development of the Indicator of Relative Need (IoRN) in Scotland, has been an attempt to standardize the assessment of needs following explicitly stated criteria, although the tool has not been widely implemented (JIT, 2011).

The majority of care remains unpaid and, in the context of formal services being targeted to meet the needs of those with the greatest needs, it is likely that people with less chronic needs may rely entirely on unpaid help. When considering the care of older people living at home, it is necessary to understand that older people who access formal home care services are likely to be among the most dependent older people who are able to remain living in private residences. As such, the needs of the majority of people living at home are likely to remain managed by unpaid help alone because their needs are not critical enough to qualify for formal support.

When considering the relationship between the needs of older people and the care they receive, it is productive to develop measures of dependency that incorporate a range of needs to enable an understanding of how people living at home are able to manage with their difficulties. For example, considering only the impact of ADL difficulties will place the focus on only those with relatively critical needs, providing limited scope for understanding the less critical needs of a wider older population who rely on other types of support to meet their needs.

#### **1.7.1.** Identifying dependency

Studies that consider the care for older people commonly use measure of need based on different objective and/or subjective health factors. For example, composite indicators of need include ADL and/or IADL difficulties, chronic conditions and functional limitations. Artaud et al (2013) define disability across 3 domains, broadly covering functional mobility, ADL and IADL difficulty, where disability in any domain is confirmed if an individual cannot perform a single domain-specific item without help. Gannon and Davin (2010) explicitly define need in terms of the existence of a single functional limitation, or any ADL or IADL difficulty, conceiving the impact of dependency resulting from potentially diverse needs as equal in their impact on care receipt. Litwin and Attias-Donfut (2009) measure disability based on numbers of ADL and IADL

difficulties, allowing for the complexity of needs in different domains to be considered. However, while this particular approach differentiates between ADL and IADL needs, the aggregation of different needs to single summary measures often disregards differences between the component ADL and IADL difficulties. As such, there is scope to improve the understanding of how different types of dependency affect the receipt of particular types of care in old age.

Without differentiating between different difficulties, for example ADL item using the toilet and IADL item doing housework, the impact of individual difficulties are not discernible from one another, with all having the same effect. In particular, Gannon and Davin's (2010) study assumes that any needs which are identified are understood to be either met, if an individual receives any care, or unmet, if no care is received from any source. Their approach fails to account for the qualitative differences between individual ADL, IADL and functional limitations, and does not consider possible differences between each type of care, as 'any care' from any source is sufficient to meet all identified needs, regardless of how complex an individual's needs may be.

For example, an assumption that all needs are met if any formal care is received, which could identify formal home care, nursing care or personal care, disregards the issue that particular needs can only be met if there are appropriate services available to meet them. Certainly, in the context of older people's care the receipt of formal or informal care does not necessarily equate to the adequate satisfaction of all needs an individual has.

Moreover, by describing the relationship between unpaid care and specialist medical care, for example care provided by a doctor or outpatients department, the degree to which one actually substitutes for the other is questionable, particularly where there can be no genuine like-for-like replacement between informal and formal care. As such, studies emphasizing only the balance between formal and informal services do not address the qualitative differences between the difficulties, which in combination *produce* dependency.

The analysis of the relationship between dependency and care is reliant on the specification and construction of the key factor 'need', and as in all quantitative research, a key consideration in the study of older people's care needs is the existence and availability of suitable data with

which to explore these questions. The absence of explicit questions asking about the satisfaction of needs, necessitates the adoption of alternate approaches to determine how care responds to need in later life when using secondary datasets such as SHARE. Some studies on the care needs of older people have collected primary survey data, and are able to include direct questions on whether needs are satisfied (McColl, Jarzynowska and Shortt, 2010), or containing purpose-built tools for assessing needs, such as the Camberwell Assessment of Need for the Elderly (CANE) (Miranda-Castillo et al, 2010).

The collection of primary data allows very specific questions regarding how needs are met to be addressed. A question, such as 'was there a time when you needed health care but did not receive it?' (McColl, Jarzynowska and Shortt, 2010), provide scope for the analysis of unmet need in terms of the self-perceived needs, what Bradshaw (2003) terms 'felt' need, of formal care service users. Such data potentially provide scope to identify disjunctions between the *perceived* needs of service users, and the *medically defined* needs used to determine eligibility for formal care (Magi and Allander, 1981).

Netten and Forder's (2007) study applies a more thorough approach to assessing how services meet the needs of older service users. Their approach applies a framework of eight optimal care outcomes, such as 'personal cleanliness and comfort' and 'control over daily life', to assess how current care services meet different dimensions of users' needs. Participants are also asked the level of need they would have in the absence of available services, providing a baseline to consider unmet need in the absence of care services. This enables their study to consider whether services meet the dimensions of need that service users consider important, or whether services under- or over-perform across the eight dimensions of care. Their research represents an 'ideal type' for analysing how needs are met by care services, since it is based upon primary data collected specifically to understand the extent to which services meet particular dimensions of need.

While Netten and Forder are able to apply a purpose-built framework for exploring care needs to primary data, there remain alternative and less intensive means of identifying and measuring

needs, utilizing and adapting standard measures provided in secondary data from large-scale sample surveys. Gaugler et al (2005) use primary data and implement an approach incorporating ADL difficulties, which are weighted according to a scale of relative dependency, to measure needs and care outcomes for American dementia sufferers. Further, they are able to show direct outcomes of multiple ADL difficulties, primary caregiver assessed unmet needs and care receipt by collecting longitudinal data at 6 month intervals across 18 months, showing that unmet needs and multiple ADL difficulties were the strongest predictors of entrance to a nursing home and mortality at follow-up (Gaugler et al, 2005). Similarly, Wimo et al (2011) conducted a follow-up study, following Nordberg et al's (2005) population-based study of over-75's living at home in Stockholm, finding people with dementia who lived at home received less informal care at follow-up, while cognitive decline was the strongest predictor of institutionalisation. The predominance of cross-sectional analysis in research on care utilisation (Bonsang, 2009; Bolin, Lindgren and Lundborg, 2008; Litwin and Attias-Donfut, 2009; Gannon and Davin, 2010; Miranda-Castillo et al, 2010) may reflect a static picture of care use, obscuring potentially dynamic aspects of care utilisation which longitudinal analysis could potentially help to unpick.

# **1.8.** Summary of chapter

After introducing the research context, this chapter began by defining care as the supply of continuing personal, nursing and medical care, before introducing formal, informal and privately-paid care as the range of contexts in which the majority of care provision occurs. Formal care arrangements in the UK were outlined along with key issues associated with current arrangements of formal care, including potential inequity in access to formal services due to localized assessment processes and eligibility criteria within England and Wales. The arrangements for formal care in the wider UK were discussed, particularly the Scottish context, where the specification of a nationally consistent assessment process using clear criteria for determining care needs and eligibility for services was considered. In this way, differences within the UK context between Scotland and England/Wales were explored, with a particular focus on

the divergence in current arrangements for funding personal care services. The chapter continued by touching on alternative approaches to supplying formal care services, and discussed proposed changes to future arrangements for funding long-term care in England.

The issue of informal care was introduced as a key dimension of current care arrangements, with the continued supply of unpaid care from partners and children plays a fundamental role in the ongoing management of formal services. Research into the interrelationship between informal and formal care was discussed, with an outline of studies identifying a substitution between informal and formal care. It was argued that studies supporting the substitution effect often ignored the supply of co-resident care, and research in the field was criticized for the simplistic conceptualisation of need which failed to consider the qualitative difference between individual ADL and IADL activities, thus failing to capture the true complexity of dependency. The chapter continued with discussion of alternative approaches to constructing and analysing care needs, utilising ADL and IADL factors, quality of life, and mental wellbeing to construct more nuanced approaches to understanding and analysing care needs.

The chapter concluded with consideration of the benefits of adopting longitudinal approaches to exploring the dynamics of care. As such, this chapter has shown that the analysis of care may benefit from disaggregating care in terms of its component aspects, such as care from coresident partners. Additionally, this discussion has identified that more nuanced measures of dependency may help to further deepen the understanding of how needs occur in old age. Specifically, illustrating the similarities and differences between difficulties that are often reduced to binary or simplistic summary measures, research in this field will benefit from analysis seeking to understand the dimensionality of dependency, and the use of longitudinal methods may further help to explain the dynamics of care across time.

# **Chapter 2**

# 2. <u>Research aims, data source, and methods</u>

The focus of this thesis is the exploration of the relationship between need, dependency and patterns of care receipt in later life. This chapter begins by outlining the aims of the research, before discussing conceptual frameworks that are relevant to the study. The chapter continues with a review of available datasets that provide scope to meet the proposed research aims. The English Longitudinal Study of Ageing (ELSA) is introduced as an appropriate dataset to examine the research questions, and a summary of the key measures of dependency and care receipt provided by ELSA is presented, along with descriptive analysis of the main dependent and independent variables used throughout the thesis. The chapter then moves to consider the impact of survey weights, discussing issues surrounding the application of weights within the proposed longitudinal analysis of ELSA. The chapter closes by defining the research sample for the study, along with the modelling approach and diagnostic tools that are used to undertake the research. The chapter begins with an outline of the aims of the research.

# 2.1. Research Aims

As discussed, research exploring the relationship between dependency and the receipt of care in later life often relies on broad measures of dependency, reducing a diverse range of needs that occur in old age to simplistic summary measures, or restricting analysis to a single dimension of dependency. As a result, the scope of research remains bounded to a very restricted understanding of how different types of care commonly respond to different needs. For example, conflating different ADL difficulties to a single binary indicator of need (e.g. Artaud et al, 2013; Gannon and Davin, 2010) debars analysis of the impact that different ADL difficulties may have on the types of care that people receive in old age. Further, such broad measures of dependency cannot account for differences in the complexity of needs experienced by those with ADL difficulties. For example, individuals may experience more than one ADL difficulty, alongside multiple other difficulties, and the differences in levels of dependency often remain unmeasured. Even when levels of dependency are considered, for example when using measurements based on a metric count of ADL and/or IADL difficulties, differences between component difficulties of the same type are ignored.

In summary, by accounting for dependency in the analysis of the relationship between need and care using predominately uni-dimensional measures of need, there is often no consideration of aspects of need beyond ADL difficulties, or the relative difference in care receipt due to differing levels of dependency. The research presented in this thesis therefore provides an unparalleled investigation of the relationship between need and care receipt in later life, focusing on the construction of measures of dependency that better account for the diversity of needs experienced by older people. In order to achieve these aims, the thesis has four areas of focus.

Firstly, the research aims to illustrate the diversity of needs in old age by presenting a detailed analysis of the prevalence of functional mobility, ADL and IADL needs to understand how different difficulties develop. Providing a more informed understanding of the development of dependency in later life will provide important background context to the rest of the research.

Secondly, the research aims to consider how measures of need can be constructed, in order that the multi-dimensional nature of dependency is captured. By explicitly acknowledging that needs in later life are not homogenous, this research aims to present a more nuanced picture of dependency, allowing for the complexity and types of needs that older people experience to be more clearly identified in the analysis of care receipt.

Next, using a number of different approaches that control for the diversity and complexity of needs, the research aims to unpick the relationship between different aspects of dependency and the receipt of different types of care, while considering the analytic benefits and limitations of adopting different measures of dependency.

Finally, the research focuses explicitly on the interrelationship between different types of care, examining the extent to which informal, formal and private care may substitute or complement one another. The next section discusses conceptual frameworks, providing a way to consider the relationship between need and the interface between informal, formal and private care.

# 2.2. Conceptual frameworks

In seeking to explore the relationship between dependency and care receipt, a number of frameworks have been proposed for conceptualizing the utilisation of care services, and relevant approaches are considered here in order to establish the most appropriate framework to investigate the relationship between dependency and care receipt.

Magi and Allander (1981) outline a framework for considering perceived and medically defined need, summarising entry into the formal care system in 2 stages – 'initiation' being the sequence of events leading to an individual making contact with the health care system, and 'continuation' once contact has been made (Magi and Allander, 1981:58). Need for medical care is defined in 2 different contexts, the needs of the individual (perceived need) and needs as determined by those acting on behalf of the formal system (medically defined need), and they provide a way to conceptualise these different and potentially conflicting perspectives. Their framework accounts for the gatekeeping role of health care professionals in determining the utilisation of resources, 'such as hospital beds, other medical personnel, laboratory facilities and prescribed drugs' (Magi and Allander, 1981:51), a position feeding directly into the planning and management of future care service provision (Magi and Allander, 1981). As a result, they propose that analysis of social care assessment processes should account for how the priorities of the health care system may not directly correspond with the expectations of individual service users as to the most appropriate course of action.

In thinking about the disjunction between the expectations of service users and the outcomes of social care, the production of welfare (POW) framework (Knapp, 1984) provides scope to consider the entire formal social care system in terms of inputs and outputs. In these terms, the basis of social care is the fulfilment of needs. Need is determined within the formal care system where it is identifiable, where removal of the need is possible and normatively desirable, and where the removal of the need will improve the well-being of the care recipient (Knapp, 1984:17). Knapp proposes that the formal care system operates in order to restore shortfalls in welfare. That is, needs as they are determined through formal assessment criteria represent a

deficit in a person's welfare that may potentially be resolved by the provision of care. In these terms, needs may potentially be met by a range of resources, both formal and informal, and it is only the improvement in welfare that is of importance. For example, an individual who has difficulty getting to the shops or doing housework could potentially receive adequate assistance from formal services, from a friend or family member, or pay for professional help from a private care provider. In this example, each would be able to provide an improvement in welfare.

Knapp (1984) argues that the output of the social care system should be measured in terms of the improvement in wellbeing of the individuals it serves, rather than through the services it provides. Formal social care services in the POW framework are simply intermediate outputs in an ongoing process of improving the welfare of individuals. However, Knapp acknowledges that difficulty in measuring the final outputs of care service provision, for example, by obtaining a measurement of the improvement in the wellbeing of individuals generated from the provision of one or potentially multiple different care services, may not be practicably possible. In such situations, intermediary outputs, being the services themselves, may represent the best measurement of outputs available (Knapp, 1984:23).

Factors affecting the POW in practice include, the characteristics and circumstances of the individual with identified needs, the quality of the services themselves, and in some cases, environmental factors such as the physical buildings in which particular services are provided. The production of welfare is a process of inputs and outputs:

- *Resource inputs,* relate to the manifest aspects of the services such as care staff, equipment and the physical environment;
- Non-resource inputs relate to qualitative characteristics of the principal actors involved, reflected in the personality, attitudes, and prior experience of those receiving care, as well as those providing care, which can influence how a given individual responds to care;

- The outputs of the production of welfare, as discussed, cover the services themselves (*intermediate outputs*) and the improvement in wellbeing generated by care service provision (*final outputs*);
- A final component in the production of welfare relates to the *costs of social care provision*. Here, the utilisation of care services in light of scant resources represents an equivalent reduction in the availability of other competing services. In these terms, all social care services represent forgone care of another type. This allows for the disjunction between Magi and Allander's (1981) *perceived* need and *medically defined* needs to be consolidated within the healthcare system.

It is easy to see that this framework provides a way to conceptualise the output of all types of care in terms of its production of welfare. However, while the needs of the individual are a central component, the framework's focus on the social care system makes the unit of analysis harder to conceptualise. As such, for the current thesis there are other more suitable conceptual frameworks for considering the interface between dependency and different types of care.

Andersen's (1995) behavioural model focuses on the individual, proposing that individuals' utilisation of care services is a function of their need for care, an individual's propensity to seek care, and other factors either inhibiting or enabling the receipt of care (Andersen, 1995). The propensity to seek care is determined by demographic characteristics (e.g. age, gender), socioeconomic factors that may affect their access to care, and the personal views someone has towards seeking care (Andersen, 1995). A similar behavioural model has been proposed by Vlachantoni et al (2015) to conceptualize the receipt of social care receipt in later life. Figure 3 reproduces the conceptual framework from Vlachantoni et al (2015).

From Figure 3, the individual determinants of social care support are demographic characteristics, living arrangements, health status, and use of equipment and household adaptations. The individual determinants component allows for the inclusion of assistive

#### Figure 3. Conceptual framework of social care support in later life.



Source: reproduced directly from Vlanchantoni et al (2015:326)

technologies, discussed in section 1.6.4, although they are not considered in the analysis presented in this thesis. The health/dependency component considered throughout this thesis is captured as a function of different ADL, IADL or mobility difficulties, which in combination with individual characteristics, including the demographic characteristics of an individual along with their propensity to seek care (Andersen, 1995), determines their utilisation of particular care resources. Enabling and/or inhibiting factors in the Vlachantoni et al (2015) model include demographic and socioeconomic characteristics, which affect the likelihood of a particular type of care being received.

This framework provides the essential components to undertake analysis of the relationship between dependency and care. The next section reviews the available secondary data sources to select an appropriate dataset with which to undertake the research.

# 2.3. Selecting data sources

It has been argued in chapter 1 that dependency in old age is more complex than is often represented in the analysis of the need/care relationship. The importance of ADL difficulties in the construction of measures of need is evident throughout this field of research. The dominant ADL-based measures of need sometimes additionally incorporate aspects of IADL dependency, which broadens the range of difficulties by which need is identified. However, the differences between ADL and/or IADL difficulties are often ignored and analysis often conflates all difficulties within a single indicator of need. In seeking to illustrate the multi-dimensional nature of dependency, and to explore how different dimensions of need affect the receipt of care in later life, this research uses ADL and IADL difficulties as the basis to construct more nuanced measures of need.

### 2.3.1. Reviewing available secondary data sources

A review of available secondary datasets was conducted, to identify the most suitable dataset to construct ADL- and IADL-based measures of dependency to explore the need/care relationship in later life. As these items have been collected in several survey datasets, a search of the ESDS database<sup>2</sup> of secondary datasets was conducted.

The preliminary search identified 4 UK-based studies: the Continuous Household Survey (CHS), the General Household Survey (GHS), the British Household Panel Survey<sup>3</sup> (BHPS), and the English Longitudinal Study of Ageing (ELSA). Further to those available through the ESDS database, a further study – the Cognitive Function and Ageing Studies (CFAS) – which deals specifically with those over the age of 65, providing information on ADL ability and aspects of care receipt, was also considered. Table 1 assesses the suitability of each source for the research, based on a representative selection of activities specified within the ADL and IADL domains of need.

In the first instance, CHS was excluded from the study since it contains very limited information on the relevant items. Moreover, as CHS samples only addresses in Northern Ireland, it is outside the intended scope of the present study.

Although the GHS questions cover the broadest range of ADL and IADL items, GHS information on individuals' abilities to perform certain tasks is only collected for individuals' who confirm having difficulty climbing up and down stairs (items marked \* in Table 1). Due to this, responses

<sup>&</sup>lt;sup>2</sup> ESDS Government and ESDS Longitudinal are now part of the UK Data Service

<sup>&</sup>lt;sup>3</sup> At the time of writing it was the BHPS, but now almost 84% of the original sample form part of the larger Understanding Society (BHPS, 2016) study

	CHS	GHS	BHPS	ELSA	CFAS
Eat a meal		x*		x	
Transfer from bed	x	х*	х	х	
Use the toilet	x	х*		x	x
Wash face and hands		x			
Give a complete bath or shower		x	x	х	х
Wash own hair					
Dress/undress	х	x*	x	х	$\mathbf{x}^{+}$
Prepare main meal		х		х	x
Prepare light snack		x			
Prepare hot drink		x			х

Table 1. Equivalent representative ADL and IADL variables available in secondary datasets

\* items only asked if person confirms they are unable or have difficulty or require help to climb stairs + item relates only to putting on shoes and socks

Source: From author's review of datasets held by ESDS and CFAS

collected in the GHS only capture full ADL information for a specific sub-sample of respondents. Further, these questions have not been collected in the GHS since 2001, and the GHS study has been discontinued as of February 2012 (ONS, 2011), and unfortunately it represents a limited resource for exploring current patterns of need, and was excluded from consideration. Notwithstanding, Pickard (2008) conducted a comparison focusing on the characteristics of people receiving informal care in the GHS compared to ELSA, using alternative definitions of informal care, and found strong similarities between the characteristics identified between these studies.

The BHPS provides repeated measures of the relevant variables across multiple waves, but only includes 3 ADL items from the full list. As such, using the BHPS would limit the scope of this thesis in successfully representing the multi-dimensionality of dependency in later life. As such, it was decided to exclude the BHPS from the study. Furthermore, the sample sizes of the population aged 60+ in the GHS and BHPS would, of course, be small.

Finally, both ELSA and CFAS appeared to cover a similar range of relevant items, and both studies are focused explicitly on older people. Therefore, both sources could potentially provide scope for undertaking the proposed analysis in this thesis. Nevertheless, ELSA contains more key ADL items than CFAS, and provides a wider range of information across the IADL dimensions. In comparison, although CFAS contains information on fewer ADL items, it specifically contains more detailed information on food preparation than ELSA. Further, Jagger et al (2009) compared ADL and IADL disability measures across ELSA, BHPS, GHS and CFAS and found that when the comparable measures were structured hierarchically there was strong degree of consistency between the different studies. As such, both ELSA and CFAS provide potentially useful resources for this study.

# 2.3.2. Selecting data sources

Another factor separating ELSA and CFAS is the way questions are worded, which can have a significant impact on the how the responses may be understood and used. Jagger et al (2009) summarise standard activity-based measures of dependency according to 2 binary outcomes: whether or not an individual experiences a difficulty with a specific activity, and whether they require assistance to perform the activity (Jagger et al, 2009:6). CFAS explicitly asks whether an individual requires assistance, while ELSA asks only if an individual who has difficulty with a relevant activity receives assistance. Table 2 compares the equivalent responses provided in CFAS and ELSA to the question on difficulty using the toilet.

The wording in CFAS directly captures aspects of the degree to which a difficulty with an activity inhibits independence. An approximate measure of dependence could potentially be derived in ELSA using responses to 3 questions, shown in Table 2.

Table 2. Equivalent question and res	ponse categories in CFAS and ELSA
--------------------------------------	-----------------------------------

CFAS	ELSA
Are you able to get to and use the toilet?	Do you have difficulty: using the toilet? <sup>1</sup>
(Yes), no difficulty (Yes), some difficulty (including using aquiamont)	'No difficulty' confirmed <sup>1</sup> 'No difficulty' confirmed <sup>1</sup> , 'uses equipment' confirmed <sup>2</sup>
(No), needs help	'Has difficulty' confirmed <sup>1</sup> , 'receives assistance' confirmed <sup>3</sup>

<sup>1</sup> Because of a health or memory problem, [do you] have difficulty doing any of the activities on this card [using the toilet, including getting up or down]?

<sup>2</sup> Do you use any of the following [mobility aids e.g walking stick/wheelchair]?

<sup>3</sup> Thinking about the activities that [you have] problems with, does anyone ever help with these activities (including partner or other people in household)?

Source: reproduced from CFAS and ELSA

However, generating measures of dependency which incorporate the dependent variable of interest – i.e. whether someone receives or requires care – disqualifies being able to use such measures in the analysis of patterns of care receipt. Importantly for CFAS, the response captures

the *need* for rather than the *receipt* of help as is reflected in ELSA. However, it can be argued that someone having difficulty with an activity – for example, using the toilet – and receiving help can be assumed to need any help that is received.

Despite these issues, the wider benefits of using ELSA are important. ELSA captures not only information on the health and disability of older people, but also provides detailed information on who provides care, along with a range of measures of socio-economic status (SES) indicators such as education, employment-based class (National Statistics Socio-economic Classification (NSSEC)) and wealth, which are not present in the CFAS study. As such, the two studies provide sufficient data to develop similar measures of dependency and both studies could usefully provide scope for examining care needs in the UK from slightly different perspectives, with ELSA allowing a richer understanding of the contextual or SES background of the sample members.

# 2.3.3. Summary of data options

ELSA is available for (academic) secondary-analysis directly through the ESDS data catalogue (ESDS Longitudinal, 2011), and as such the process of accessing the data is straightforward, while access to the CFAS study involves an application process. A successful application was made to use CFAS data, but on consideration the data provided excluded satisfactory supplementary information on background characteristics – for example, no SES information was provided – and it was decided that CFAS would allow only very limited analysis to be undertaken. Although both studies potentially represent resources to investigate the relationship between dependency and care receipt, this study uses ELSA due to the wealth of additional supplementary background information it collects. The next section discusses ELSA in more detail.

# 2.4. The English Longitudinal Study of Ageing (ELSA)

ELSA collects data on people aged 50+ who live in private residential accommodation in England, including information on subjects including health, socio-economic background and aspects of care giving and receiving. ELSA is a longitudinal study, and the same respondents are interviewed repeatedly, once approximately every 2 years. As an ongoing repeated panel study, data from

multiple waves can be linked and analysed longitudinally to explore questions relating to care receipt over time. This provides scope for meeting the research aims of exploring the dynamics of care in old age. At the time of writing, 5 waves of data were available which places limitations on the extent to which long-term trends are able to be identified.<sup>4</sup>

ELSA interviews only people living at home in non-institutional settings, and thus does not allow consideration of those living in nursing homes or residential care settings. Later waves of ELSA include a follow-up interview, for respondents who have left the study by moving into residential care. However, the ongoing limited availability of appropriate data on those living in non-domiciliary settings necessitates that this study focus exclusively on the dependency and care of those living at home. Since dependency develops dynamically across time, the current study will focus on those aged 60+, as this will enable an understanding of how need and care arrangements may change in the period from retirement to very old age.

As discussed, ELSA collects detailed information on the health of older people, including their ADL and IADL difficulties, as well as information on whether individuals give and/or receive care. The next section introduces the ELSA variables from the questionnaire, relating to the difficulties older people experience, which are used in the thesis to derive measures of need, and indicators of care receipt.

### 2.4.1. Indicators of Mobility, ADL and IADL difficulty

ELSA asks individuals whether they have difficulty performing 23 different actions or activities and whether they receive help with the items which they have difficulty performing. The 23 activities asked in all waves of ELSA are grouped within 3 *domains*, collectively identifying Mobility, ADL, and IADL needs. The 23 component items for the 3 domains are listed in Table 3, alongside shortened descriptions for each item which will be used in charts and tables throughout, where space does not allow the full descriptions/labels to be included.

<sup>&</sup>lt;sup>4</sup> The majority of research and analysis was already carried out on waves 1-4 before the release of wave 5 in late 2012 meaning it was not feasible to rerun the analysis to include the more recent wave in the time-frame of the funded PhD period.

Table 3. Individual domain items full and shortened item descriptions.

Domain	Item – full description	Item - short description
Mobility	walking 100 yards sitting 2 hours getting up from chair after sitting long periods climbing several flights stairs without resting climbing one flight stairs without resting stooping, kneeling or crouching reaching or extending arms above shoulder level pulling or pushing large objects lifting or carrying weights over 10 pounds picking up 5p coin from table	100yds sit2hrs getup stairs stair stoop extend pull weights coin
ADL	dressing, including putting on shoes and socks walking across a room bathing or showering eating, such as cutting up food getting in and out of bed using the toilet, including getting up or down	dress wroom bath eat bed toilet
IADL	using map to figure out how to get around strange place preparing a hot meal shopping for groceries making telephone calls taking medications doing work around the house or garden managing money, such as bills and expenses	map meal shop phone medi hwork money

Source: ELSA

Mobility covers 10 measures of basic upper and lower body movement, assessing the degree to which an individual is inhibited in basic mobility. ADL covers 6 activities relating to self-maintenance and personal care, reflecting essential activities which would fundamentally restrict a person's ability to live independently. IADL covers a broader range of 7 activities, involving physical and mental capacity, where dependency may negatively affect an individual's capacity to engage in wider society. In wave 4 of ELSA, a further 2 items – 'difficulty recognising when in physical danger' and 'difficulty in communication (speech, hearing or eyesight)' – were introduced within the IADL group of activities. In order to maintain consistency across all waves, the 2 new items are not considered in this thesis.

Bickenbach et al (1999) suggest an important differentiation between *impairments* – the functional limitations people experience – and *disability* – how someone is less able to perform a particular task, 'activities such as grasping, moving, reaching are themselves abstractions, derived from truly basic in the sense of concrete and actual activities such as grasping a jar, moving a chair, or reaching for a glass of water' (Bickenbach et al, 1999:1176). In these terms,

mobility difficulties identify impairments, while ADL and IADL difficulties can be considered disabilities. ADL and IADL difficulties are commonly adopted and validated to capture the most fundamental activities most likely to cause dependency in old age (Katz et al, 1963; Lawton and Brodie, 1969). In the context of understanding the needs of older people able to live at home, it is of interest to understand how care responds to both more and less intensive needs, and how other dimensions of dependency affect the receipt of care. For this reason, both ADL/IADL difficulties (disabilities) and Mobility difficulties (impairments) are considered in this thesis to help measure the broadest range of needs, beyond those used in studies relying solely on ADL and IADL difficulties.

### 2.4.2. Indicators of care receipt

Respondents who report any difficulty are asked further questions to identify if they receive help (variable *hehpa* – 'thinking about the activities that you have problems with, does anyone ever help you with these activities?'), and who provides any help received. The range of sources that can be specified as providing help include individual family members and friends, care provided by a health board or LA, and care which is paid for or arranged privately. Table 4 shows the complete list of possible care sources specified within ELSA, and whether each is identified in all waves of ELSA. A collective 'care source' is given in the first column, and these are discussed below.

Following the grouping shown in Table 4, the full range of 25 individual sources are used to generate 5 new binary measures, reflecting whether care is received from one or more of the individual component sources in each group. Grouping individual sources into broader categories of care conceptually makes sense, and is necessary in order that there are sufficient numbers of cases in each group for analysis to be productive. Further, across different waves of ELSA there is variation in the way particular types of care are identified. This is most notable for sources of care classified as Formal and Private. It is assumed that, although these types of care are identified in slightly different ways in different waves of ELSA, they remain consistent when

Care source	Source of care:	Wave 1	Wave 2	Wave 3	Wave 4
None	none	х	х	х	х
Informal:	partner	x	х	х	х
partner/child	son	x	х	х	х
	son-in-law	x	х	х	x*
	daughter	x	х	х	х
	daughter-in-law	x	х	х	x*
Informal:	parent	x	х	х	x*
other	sister	x	х	х	х
	brother	x	х	х	х
	grandson	x	х	х	x*
	granddaughter	x	х	х	x*
	other relative	x	х	х	х
	friend/neighbour	x	х	х	х
Formal	social/health worker	х	х		
	social services arranged care			х	
	local authority/social services				х
	nurse			х	
	health visitor or district nurse				х
	other health/social services			х	
Private	privately paid employee	x	х		
	privately arranged care			х	
	privately paid help				х
Other (specified)	unpaid volunteer	x	х		
	voluntary organisation			х	
	other person	x	x	х	х
	member of staff at care home				х

#### Table 4. Sources of care identified in ELSA waves 1 to 4

\* these items are only asked if no other sources are confirmed as providing help with ADLs and IADLs Source: ELSA questionnaire waves 1-4

considered at the broader group level, and reflect receipt of the same type of care from 'formal' and 'private' sources respectively. Turning to consider the 4 remaining individual sources of care, it is of interest to explore the role of voluntary care in meeting the needs of older people. Unfortunately, voluntary care is not identified in wave 4, and where voluntary care is identified there are very few cases receiving this type of care (73 of 19,396 cases, representing less than 0.4% of responses given in waves 1 to 3). For the purposes of undertaking longitudinal analysis, it was necessary to exclude voluntary care from further analysis in this thesis due to missing data for wave 4.

Care from a 'member of staff at care home' could be considered a form of private care. However, the component sources within the private care group are broadly the same while care provided in a care home is not consistent with the other definitions of private care. In wave 4 there were 88 cases out of a possible 7,319 cases (1.2% of all cases in this wave) receiving care from care home staff. This is a significant number of cases, and although the exploration of care would ideally consider this type of care, as with voluntary care this type of care is excluded from further analysis due to missing data in waves 1 to 3.

Finally, the remaining component source in this group – 'other person' – is identified in all 4 waves of ELSA. There are 259 cases reporting care from 'other person', representing 1% of all responses and 3.3% of cases from those who receive care. However, no further information is provided to identify the source of this care and this source cannot usefully be considered in the analysis in this thesis.

For the purposes of classifying the remaining care sources in this study, they are collectively referred to as 'Other (Specified)' due to the issues described. Although collectively they represent a significant number of cases (412 cases in total, representing 5.2% of responses from those receiving care), they do not collectively represent a coherent type of care and will not be considered in the analysis presented in this thesis.

To summarise, the following binary measures are used throughout this thesis to identify the receipt of care:

- ANY care from any source (including care from 412 cases outlined previously as 'other')
- 2. PARTNER or CHILD care from a partner or child
- 3. OTHER INFORMAL care from any other informal source
- 4. FORMAL care provided by local authority, social services, or NHS
- 5. **PRIVATE** care which is purchased privately by an individual

### 2.4.3. The supply of care

In addition to collecting information on the receipt of care, ELSA respondents are asked about their care giving behaviour in the past week. Caring has been shown to be a socially productive activity, for example improvements in quality of life experienced by those providing care to grandchildren (Breeze and Stafford, 2010). However, there are likely to be negative outcomes for those providing care, particularly those providing a large amount of care. For example, older carers providing 20+ hours of care a week were less likely to be in paid employment, and those in paid employment were likely to live in lower income households (Ross et al, 2008), while wealthier individuals are less likely to be care givers (Mentzakis, McNamee and Ryan, 2009). Those caring for a partner are likely to care for longer (Breeze and Stafford, 2010) and experience a lower quality of life (Breeze and Stafford, 2010). Caring for 20+ hours a week was more common among those living in more deprived areas (Breeze and Stafford, 2010; Young, Grundy and Jitlal, 2006) and more intense care was associated with greater functional mobility difficulties (Ross et al, 2008). However, those providing care to a partner for 20+ hours per week reported less ADL and IADL difficulties than non-carers (Rolls et al, 2011), although this potentially reflects a requirement for good health among those providing large amounts of care. Additionally, younger carers are likely better equipped to enable access to care services than older carers (Rolls et al, 2011).

In the context of this thesis exploring the relationship between dependency and care receipt, understanding the characteristics of those providing care may provide scope to consider the relationship between care giving and care receipt. However, this thesis focuses explicitly on the determinants of care *receipt* rather than *supply*, and although these measures represent an avenue for considering care-giving behaviour, they are not considered in the analysis in this thesis.

The next section details and discusses the dependent variables that are used throughout this thesis.

# 2.5. Dependent variables

Table 5 shows data on care receipt from any source, and from each of the 4 specified sources. Data is based on the whole sample (waves 1-4), including multiple response from respondents present in more than one wave of ELSA. The receipt of each type of care is shown as a proportion of the total sample, the subsample experiencing difficulties (any Mobility, ADL or

IADL difficulty), and the subsample who receive any care, and by age group. The  $chi^2$  test of bivariate association between each type of care and age were significant (p<0.001) in all cases.

# 2.5.1.1. Receives care: Any source

The proportion of people with needs increases in older groups, from 53% aged 60-64, to 88% at ages 85+. Around 60% of those aged 60-74, 50% of those aged 75-84 and 30% of those aged 85+ have a difficulty but receive no care. This illustrates the decline in the proportion of people who are able to manage their needs without help in older age groups.

Receives care:	60-64	65-74	75-84	85+	Total
% total sample					
ANY CARE	20.0	24.2	38.8	63.2	29.6
Partner or child	17.1	19.6	28.5	39.5	22.7
Other informal	3.3	4.3	8.8	17.3	6.1
Formal	0.4	1.1	3.5	11.3	2.3
Private	0.7	2.0	6.0	14.5	3.6
TOTAL	6,820	11,255	6,733	1,907	26,715
% with a difficulty					
ANY CARE	37.3	38.7	50.8	71.5	45.1
Partner or child	32.0	31.4	37.3	44.7	34.5
Other informal	6.2	6.9	11.5	19.5	9.3
Formal	0.8	1.7	4.6	12.8	3.4
Private	1.3	3.2	7.8	16.4	5.5
TOTAL	3,646	7,036	5,151	1,685	17,518
% receiving any care					
Partner or child	85.7	81.3	73.5	62.6	76.6
Other informal	16.7	17.7	22.6	27.3	20.6
Formal	2.1	4.5	9.1	17.8	7.6
Private	3.5	8.4	15.4	23.0	12.1
TOTAL	1,361	2,720	2,615	1,205	7,901

Table 5. Proportion of sample receiving care, by care type and age<sup>a</sup>

<sup>a</sup> chi<sup>2</sup> test of bivariate association between each type of care and age were significant (p<0.001) in all cases. Source: ELSA, waves 1-4

# 2.5.1.2. Receives care: Partner or child

Care from a partner or child is the dominant source of help, with 23% of all cases receiving help from a partner or child, representing around 1 in 3 of those with difficulties. More than 3 in every 4 receiving care have help from a family member, which remains highly prevalent across all age groups. Less than 15% of those receiving care aged 60-64 do not receive care from a partner or child, compared to 37% aged 85+. This suggests that partners and children are unable to provide support for all needs to those in very old age.

### 2.5.1.3. Receives care: Other informal

A much smaller proportion of older people receive care from other informal sources. 3% of the youngest group and 17% of the oldest age group receive this type of care, representing 21% of those receiving care.

# 2.5.1.4. Receives care: Formal

Formal care is the least common type of care, and less than 3% of cases in the total sample receive formal care, which is more prevalent in older ages. Less than 1% of those in the sample aged 60-64 receive formal care, while 11% aged 85+ (representing 18% of those receiving care at this age) receive care from a formal source.

# 2.5.1.5. Receives care: Private

Private care is more common than formal care, although less than 4% of the sample receive care from this source. Of those receiving care, 12% get help that is paid for privately. As with formal care, there is a marked increase in very old age. Around 16% of those aged 85+ who receive care pay for private care, compared to around 1% of the group aged 60-64.

# 2.5.1.6. Receives care: Unspecified

There are 389 cases where help is confirmed (variable *hehpa*) but no source is specified in follow-up questions. Table 6 shows the proportion confirming that they receive help without identifying a source.

Receives care:	60-64	65-74	75-84	85+	Total
Unspecified	n=69	n=126	n=113	n=81	n=389
% All respondents	1.0	1.1	1.7	4.2	1.5
Total	6,820	11,255	6,733	1,907	26,715
% with 1+ difficulties	1.9	1.8	2.2	4.8	2.2
Total	3,646	7,036	5,151	1,685	17,518
% Receiving any care	5.1	4.6	4.3	6.7	4.9
Total	1,361	2,720	2,615	1,205	7,901

#### Table 6. Care from unspecified source, by age

<sup>a</sup> chi<sup>2</sup> test of bivariate association between unspecified care and age is significant (p<0.001); significance is weaker in sample 'Receiving any care' (p<0.05).

Source: ELSA, waves 1-4

At almost 5% of responses from people who receive care, a relatively large proportion of the sample of interest, specifies no source. There is a similar proportion without information on a care source across all age groups. To examine this further, Table 7 shows the proportion of cases in each wave who confirm receiving help with a difficulty without specifying a source, by whether the response was given by the person or a proxy.

Table 7. Individual status	for respondents	receiving care from	unspecified source,	by wave
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	Care from unspecified source:				
	Wave 1	Wave 2	Wave 3	Wave 4	All waves
Full interview in person		15	226	6	247
Full interview by proxy		1	107		108
Partial interview in person			3		3
Institutional interview by proxy			31		31
TOTAL		16	367	6	389
Source: ELSA, waves 1-4					

Almost all the cases with missing information on the source providing help are from wave 3, with only 22 cases from other waves. There are a high number of responses of unspecified care from proxy interviews, and further investigation identified that all proxy responses confirming care fail to confirm a source. This suggests that non-response on this question is due to problems with data collection in this particular wave, which has been corrected in wave 4. However, although these cases can be included in analysis of whether *any* care is received, they are necessarily excluded from analysis when exploring the relationship between dependency and receipt of particular types of care.

### 2.5.1.7. Correlations between dependent variables

Finally, the receipt of different types of care are likely to be intertwined, whereby care or the absence of care from one source is likely to influence whether care is received from another source. The association between 2 binary variables can be calculated from the 2 x 2 table shown in Figure 4, following the formula shown in Equation 1.

Figure 4. 2 x 2 table

	$X^{-}$	$X^+$	Total
$Y^-$	a	b	е
$Y^+$	С	d	f
Total	g	h	n

Source: reproduced from http://www.pmean.com/definitions/phi.htm

Equation 1. Calculation of association statistic phi from 2 x 2 table.

$$\phi = \frac{ad - bc}{\sqrt{efgh}}$$

Source: reproduced from http://www.pmean.com/definitions/phi.htm

The phi coefficient ( $\phi$ ) is equal to Pearson's correlation coefficient *r*, and Table 8 reports the phi coefficient measuring association between the 4 dependent variables. Since the data are longitudinal, Table 8 reports the overall phi coefficient from all waves and minimum and maximum values across the 4 waves separately.

Table 8. Association between dependent variable	, overall phi coefficient and min and max across 4 waves
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	Partner or child	Other informal	Formal	Private
Partner or child	1.00			
Other informal range*	0.18 0.16-0.20	1.00		
Formal	0.13	0.18	1.00	
range*	0.10-0.15	0.15-0.22		
Private	0.10	0.15	0.11	1.00
range*	0.08-0.11	0.12-0.18	0.09-0.13	

Note: \* Minimum and maximum phi value across the 4 waves of ELSA Source: ELSA, waves 1-4

The associations between receipt of care from one source and receipt of care from another source are generally weak, regardless of the source, with stronger correlations between other informal care and other types of care. The phi coefficient remains broadly consistent across waves of ELSA.

# 2.6. Independent variables for the modelling

Guided by the literature, this section discusses the independent variables that are entered in logistic regression analysis presented in this thesis. The independent variables considered cover demographic factors (age and gender), familial characteristics (whether an individual lives with a partner or has children) and indicators of socio-economic status (SES).

# 2.6.1. Gender

Although people are living longer, it is established that men's life expectancy is shorter (Gjonça, Tomassini and Vaupel, 1999; Townsend and Whitehead, 1982), while healthy life expectancy has not extended in the same way, and people now live longer but in poorer health (Acheson, 1998), and particularly women (White and Edgar, 2010). In terms of care provision, women are more likely to care than men (Blomgren et al, 2008; McMunn et al, 2008; Vlachantoni, 2010), men are more likely to be caring for a partner at older ages than women (Arber and Ginn, 1990), while women with high levels of need are more likely to receive private care (Vlachantoni et al, 2015),. As such, gender is an important factor to consider in this thesis. Figure 5 shows the breakdown of gender by age.





Source: ELSA, waves 1-4

The gender balance within the ELSA sample shows an increase in the proportion of women to men in older ages. Given the base sample was collected in 2002, the greater proportion of women could be due to shorter male life expectancy in old ages.

### 2.6.2. Conjugal family structure

There is a high rate of older people living alone in the UK, particularly among women, and in 2007 '20% of men and 30% of women in the 65–74 year age group lived alone, whilst 34% of men and 61% of women aged 75 and over lived alone' (Rolls et al, 2011:652). The presence or otherwise of a partner or child are likely to be key drivers of whether care is received from outside the conjugal family unit. For example, living with a partner or child is likely to limit reliance on other types of care from outside of the household (Litwin and Attias-Donfut, 2009). Where needs are equal, the presence of a partner would be expected to lower the chance that care from other sources will be received. The roles that children assume in caring for a dependent parent may extend beyond the direct provision of care, with younger carers more capable at accessing support services than older partners (Rolls et al, 2011:654).

To consider the degree to which partners and children affect the receipt of care, and the way in which the type of care received may vary according to whether a partner or child is available, the research adopts 2 indicators of conjugal family structure – whether someone lives with a partner and whether they have any children. Using a binary measure of whether a person has children is a simplistic approach to accounting for the role of children in providing and organising care for a parent in need.

The endogeneity in decisions about care provision made between children and parents, whereby 'the parent chooses the amount of formal care ... given the amount of informal care provided by the child and vice versa' (Bolin, Lindgren and Lundborg, 2008:394), makes it necessary to control for the effect of children. Previous studies (Bonsang, 2009; Van Houtven and Norton, 2004) engage with the issue of endogeneity using instrumental variables based on the characteristics of children, restricting analysis to older people living alone to extricate co-residence as a factor

in determining the contribution that children make in patterns of care receipt for their parents. By accounting for the endogeneity caused by co-residence these approaches are able to assume independence in the effects of the explanatory factors considered. However, restricting analysis only to older people living alone such approaches are unable to consider the impact that dependency and need has on how care is received by the greater number of older people who live with a partner.

Unfortunately, the characteristics of non-resident children are not available in ELSA, and it is therefore not possible to consider how factors such as the relative proximity or financial circumstances of children affect decisions to provide care. As such, the presence or absence of a partner and/or children represents the best measure available to help control for family dynamics in the provision of informal care given the limitations of the ELSA data. Figure 6 shows the proportion of the ELSA sample living with a partner and the proportion with children.





As suggested, a high proportion of ELSA respondents live with a partner although the proportion drops as age increases. In the youngest group, more than 70% live with a partner, dropping to less than 20% in the oldest group. For those in the sample with a difficulty, the loss of a partner in old age is likely to have direct consequences on their reliance on other forms of help,

Source: ELSA, waves 1-4

particularly for the oldest old. The majority of respondents have children, with the proportion declining from almost 80% at ages 60-74 to around 55% at 85+.

### 2.6.3. Socio-economic factors

The socio-economic gradient of health is well established, with poorer health outcomes disproportionately among less advantaged groups (Acheson, 1998; Townsend and Whitehead, 1982; Marmot at al, 2010). People living in poorer areas die earlier and spend more of their lives with a disability than those in the richest areas, with the difference being 7 years and 17 years respectively (Marmot et al, 2010). People working in routine or manual occupations are most likely to suffer poor health, and to be in poorer health earlier in their lives, than those in more advantaged positions (Arber and Ginn, 1993; Chandola et al, 2007; McMunn et al, 2008). Less educated people and those on lower incomes are dramatically more likely to experience health conditions including diabetes, heart disease, stroke, and lung disease (Banks et al, 2006), with women on lower incomes suffering worse health (Avlund et al, 2003).

In the context of older people, it has been argued that some socioeconomic measures are less appropriate when applied to people in later life, and occupation-based measures in particular are less relevant when applied to a population that is predominately out of the labour market (Glaser et al, 2009). For example, income may be less applicable to older people who have retired, while state-pension income in retirement acts to reduce the earlier stratification of health (Banks, Muriel and Smith, 2010). Other studies further confirm a reduced socioeconomic effect on health at older ages (Arber and Ginn, 1993; Avlund et al, 2003; Gjonca, Tabassum and Breeze, 2009; McMunn et al, 2003). The analysis of health of older people in longitudinal panel studies such as ELSA may also be subject to a 'survival effect', particularly at the very oldest ages, whereby those in poor health are more likely to leave the study with those remaining being in better health. Therefore, older people from lower social status groups may potentially be more prone to leave the study due to poor health.

Health and care are closely connected, and as such, the need for care and care utilisation are likely to reflect differences across social status groups. Analysis of people aged 65+ in the 2011 Health Survey for England (HSE) confirmed greater need for and receipt of care amongst those in the lower third of the income distribution, where there was also a greater provision of informal care (Craig et al, 2012).

Following this discussion, the next section discusses key measures of socioeconomic status. ELSA provides several SES measures, including National Statistics Socio-economic Classification (NSSEC) (employment relations-based classification scheme), household wealth (provided as quintiles), and highest educational qualification.

### 2.6.3.1. National Statistics Socio-economic Classification (NSSEC)

SES is an important measure capturing social position, although employment-based class measures are potentially problematic as an indicator of social status in old age where conventional employment based roles are less stable in the transition from long-term employment to retirement. NSSEC data is collected and provided in all waves of ELSA except wave 3 (NSSEC data for wave 3 had not been released at the time of writing), providing a purpose-built measure for capturing a dimension of social status derived from previous employment. The format of the NSSEC varies between waves: wave 1 provides the long-form version of the NSSEC, collected as part of the original Health Survey for England (HSE) (ELSA, wave 0), which is updated at ELSA wave 1 if different or not collected in the previous stage. These 2 variables were used to derive a single variable (soc class), reflecting the current NSSEC status, coded following the 8-category version of the NSSEC. In ELSA wave 2, the 8-category version is provided in a separate 'derived variables' dataset. In wave 4, NSSEC status is given either if it has changed since a previous wave or if it has not previously been collected. NSSEC data for wave 3 had not been released during the period that analysis was conducted. Due to the missing NSSEC variables, an NSSEC indicator was generated for wave 3 by imputing the most recent NSSEC response from the previous wave, where available. As such, this variable has a
greater amount of missing values in wave 3 than in other waves for respondents who were either not present or did not provide a valid response in a prior wave. Table 9 presents a breakdown of the new variable by age.

Table 9	9. NS	SEC b	y age
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NSSEC	60-64	65-74	75-84	85+	Total
1. Higher managerial	10.3	8.2	6.9	6.4	8.3
2. Lower managerial	21.9	19.3	19.9	19.2	20.1
3. Intermediate	12.4	13.5	14.8	16.4	13.8
4. Small employers	11.1	11.2	9.2	8.3	10.4
5. Supervisors	10.0	10.9	13.3	12.3	11.4
6. Semi-routine	18.6	18.6	17.0	16.5	18.1
7. Routine	14.4	16.4	15.5	15.8	15.6
8. Never worked	0.6	0.7	1.8	3.2	1.2
Total	6,276	10,499	6,599	1,895	25,269

Source: ELSA, waves 1-4

From Table 9, around 1% of the sample report having never worked with the percentage being noticeably greater in older age ranges. Of those who have worked, lower-managerial (NSSEC 2) represents the most common classification (around 20%), which is consistent across all age categories at around 20% of the sample. The higher managerial category (NSSEC 1) represents the smallest employment classification for those with a response, and is greater at younger ages with more than 10% of the youngest group being in this category.

# 2.6.3.2. Education

Education is known to be a key indicator of social status across the lifespan, and has been widely used in studies exploring the relationship between dependency and care utilisation, particularly in research using ELSA itself (most of the literature presented so far in the thesis using ELSA made use of education as an indicator of SES). The ELSA sample being analysed in this thesis is likely to have completed their education more than 35 years previously, and around 7% of the sample are aged 85+ and are likely to have completed education more than 70 years ago.

As such, it is necessary to be aware that cohort differences in educational experience due to changes in the provision of state education since the oldest respondents were at school may make social status associated with particular qualifications inconsistent across time. However, using a measure of highest educational qualification provides a way to capture aspects of social status that cannot otherwise be captured.

Waves 1 and 2 of ELSA provide a 7-item categorical measure of highest educational qualification, and this was used to derive a new 4-item categorical variable *ed\_level*, recoded following the ESDS Government-suggested 4-item categorization ('First or higher degree', ''A' level or equiv.', ''O' level or other', and 'None') (ESDS Government, 2010). Waves 3 and 4 of ELSA use multiple indicator variables for each possible qualification, which were used to derive the same measure as in earlier waves. Figure 7 presents the breakdown of the new education measure by age.





Figure 7 shows education is uncommon in older groups, and more than half of those aged 75+ have no qualifications. Conversely, the proportion with a degree is 17% in the youngest group and becomes less common in older groups, with less than 8% of those aged 85+ having university education, illustrating the expansion of educational qualifications among younger cohorts.

# 2.6.3.3. Wealth

The ELSA data provides detailed information regarding participants' economic resources, including data on pension, housing and financial wealth. Access to and receipt of particular care

<sup>&</sup>lt;sup>a</sup> chi<sup>2</sup> test of bivariate association between education and age is significant (p<0.001) Source: ELSA, waves 1-4

services in later life are likely to be heavily influenced by individual financial circumstances. Financial resources are likely to be a factor in determining eligibility to receive social care services, as well as being able to purchase care from the private sector. Each wave of ELSA has an additional dataset containing *financial derived variables*, providing a number of different individual wealth indicators, including a measure of total net wealth. In order to allow comparison between the effects of low and high wealth, a 'wealth quintile' measure (variable *totwq5\_bu*) was chosen to capture the relative advantages or disadvantages experienced by the least wealthy (quintile 1) relative to the most wealthy (quintile 5). This measure is based on the calculated total wealth from savings, investments, physical wealth and housing wealth, net of financial and mortgage debt (at the benefit unit level). Wealth quintile is collected in all waves of ELSA, and the relevant variable was subsequently merged with the core ELSA data at each wave. Figure 8 shows the breakdown of wealth quintile by age.





<sup>a</sup> chi<sup>2</sup> test of bivariate association between wealth and age is significant (p<0.001) Source: ELSA, waves 1-4

There are marked differences in wealth by age within the ELSA sample, with younger respondents tending to be wealthier. Only 15% of those aged 60-64 are in the poorest quintile, compared to almost 35% in the oldest age group.

#### 2.6.3.4. Selecting socio-economic status measures

In exploring the receipt of care for older age groups, the issue of representativeness of those in the oldest age ranges is commonly problematic, due to difficulties in sampling those at the very oldest ages. It is therefore preferential to maintain as large a sample of those in the oldest age ranges as possible. All SES indicators have missing data, ranging from 1,074 cases for wealth quintile, to 1,446 cases for NSSEC, and 1,377 missing cases for education. Table 10 shows the number of non-missing cases for each by age.

Table 10. Non-missing cases for SES measures by age

	60-64	65-74	75-84	85+	TOTAL
NSSEC	6,276	10,499	6,599	1,895	25,269
Education	6,324	10,518	6,601	1,895	25,338
Wealth	6,451	10,875	6,501	1,814	25,641

Source: ELSA, waves 1-4

Overall, all measures have a broadly similar number of valid cases, although there are a greater number of cases for wealth quintile in younger groups, while there are more cases for NSSEC and education in older groups. Choosing the wealth measure as a single indicator of relative social advantage would maximise the number of valid cases across the whole sample, but would limit the number of cases in the oldest age range who are commonly the most difficult to capture. Further, wealth represents the most current measure and captures ongoing changes in circumstances occurring after leaving the labour market, derived as it is from information on wealth during the data collection period. The education and NSSEC indicators are based on historically determined information, and can be expected to better capture the effects of longer term socio-economic trends accumulated across the life-course. Further, NSSEC includes imputed information at wave 3 and as such can be considered a less reliable measure than education or wealth, which are given in all 4 waves of ELSA.

In evaluating the best measure to include in analysis, it is important to acknowledge that all 3 measures capture different aspects of underlying socio-economic differences within the sample population. As such when considered simultaneously they are likely to cause issues in

interpreting the independent effects of each measure when all 3 measures are expected to be correlated. Table 11 shows the correlation matrix for these items, and the correlations presented are based on the Pearson correlation coefficient, measuring the correlation between 2 continuous variables. While these measures are categorical, given they can be considered to be reflecting an underlying ordinal scale they are treated here as continuous for exploratory data analysis purposes.

Table 11.	Correlation	matrix for	the SES	indicators
-----------	-------------	------------	---------	------------

	NSSEC	Education	Wealth
8 category NSSEC	1.00	1.00	
4 category Education	0.51	1.00	
5 category Wealth	-0.40	-0.40	1.00

Source: ELSA, waves 1-4

Correlations are higher between NSSEC and education, suggesting that both items capture similar aspects of underlying social status despite reflecting chronologically disparate periods of the life course. Wealth has lower correlations with both employment and education, and is likely more able to dynamically reflect an individual's current circumstances. Selecting 2 items with lower correlations may allow both historical and recent dimensions of social status to be retained, while minimising the adverse effects associated with using more highly correlated measures. Finally, in order to consider the relative usefulness of each of the 3 measures in the final analysis, preliminary logistic regressions were run to assess the relative contribution of each measure towards explaining the receipt of care (analysis not shown). This exploratory analysis showed all 3 measures are significant predictors of care use. Further, the BIC value was lower in models controlling for wealth and either education or NSSEC.

From the literature on the relationship between need and care, the convention is to use education to control for socioeconomic status, although some studies have used income, wealth and social class. As such, education is considered throughout this thesis. Analysis in later waves additionally includes wealth, which appears from preliminary analysis to be a stronger predictor of care receipt in later life. The later models will therefore allow for both early life effects of education and lifetime-accumulated effects reflected by wealth. The next section discusses ELSA weights.

# 2.7. Weights

ELSA is a repeated panel survey with the same respondents interviewed repeatedly, with interviews with participating respondents conducted approximately every 2 years. The sample for the first ELSA wave aimed to be nationally representative of the English older population aged 50+ and resident in private accommodation. The initial ELSA sample was selected from households that had previously responded to the Health Surveys for England (HSE) in 1998, 1999 or 2001. The HSE followed a 2-stage sampling strategy to ensure that all addresses on the small users Postcode Address File (PAF) in England had an equal chance of inclusion (Taylor et al, 2007). Additionally, new younger sample members were introduced at waves 3 and 4 to maintain the representativeness of the younger population.

While the design of ELSA retains a sample that is representative of the older English population, there is potential for bias in the sample due to non-response at HSE, refusal to be re-interviewed post-HSE, and non-response at each wave of ELSA (Cheshire at al, 2012). As such, weights are provided in ELSA to correct for attrition and non-response prior to the ELSA data collection period in a given wave. ELSA provides 2 different sets of weights, cross-sectional and longitudinal, which are relevant to considering the analysis presented in this thesis.

Turning to longitudinal weights first, these are provided in wave 3 onwards to account for potential bias due to the original HSE/ELSA sampling design, and from ongoing attrition in each subsequent wave of ELSA. Longitudinal weights are only given for core sample members who responded at wave 1 and all successive waves, correcting for attrition from the initial ELSA cohort as the study continues. As such, the available longitudinal weights exclude additional sample members introduced in waves 3 and 4, correcting only for prior and ongoing non-response from the first ELSA cohort. Further, the longitudinal weights are designed to be used in analysis of change from one wave to another, for example, when looking at changes in health between wave 1 and wave 4 these weights would attempt to correct for attrition by placing

greater weight on remaining ELSA wave 1 cohort members in later waves. This type of analysis is not undertaken in this thesis, and therefore the longitudinal weights are not appropriate in this research.

The provided cross-sectional weights are used to weight the sample at each ELSA wave, to reflect the age distribution of the wider population of England (based on ONS-provided 2008 household population estimates), accounting for 'the propensity to respond amongst key sub-groups' (Cheshire at al, 2012:18). As such, analysis conducted using the cross-sectional weights aims to reflect the population-level distributional characteristics of older people in England.

There are arguments against the use of weights in survey data. For example, Deaton (1997) argues there is no case for applying survey weights when undertaking regression analysis, as weights are only able to force the sample to reflect the population from which they are drawn but 'the difference in parameter values across strata is a feature of the population, not of the sample design' (Deaton, 1997:70). If a given strata are homogenous, then the unweighted model will provide an accurate and more efficient estimation of the population while if the group is heterogeneous then neither approach will be a good estimator of the population (Deaton, 1997:70).

However, the analysis presented in this thesis uses data from multiple waves of ELSA, linked to make use of the longitudinal structure of the ELSA study to provide robust estimates of explanatory factor effects, fully accounting for repeated responses (i.e. modelling clustering of the responses) from the same individuals at different time points. As such, cross-sectional weights are not appropriate for undertaking the type of analysis presented in this thesis. However, in order to examine the impact that weights could be expected to make on the findings presented in this thesis, this section presents exploratory bivariate cross-sectional analysis using the cross-sectional weights supplied with ELSA. Discussion is limited to the analytical impact of conducted analysis using weighted and unweighted data. Table 12 presents data from ELSA wave 1 on some of the key dependent and independent variables considered in this thesis, with results for both unweighted and weighted samples.

	60	-64	65	- 74	75	- 84	8	5+	Total	
	% <sup>1</sup>	% <sup>2</sup>								
Receives care?										
Yes	20.3	19.8	22.9	22.8	36.6	36.1	59.6	60.4	28.2	28.7
Sex										
Female	52.1	51.0	53.5	53.3	57.6	59.1	61.2	68.9	54.7	55.6
Has Partner?										
Yes	73.8	73.4	63.2	63.2	43.1	42.8	20.2	17.4	57.6	56.4
Has children?										
Yes	83.3	82.7	79.8	79.5	70.5	70.6	60.3	58.3	77.0	76.1
TOTAL	1,688	1,704.7	3,181	2,981.3	1,900	1,957.2	456	581.8	7,225	7,225.0
Education										
Degree	12.1	11.8	8.0	7.7	6.4	6.2	4.0	3.2	8.3	7.9
'A' level	18.8	18.8	13.8	13.4	11.1	10.8	6.6	6.4	13.8	13.4
'O' level	29.4	29.1	28.4	28.3	23.8	23.6	18.5	17.4	26.8	26.3
None	39.7	40.3	49.8	50.6	58.7	59.4	70.9	73.0	51.1	52.4
TOTAL	1,681	1,697.8	3,172	2,972.4	1,894	1,951.9	453	577.9	7,200	7,200.0
Wealth										
Qunitile 1 (low)	15.2	15.6	18.8	19.3	28.5	28.9	38.9	39.9	21.8	22.7
Qunitile 2	17.8	17.5	21.1	21.1	20.7	20.6	19.9	19.5	20.1	20.0
Qunitile 3	20.8	20.9	20.1	20.0	19.8	19.9	15.7	15.3	19.9	19.8
Qunitile 4	20.9	21.0	20.7	20.6	15.5	15.3	13.0	13.6	18.9	18.7
Qunitile 5 (high)	25.3	24.9	19.4	19.1	15.6	15.3	12.6	11.7	19.3	18.8
TOTAL	1,661	1,678.3	3,137	2,939.2	1,876	1,932.5	453	577.0	7,127	7,127.0

Table 12. Bivariate analysis of key dependent and independent variables, ELSA wave 1 - unweighted and weighted samples

<sup>1</sup> 2002 unweighted sample – core ELSA members; <sup>2</sup> 2002 weighted sample – core ELSA members Source: ELSA, wave 1

Table 12 shows that older members are under-represented in the ELSA sample, with the group aged 85+ being more than 20% greater when the population weights are applied. This is understandable as this group are likely to be under-represented in such studies, due to attrition for reasons such as poor health, movement into a care home, or mortality. The proportion receiving care appears relatively stable, even among the oldest group, and the gender balance remains broadly consistent except in the oldest group where the proportion of women in the oldest group is around 8% smaller in the un-weighted sample than the weighted sample. Turning to socio-economic status indicators, there is a slight difference among the most educated and the wealthiest, which appear to be slightly over-represented in the unweighted ELSA sample. However, differences are relatively small and most measures remain broadly consistent. For completeness, Table 13 shows the same descriptive statistics from ELSA wave 4, using unweighted and weighted samples.

	60	-64	65	- 74	75	- 84	8	5+	Total	
	% <sup>1</sup>	% <sup>2</sup>								
Receives care?										
Yes	18.3	18.8	23.0	23.3	38.3	39.8	57.1	57.8	27.3	29.2
Sex										
Female	54.7	51.2	53.5	52.4	55.7	56.3	65.1	66.8	55.1	54.3
Has Partner?										
Yes	70.2	69.4	62.7	62.1	44.4	43.2	19.5	18.0	57.9	55.5
Has children?										
Yes	76.5	75.7	78.0	77.0	72.1	70.9	56.9	55.9	74.8	73.2
TOTAL	2,007	1,912.4	2,941	2,677.4	1,490	1,711.0	476	613.3	6,914	6,914.0
Education										
Degree	20.6	17.5	15.4	12.5	10.7	8.3	8.8	6.5	15.1	12.0
'A' level	25.8	24.0	21.2	19.1	15.6	13.3	16.6	13.8	20.7	18.1
'O' level	31.1	31.3	30.9	30.5	30.8	29.8	26.3	25.2	30.5	30.0
None	22.5	27.1	32.4	37.9	42.9	48.6	48.3	54.4	33.7	39.9
TOTAL	1,570	1,475.4	2,250	2,015.4	1,454	1,652.3	476	606.9	5,750	5,750.0
Wealth										
Qunitile 1 (low)	15.7	18.1	16.3	18.2	22.0	24.4	31.7	36.2	18.5	21.3
Qunitile 2	16.4	16.2	18.1	18.3	22.6	23.1	20.3	19.0	18.7	19.0
Qunitile 3	20.0	20.4	21.3	21.4	21.1	20.7	19.0	18.3	20.7	20.7
Qunitile 4	22.5	21.9	21.5	20.8	19.8	18.7	17.5	16.5	21.1	20.2
Qunitile 5 (high)	25.3	23.4	22.8	21.3	14.5	13.1	11.4	10.0	20.9	18.8
TOTAL	1,947	1,852.6	2,894	2,635.1	1,466	1,683.7	473	608.6	6,780	6,780.0

 Table 13. Bivariate analysis of key dependent and independent variables, ELSA wave 1 - unweighted and weighted samples.

<sup>1</sup> 2008 unweighted sample – core ELSA members; <sup>2</sup> 2008 weighted sample – core ELSA members Source: ELSA, wave 4

As in the wave 1 sample, the 65-74 group are over-represented in wave 4, while the older groups are under-represented. With reference to the socio-economic status measures, those in most advantaged groups are over-represented, and by a slightly larger margin than in wave 1. For example, those with degree or 'O' level education, and those in the 2 wealthiest quintiles. Women aged 60-74 are over-represented, but under-represented at ages 75+ in the unweighted sample. The proportion receiving care is broadly consistent when the weights are applied and is broadly stable for each age group after weighting. To reiterate, ELSA includes younger cohorts in subsequent waves (waves 3 and 4), thus there is some replacement of sample members, so loss to follow up/attrition leading to the sample no longer reflecting the population should not be a big issue.

Further exploratory work was conducted to test the impact of weights in the context of multivariate analysis, involving cross-sectional logistic regression (results not shown due to space limitations). The first set of models used a count-based measure of dependency (replicating independent variables used in section 4.2.1), the second set of models using a domain-based count of dependency (replicating independent variables from section 4.3.1). All models included the same dependent variable 'receives any care', and were run using 2002 data and 2008 data, with each regression run with and without cross-sectional weights.

This exploratory analysis identified that differences in the odds ratios (OR) of explanatory factor effects when weights were applied were marginal. In the weighted analysis, the effects of explanatory factors were slightly smaller, but the significance of all explanatory variables remained consistent whether or not weights were applied. This suggests that when using the data without weighting, the effects of explanatory variables may be overestimated, although the difference was small. While this issue must be acknowledged, it was considered that the analysis remained representative of the wider population.

# 2.8. Research sample and modelling approach

This thesis explores the relationship between dependency and care receipt by considering and implementing a number of different measures of need in the analysis of care receipt in later life. The independent variables outlined in this chapter are used throughout this thesis, except where indicated.

# 2.8.1. Final research sample

Since ELSA respondents without a difficulty are not able to identify receipt of care, the sample under analysis is restricted to only respondents with at least 1 mobility, ADL or IADL difficulty, to focus explicitly on how differences in dependency are related to the type of care received by those who have needs.

### 2.8.2. General modelling approach and model diagnostics

This section discusses the modelling diagnostics adopted for the main analysis method of logistic regression presented throughout the thesis.

# 2.8.2.1. Bayes Information Criteria

Throughout the thesis, the modelling diagnostic the Bayes Information Criteria (BIC) will be used to compare models. The BIC (Raftery, 1986) provides a way to systematically compare models to select the model of best fit. The BIC provides a way to directly measure the effectiveness of a given model in describing the outcome of interest, given the data and number of explanatory variables included in the model. As such, this approach allows comparison between two-or-more models to determine the most efficient, with the lowest BIC representing the optimal model of those considered. Differences in BIC between models can be interpreted as the strength of evidence for selecting one set of parameters over another to model a given outcome. In terms of the strength of evidence to support one model over another, the difference in BIC across models is interpreted as follows: 0-2 Weak evidence; 2-6 Positive evidence; 6-10 Strong evidence; >10 Very strong evidence (Raftery, 1995:139). For the purposes of comparing the different approaches to modelling dependency considered in this thesis, BIC is reported for all models where appropriate to evaluate the relative benefit of adopting different measures of dependency when modelling care receipt in later life.

#### 2.8.2.2. Pseudo r<sup>2</sup>

Although the BIC value provides a way to evaluate the choice of one model over another, it does not provide scope to directly interpret the relative benefits of one model over another. An alternative diagnostic tool used for such purposes is the  $r^2$  value, which is conventionally interpreted as the proportion of the total variance in the dependent variable explained by the independent variables. In this way, it is possible to understand the degree of improvement that one model provides in explaining the outcome of interest. However, due to the nature of undertaking longitudinal analysis, the statistics generated when undertaking longitudinal regression with the xtlogit function cannot produce an  $r^2$  statistic. As an alternative, all xtlogit models were also run as standard logit models, that is all responses are analysed as independent responses from unique individuals and there is no additional control for within-subject clustering. Acknowledging this, models presented in this thesis additionally report the pseudo r<sup>2</sup> value alongside the BIC statistic, simply as a guide to the relative contribution made by each approach,

### 2.8.2.3. Rho

The conditional intra-class correlation, reported in the *rho* statistic, measures the proportion of the overall variance in the dependent variable being modelled, due to variance in responses from the same respondent at different time points (Skrondall and Rabe-Hesketh, 2008). For example, a rho statistic of 0.75 identifies that a high proportion (75%) of the variance in the outcome being modelled can be attributed to variability between responses from the same individuals (within-subject), as opposed to variation in the responses of different respondents (between-subject). As such, the rho statistic is reported in all models to consider how the stability of responses from the same individuals contributes to the outcomes of interest, being care received from different sources.

# 2.8.2.4. Modelling approach using xtlogit

All logistic models presented in this thesis follow the same approach, presenting odds ratios (OR) and 95% confidence intervals (CI) for each independent variable, along with the statistical significance of the parameter estimates. As described, the model diagnostic statistics presented include the BIC and the conditional intraclass correlation (rho). Additionally, the pseudo  $r^2$  statistic is also reported to allow easier interpretation of the descriptive power of each approach in explaining the outcome of interest. In line with normal reporting of significance levels, stars are included to aid interpretation (Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001). Analysis is conducted in Stata using the xt suite of commands, allowing for the longitudinal nature of the 4 waves of ELSA data to be accounted for, setting the id (idauniq) and time series (year). Models were run using the xtlogit command for a logistic random intercept model (Rabe-Hesketh and Skrondal, 2008). The xtlogit command is an extension of a logistic regression model

applied to longitudinal panel data, accounting for the fact a person may be in the model more than once.

# 2.9. Summary of chapter

This chapter outlined the research aims of the thesis, the framework used to conceptualise the use of social support in later life, and reviewed available secondary data sources. ELSA was identified as the dataset that will be used to undertake analysis to meet the specified research aims. Discussion and descriptive analysis of key variables provided in ELSA was presented. The chapter continued with discussion of the issue of weights in the context of longitudinal analysis, and exploratory analysis was presented to consider the potential impact of undertaking analysis both with and without weights. The chapter finished with a discussion of the analytical methods that are to be used to undertake the analysis in this study. The next chapter discusses previous research that has used ELSA to explore questions relating to care and dependency, and presents a detailed descriptive analysis of the prevalence of the measures that will be considered to classify dependency throughout this thesis.

# Chapter 3 3. <u>The English Longitudinal Study of Ageing</u>

This chapter begins with notable existing research that has used ELSA to explore aspects of care and dependency. The chapter then presents a detailed descriptive analysis of the 23 mobility, ADL and IADL items, which are central to the thesis in understanding how such measures may be used to capture the dimensionality of need in later life.

# 3.1. Relevant previous research using ELSA

Before beginning the analysis, notable literature from a review is discussed, as many of the most important sources have already been highlighted throughout chapters 1 and 2. The review of literature in this chapter was conducted specifically to identify research that has used ELSA to explore questions associated with dependency and care. As such, a search was performed through the Web of Science for studies referencing ELSA, including relevant key words (for example, 'informal care', 'activities of daily living' and 'disability') to focus the search. The following provides an overview of research using ELSA relating to the thesis' key themes of dependency and care, focusing on key areas: dependency, care supply and care receipt.

# 3.1.1. Dependency

Steel et al (2003) conducted cross-sectional analysis of ELSA wave 1, finding ADL, IADL and mobility problems among older people from routine and manual occupational backgrounds, finding differences in levels of dependency are weaker in older ages. They consider differences in the prevalence of individual ADL and IADL difficulties, limiting their reporting to noting a high prevalence of difficulties with IADL items housework and shopping (Steel et al, 2003).

Gjonça, Tabassum and Breeze (2009) use data from ELSA wave 1 to define a summary measure of disability, based on the number of ADL, IADL and mobility difficulties, which is then used to explore the socioeconomic characteristics of disability. They report that wealthier older people suffer lower levels of disability, and their analysis of socioeconomic determinants of disability provides further support to the theory that the socioeconomic gradient in health is weaker at older ages. Breeze and Stafford (2008) use the longitudinal design of ELSA to consider factors affecting the development of ADL, IADL and mobility need from wave to wave 3, finding lower wealth and neighbourhood deprivation predicting limitation in all domains at wave 3. They also consider the effects of quality of relationships between children and partners, suggesting an association between weak family support and the onset of difficulties, particularly for mobility limitations (Breeze and Stafford, 2008).

Nazroo, Zaninotto and Gjonça (2008) use principal components analysis (PCA) of 13 ADL, IADL and mobility difficulties to construct an ordinal scale of disability, which is then dichotomised. The new measure is used to estimate disability-free life expectancy and life expectancy with a disability, and no further analysis using this measure is considered. This approach reduces the multidimensionality of multiple needs to a single binary indicator, representing a useful approach to accommodate a large number of dependency measures while retaining unique differences between particular difficulties.

Zaninotto, Nazroo and Banks (2010) use ADL, IADL and mobility difficulties to construct a summary of measure of limitation across the 3 domains, with limitation classified across 3 categories (None, Mild, and Severe). The *severe* category captures any respondent with any ADL difficulty, or any specific IADL difficulties, so while there is differentiation between some IADL measures (for example, those with difficulty taking medications or preparing a meal are classified with mild limitation), there is an aggregation of all ADLs to a single binary measure. They use the new measures to compare the prevalence of limitation in ELSA wave 1 to ELSA wave 4, considering differences by level of education, reporting an increase in those without limitation among the most educated, with varying patterns of change across different age groups.

# 3.1.2. Care supply

Rafnsson, Shankar and Steptoe (2015) consider the effects of transitions from and to caring for partners and children, using wave 3 and 4 of ELSA. They find those providing care suffered worse quality of life outcomes, whether the supply of care was recent, ongoing, or had since ended.

Although their analysis does not differentiate care provision to partners from care to children, it provides important context to the present study, illustrating the detrimental effects that the burden of caring for a partner or child can bring.

Bordone (2015) uses data from 4 waves of ELSA to explore how the transfer of different types of support, classified by affectual and functional solidarity, between children (including grandchildren) and their parents affects older people's sense of control. Their descriptive analysis confirms women in their sample experience worse health than men, including depression, greater ADL and IADL difficulty, and worse self-reported health. Although their study considers support with functional difficulties, help from children was considered as an explanatory measure. As such, there is no consideration of the factors affecting care supply from children, only how the transfer of functional solidarity affects older people's sense of control. For example, they report older fathers receiving large amounts of support from children are likely to suffer loss of their sense of purpose (Bordone, 2015:1268).

Vlachantoni (2010) uses data from ELSA waves 2-4, presenting a predominately-descriptive summary of the characteristics of older carers. She finds women more likely to care than men, more likely to care in all age groups except for those aged 80+, and more likely to care regardless of their marital state (Vlachantoni, 2010). Additionally, she finds caring for a partner more likely at older ages, with men more likely to care for a partner than women (Vlachantoni, 2010). Women often cared for more than 19 hours in a week, and those providing intense care were more likely to report good health, although this could be explained by good health being a necessary characteristic for those caring for long hours (Vlachantoni, 2010). Finally, undertaking cross-sectional analysis of ELSA wave 3, she finds the provision of intense care was mainly predicated on someone not being employed, and his or her relationship to the person being cared for. This study identifies key differences amongst men and women who care, and provides important contextual detail to the analysis presented in this thesis.

#### 3.1.3. Care receipt

Blomgren et al (2012) conduct comparative analysis of informal care in England and Finland, using data from ELSA wave 1 for the English analysis. They model care from children and care from spouses separately, finding greater dependency (ADL and IADL difficulties, problems climbing stairs) increased the likelihood of care from children and partners, and less educated older people more likely to receive care from a child but not from a spouse (Blomgren et al, 2012). Additionally, they report women more likely to receive both types of care, with greater age only significant in terms of receiving care from children (Blomgren et al, 2012).

Breeze and Stafford (2008) conduct cross-sectional analysis of care receipt using data from ELSA wave 3, focusing on help with 6 types of activity (e.g. moving around the house, preparing and eating food, etc). Their analysis focuses on informal and formal help, differentiating between different types of informal care (partners, children and other family) but aggregating private and state-funded care services into a single formal category. Their analysis suggests partners are the most common source of help, except amongst very old women who were predominately widowed (Breeze and Stafford, 2008). They report children help with tasks such as housework and shopping, but may be less likely to help with more intimate tasks, such as help with bathing or helping (Breeze and Stafford, 2008). Their analysis gives less attention to formal care, perhaps due to the aggregation of private and state-funded are, but finds professional care more common amongst older women (Breeze and Stafford, 2008).

Vlachantoni et al (2011) undertake analysis of ELSA, BHPS and GHS data to explore the association between particular ADL needs and different care outcomes, focusing on the existence of unmet need. In order to provide comparison between the three datasets they restrict their analysis to 2 specific ADLs (difficulty bathing, and getting dressed), exploring care receipt for those with either one or both difficulties, finding that unmet need varies according to the specific difficulty being considered. Care in their analysis covers three types – informal (including all types of informal care in a single category), formal, and private care. Their study provides detail on the importance of accounting for differences between particular difficulties

when examining the need/care relationship. Further, their research provides evidence against the aggregation of needs, a commonly used approach in the analysis of dependency in later life.

Vlachantoni et al (2015) use cross-sectional descriptive analysis of ELSA wave 4 to consider differences in the receipt of informal, formal and private care for different types of difficulty. The report bathing and dressing as commonly supported by formal care, shopping and housework by private care, and moving around the home, using the telephone and managing money by informal support. Notably, they find men with high IADL needs have a disproportionately greater likelihood of receiving informal care, while women with only moderate rather than high IADL needs are most likely to receive informal support, particularly if a woman was married (Vlachantoni et al, 2015). Considering formal care, they find older people with greater ADL needs more likely to receive this type of care, but the effects of IADL need is shown to have a greater effect than ADL needs by comparison (Vlachantoni et al, 2015). Finally, while women are more likely to receive private care, it was moderate or high IADL need that almost completely drives receipt of private care, with was a positive effect from greater wealth (Vlachantoni et al, 2015). Their analysis reflects similar interests to the present study, unpicking the effects of different types of need on patterns of care receipt. However, one limitation of their study is the conflation of a number of differences sources into a single category of informal care, which the present thesis will help to unpick.

### 3.1.4. Research using the Irish Longitudinal Study on Ageing (TILDA)

In addition to ELSA, similar studies are currently being established in each of the different nation states, which compose the British Isles, including the Irish Longitudinal Study on Ageing (TILDA), the Northern Ireland Cohort for Longitudinal Study of Ageing (NICOLA) and the prospective Healthy Ageing in Scotland study (HAGIS). Since the oldest of these studies, TILDA, has only one wave of data currently released, with the other studies still at the data collection stage (NICOLA) or at the preliminary pilot study stage (HAGIS), there is a limited amount of research published. For example, a review of studies undertaken with the Irish Longitudinal Study on Ageing (TILDA) found only one study exploring health care utilisation, which considered differences in GP visits between older Irish people who pay for health care and those that do not (Hudson and Nolan, 2015). As such, the study is not relevant in the specific context of this thesis, focusing on formal and informal care to dependent older people at home.

#### 3.1.5. Summary of section 3.1

This section has reviewed existing literature that has used ELSA to explore questions around dependency and care in old age. There are a number of studies with similar research aims, notably the work of Vlachantoni et al (2011) and Vlachantoni et al (2015), which use ADL, IADL and mobility measures in ELSA in different ways. However, the majority of studies are cross-sectional, and where the longitudinal aspects of ELSA have been used they have not been used to directly explore links between dependency and care in later life. Further, there are no studies undertaking a detailed analysis of the dimensionality of dependency. As such, using ELSA to consider the key research aims through the application of longitudinal analysis, this thesis addresses a gap in existing research literature on dependency and care.

The next section undertakes descriptive analysis of the ELSA data, to unpick the characteristics of dependency resulting from specific ADL, IADL and mobility needs.

# 3.2. Prevalence of individual difficulties

Needs requiring care and support are most likely to develop progressively, as a result of the gradual accumulation of different difficulties and, for the purposes of this thesis, this process of progressive accumulation is reduced to 3 stages:

- No needs or minor needs, which do not directly impede a person from performing everyday tasks
- Dependency develops in relation to a combination of different functional difficulties, directly affecting a person's ability to perform one or more common day-to-day tasks independently
- Complex needs develop from the accumulation of multiple difficulties, where assistance is necessary to perform necessary daily routines and activities

The development of needs is unlikely to follow such a discrete path, as different difficulties may develop at different points in time, and the impact of a difficulty on a person's overall levels of dependency and the care they receive will vary from one person to another. However, for the purposes of describing the development of needs resulting in care being received, the progressive accumulation of minor impairments leading to the development of more complex needs is most likely to follow this order. Of course, there may be circumstances in which severe dependency occurs suddenly without a prior history of existing need, perhaps due to the onset of a debilitating illness or a fall or injury. In seeking to understand the characteristics of need, and how dependency develops over time, this section discusses the prevalence and characteristics of 23 Mobility, ADL and IADL difficulties reported by ELSA respondents.

Considering the prevalence of Mobility, ADL and IADL difficulties initially as individual isolated items, Table 14 shows the proportion of cases reporting each difficulty, by age category. As with all subsequent tables presented throughout the thesis (unless otherwise specified), Table 14 shows data from all 4 waves of ELSA, potentially including more than one response from respondents present in more than one wave. Due to the centrality of these measures in this thesis, 7 cases with missing data on Mobility or ADL/IADL difficulties are excluded from further analysis, alongside 1 case with missing age data.

From Table 14, there is wide variability in the numbers reporting individual Mobility, ADL or IADL difficulties across age groups. On average, less than 3% have difficulty with the least common items (ADL *eat* and IADL *medi*). In contrast, 42% confirm difficulty with the most commonly reported items (Mobility *stairs* and *stoop*), 19% report the most common IADL item (*hwork*), and 15% report the most commonly reported ADL difficulties (*dress* and *bath*). With the exception of one item – Mobility *sit2hrs* – all items become more common as age advances. The item sit2hrs is more prevalent at ages 60-64 than 65-74, which may suggest that this particular item is excessively prevalent in the early stages of old age, or simply that this item is more likely to be reported by younger respondents. It is worth restating that the ELSA sample

		60-64	65-74	75-84	85 plus	TOTAL
Mobility	100vds	9.7	12.1	19.8	38.2	15.3
,	sit2hrs	14.3	13.9	14.7	15.7	14.3
	getup	23.9	27.1	35.4	44.9	29.6
	stairs	31.5	39.7	52.2	69.0	42.8
	stair	10.7	15.6	24.8	42.7	18.6
	stoop	32.3	38.7	51.6	61.9	42.0
	extend	10.0	11.0	14.9	21.8	12.5
	pull	15.0	18.7	27.2	43.8	21.7
	weights	20.7	24.6	38.3	59.8	29.6
	coin	4.5	5.4	8.4	15.1	6.6
ADL	dress	11.3	14.2	19.6	27.8	15.8
	wroom	2.5	3.0	5.1	13.4	4.2
	bath	7.8	11.5	20.0	35.9	14.4
	eat	1.6	2.0	3.5	8.3	2.7
	bed	5.7	5.7	7.6	13.3	6.7
	toilet	2.9	3.3	5.3	9.7	4.2
IADL	map	3.6	4.8	9.1	22.0	6.8
	meal	3.1	4.1	7.1	22.1	5.9
	shop	6.5	8.0	15.6	37.3	11.7
	phone	1.1	1.8	4.7	11.6	3.1
	medi	1.2	1.8	3.2	10.2	2.6
	hwork	11.9	14.9	25.7	46.4	19.1
	money	1.4	2.4	5.4	18.0	4.0
	TOTAL	6,820	11,255	6,733	1,907	26,715

Table 14. Primary domain difficulties reported, by broad ages (percentage of total sample reporting each difficulty)

Note: full label descriptions in Table 3 Source: ELSA, waves 1-4

includes only older people living at home. This excludes those in society with dependency needs that cannot otherwise be managed at home, including some younger pensioners with high dependency needs.

As mentioned, Table 14 uses data from all 4 waves of ELSA simultaneously. In order to understand the prevalence of individual difficulties as they occur longitudinally, Figure 9 shows the proportion of responses across all waves where each difficulty is confirmed (marked 'Overall'), the proportion of respondents who *ever* report each difficulty ('Between') and, for those who ever report each difficulty, the proportion of responses in which the difficulty is confirmed ('Within'). For the purposes of better illustrating differences in the patterns of prevalence between different difficulties, the difficulties in Figure 9 are ordered within each of the 3 domains from the difficulty most commonly ever reported to the least commonly reported difficulty.





Note: full label descriptions in Table 3 Source: ELSA, waves 1-4

Figure 9 shows that the order of prevalence for each difficulty is the same, whether including multiple responses from the same individual at different waves (Overall) or restricted to individuals who ever have the difficulty (Between). Over half of ELSA respondents report difficulty with Mobility items stairs and stoop in at least 1 wave. Of those ever having either difficulty, almost 80% of all responses confirm the difficulty. This suggests that these particular difficulties are experienced commonly and consistently. Compared to the Mobility difficulties, ADL and IADL difficulties are less common, and less than 20% of respondents ever report 10 of the 13 items and less than 10% of all ELSA respondents ever report 7 of these difficulties. Notably, more than 20% of all ELSA respondents report difficulty with ADLs *dress* and *bath* and IADL *hwork* in at least one wave.

When ordered from most to least prevalent, difficulties that are more prevalent tend to be reported more consistently across time. However, difficulties associated with walking – i.e. Mobility *100yds* and ADL *wroom* – are both more consistently reported than would be expected given their prevalence. A similar pattern can be seen for IADLs *meal* and *shop*, which are reported more consistently than their prevalence might suggest. This suggests that while some difficulties may come or go across time, others are likely to be ongoing for those who develop them.

Figure 9 showed that the prevalence of different difficulties maintained an ordinal consistency whether considering all responses or the proportion of respondents to ever report each item. In order to focus explicitly on older people with needs, Table 15 presents Overall proportions of the sample (sample with any difficulties) reporting individual Mobility, ADL and IADL difficulties, ranked by prevalence within 3 age groups (65-74, 75-84 and 85+). To enable easier identification of each type of difficulty, ADL items are shown in *green* and IADL items are shown in *blue*, while Mobility items are shown in black.

From Table 15, difficulties are far more prevalent in very old age, with IADL hwork and shop and ADL bath reported in more than 40% of all cases from those with needs. By contrast, only around 10% of cases include ADL toilet or eat. Common Mobility difficulties are highly prevalent even among younger respondents, with over 60% of responses from those aged 65-74 having difficulty with Mobility stairs and stoop. There are also differences in the way prevalence of difficulties changes with age. For example, while more than half of all difficulties show an absolute increase of 10% or less between ages 65-74 and 85+, for example ADL wroom (walking across a room) and dress, and IADL phone and medi (taking medications), other difficulties increase by more than 20%, including ADL bath and IADL shop and hwork. This suggests that approaches operationalizing need with binary measures reflecting any ADL or IADL difficulty, may fail to account for the way different activities may reflect quite different needs, depending on which needs are experienced and when they occur.

Of course, differences in the prevalence of Mobility difficulties appear more pronounced, with highly prevalent items such as stairs, stoop and weights remaining far more prevalent in both early and later old age. Although Mobility difficulties 100yds and stair are less prevalent among younger respondents than other Mobility difficulties such as weights and stoop, they increase in absolute terms by a similar amount between the youngest and oldest groups.

While almost all difficulties increase in prevalence, the proportion with Mobility difficulty sit2hrs actually declines from ages 65-74 to 85+. Table 3 showed that when responses from respondents

	Age 65 – 74	%	Age 75 – 84	%	Age 85+	%	Total	%
>60%	stairs stoop	63.5 62.0	stairs stoop	68.3 67.5	stairs stoop weights	78.0 70.0 67.7	stairs stoop	67.0 65.0
>50%			weights	50.1	<mark>hwork</mark> getup	52.5 50.9		
>40%	getup	43.3	getup	46.2	pull stair 100yds shop bath	49.6 48.3 43.3 42.3 40.6	weights getup	46.8 45.3
>30%	weights pull	39.4 30.0	pull hwork stair	35.5 33.5 32.5	dress	31.5	pull hwork stair	34.4 30.9 30.6
>20%	stair hwork dress sit2hrs	25.0 23.9 22.6 22.2	bath 100yds dress shop	26.1 25.9 25.7 20.4	meal map extend money	25.0 24.9 24.6 20.4	dress 100yds bath sit2hrs	24.8 24.7 24.0 20.5
>15%	100yds bath extend	19.4 18.4 17.7	extend sit2hrs	19.4 19.2	sit2hrs coin wroom bed	17.7 17.1 15.2 15.0	shop extend	19.2 19.2
>10%	shop	12.8	map coin bed	11.9 10.9 10.0	phone medi toilet	13.2 11.6 11.0	map coin bed	11.4 10.5 10.1
>5%	bed coin map meal toilet	9.1 8.6 7.7 6.5 5.2	meal money toilet wroom phone	9.2 7.0 7.0 6.7 6.1	eat	9.4	meal money wroom toilet phone	9.8 7.0 6.8 6.6 5.3
<5%	wroom money eat phone medi	4.8 3.8 3.3 2.9 2.8	eat medi	4.5 4.2			eat medi	4.5 4.4
TOTAL		7,036		5,151		1,685		13,872

Table 15. Primary domain difficulties reported ordered by % of respondents reporting the difficulty, by age group (% of people with 1+ difficulty)

Note: ADL items are shown in green, IADL items are shown in blue Source: ELSA, waves 1-4

who have no difficulties are included, the proportion actually increases with age. This is shown more clearly in Figure 10.

Although the proportion of all responses with this difficulty does increase with age, the increase is minimal and remains around 15% of responses regardless of age. However, when considered only in terms of the prevalence amongst those with needs, there is a consistent decline across

Figure 10. Proportion reporting Mobility difficulty sit2hrs, by age



Source: ELSA, waves 1-4

age groups. This suggests that this item is more prevalent amongst those experiencing underreporting this particular difficulty, 'because they do social comparisons with respect to the ageing process and their own health' (Dale et al, 2008:200). Younger respondents may identify this as problematic 'considering their age', when better health might reasonably be assumed. In turn, older respondents may consider their needs in terms of older age, when such mobility problems become more commonplace. As such, it could be hypothesised that younger respondents may report their needs differently to older respondents, and further investigation of ELSA and modelling could help to unpick this.

While this section has considered the prevalence of individual difficulties, care is likely to be received in response to combinations of difficulties, which together may result in more complex dependency needs. It is therefore of interest to examine how combinations of difficulties occur in later life, and what cumulative or additional impact combinations of difficulties have on the care older people receive.

# 3.2.1.1. Considering multiple Mobility, ADL and IADL difficulties

This thesis explores the relationship between need and care. In these terms, the term *dependency* describes a state in which an individual experiencing one or more difficulties is

unable to perform key activities or tasks unaided. The 23 difficulties measured In ELSA cover a range of functional movement and practical activities that may potentially impede independence in old age. As the prevalence of different Mobility, ADL and IADL difficulties increases in later life (as discussed in section 3.1), it becomes increasingly likely that multiple difficulties accumulate, and more complex needs are likely to develop with advancing age. The progressive development of dependency, as a result of accumulating multiple difficulties, would commonly see the greatest dependency at older ages. It is important to note that people of all ages may become dependent on others regardless of their age. As needs accumulate in later life, individuals may begin by managing with their impairments and coping with less complex needs. For some, a point will be reached at which they are unable to perform particular activities unaided. Others may be affected by the sudden development of needs, for example, those caused by a fall, accident or debilitating illness. Further, dependency may be transient, needs affecting a person only temporarily and from which they recover, or more long-term, for some affecting them throughout later life.

Care for someone with dependency is a way of managing with difficulties, and the point at which an individual seeks or receives assistance will be a result of both the combination of impairments and disabilities they have, as well as background characteristics and potentially unmeasurable behavioural factors, such as the propensity to seek care. Similarly, care is not simply provided automatically in response to emerging dependency. Decisions about the provision of unpaid care must be determined by negotiation with family members or friends, with formal care involving a process of referral and assessment by health care professionals, while the decision to pay for private care will involves negotiations about what and which services to buy. There are of course overlaps across these different contexts of care, but impairments and disabilities reflected by Mobility, ADL and IADL difficulties are only part of the process by which care is ultimately received.

Keeping this in mind, this section explores how Mobility, ADL, and IADL difficulties commonly occur collectively. Building on the discussion of these difficulties in section 3.1, this section

considers the progressive accumulation of difficulties and considers the complexity of needs in later life. To begin this discussion, Table 16 shows the total number of difficulties (range 0-23) reported by a more refined age breakdown. Figures presented in Table 16 reflect the total number of responses across all 4 waves of ELSA (i.e. the Overall proportion).

Number of difficulties - % of age group									
# difficulties	60-64	65-69	70-74	75-79	80-84	85-89	90+	TOTAL	
0	46.5	41.2	33.3	26.5	19.2	12.3	9.7	34.4	
1	16.6	16.4	16.3	14.5	13.7	8.4	4.4	15.2	
2	8.9	10.3	11.7	11.5	9.9	9.3	5.9	10.2	
3	6.0	6.8	7.8	8.7	8.2	9.1	4.4	7.3	
4	4.5	5.1	5.8	7.5	7.3	8.4	5.9	5.9	
5	2.8	3.7	4.8	6.2	6.1	6.0	6.1	4.5	
6	2.5	3.1	3.6	4.5	5.2	6.2	3.4	3.6	
7	1.8	2.2	3.1	3.4	4.6	4.7	6.3	2.9	
8	1.8	1.9	2.5	3.3	4.2	5.5	5.9	2.7	
9	1.6	1.7	2.2	2.6	3.4	4.0	5.7	2.3	
10	1.5	1.5	1.5	2.1	4.0	4.5	4.8	2.0	
11	1.1	1.3	1.5	2.1	3.4	3.8	3.4	1.8	
12	0.9	1.0	1.2	1.5	2.5	3.5	4.8	1.4	
13	0.9	0.9	1.2	1.4	1.7	2.8	4.0	1.3	
14	0.8	0.8	0.8	0.9	1.8	3.0	5.9	1.1	
15	0.5	0.6	0.8	0.8	1.3	2.1	3.6	0.8	
16	0.4	0.5	0.7	0.6	0.9	1.7	3.8	0.7	
17	0.2	0.3	0.4	0.5	0.7	1.2	1.2	0.4	
18	0.2	0.2	0.2	0.5	0.4	1.2	2.0	0.4	
19	0.2	0.1	0.2	0.4	0.4	0.3	1.4	0.3	
20	0.1	0.1	0.1	0.2	0.4	0.2	2.2	0.2	
21	0.1	0.1	0.1	0.1	0.4	0.8	1.8	0.2	
22	0.0	0.1	0.1	0.2	0.2	0.6	1.2	0.1	
23	0.0	0.0	0.1	0.1	0.1	0.3	2.0	0.1	
Total	6,820	5,912	5,343	3,977	2,756	1,412	495	26,715	

Table 16. Number of difficulties reported, by a	ge
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Source: ELSA, waves 1-4

Table 16 shows for 1 of every 3 of all responses, no Mobility, ADL or IADL difficulties are reported, and a similar proportion reports 1-3 difficulties. The proportion with a difficulty and the number of difficulties increase with age: 22% aged 60-64, 43% aged 75-84, and 65% aged 85+ have 4-or-more difficulties. As expected, the most complex needs are experienced by the oldest old. For example, less than 5% of all cases have 14+ difficulties – less than 3% aged 60-64 compared to 15% aged 85+. In order to make the data from Table 16 easier to interpret, the continuous 'total number of difficulties' was recoded to a new categorical measure, combining the number of difficulties into 6 bands as follows: [None], [1-3], [4-8], [9-13], [14-18], and [19-

23]. Figure 11 shows the differences in complexity of needs using the new measure, by broad age group.



Figure 11. Number of difficulties reported (6-item categorical version), by proportion of age group

Source: ELSA, waves 1-4 (following Table 16)

Figure 11 shows the marked drop in the proportion reporting no difficulties in older ages, while the proportion with more complex needs increases markedly in the oldest group. Amongst the youngest group, the largest proportion has no needs. At ages 65-74 there is a broadly equal proportion without needs as with 1-3 difficulties. At ages 85+, almost 90% have a difficulty and 65% have more than 3 difficulties, compared to 43% of the group aged 75-84.

Considering age as a continuous measure, the progressive nature of needs in old age is illustrated in Figure 12, showing the mean number of difficulties reported at each age from age 60 onwards. In the whole sample, the mean number of difficulties reported is around 3.3 and the average is slightly higher at around 5.1 when only the sample with any difficulties is considered.

Figure 12 clearly demonstrates a consistent increase in difficulties with age. The increase is more moderate between age 60 and 80, showing a more pronounced rate of increase from this point. Further, as age increases the number of difficulties in the total sample approaches the



Figure 12. Mean number of difficulties, by age (all, and those reporting 1+ difficulty)

Source: ELSA, waves 1-4

number of difficulties in the subsample with a difficulty, reflecting the commonality of complex needs in very old age.

To illustrate differences in the types of needs occurring in later life, Figure 13 shows the mean number of Mobility, ADL and IADL difficulties for the whole sample (based on responses from all 4 waves of ELSA). Given that each domain is comprised of a different number of difficulties (10 Mobility, 6 ADL and 7 IADL items), there is a broadly similar pattern of increase in all 3 domains, with the most notable increase occurring at around age 80. At age 60, an average person will have 1.6 Mobility difficulties, 0.3 ADL difficulties, and 0.3 IADL difficulties. By age 80, the average person will have 2.8 Mobility difficulties, 0.6 ADL difficulties, and 0.7 IADL difficulties. Until age 80, the rate of increase for ADL and IADL domain difficulties are broadly the same, despite the slight difference in the number of component difficulties in each domain, although the number of ADL difficulties increases at a greater rate at age 80+.



Figure 13. Mean number of Mobility, ADL and IADL difficulties reported, by age

Turning to consider the development of dependency for those experiencing needs, Figure 14 shows the mean number of difficulties within each domain of the sample with any difficulties.



Figure 14. Mean number of Mobility, ADL and IADL difficulties reported by those with 1+ difficulties, by age

When ignoring those in the sample without difficulties, the average number of ADL and IADL difficulties is slightly larger, while there is a more pronounced increase in the number of Mobility difficulties. The average number of difficulties remains broadly stable until around age 70, a slight increase to age 75, and a sharper rate of increase from age 80 onwards. At age 60, an average person with at any needs has 3.2 Mobility, 0.6 ADL, and 0.6 IADL difficulties; by age 80

Source: ELSA, waves 1-4

Source: ELSA, waves 1-4

they will have 3.7 Mobility, 0.7 ADL, and 0.9 IADL difficulties; by age 80 there is only a modest difference in the relative complexity of ADL and IADL needs, whether or not those without needs are accounted for.

The impact of experiencing different difficulties will vary according to the nature of the difficulties themselves. For example, a single Mobility difficulty such as 'lifting a heavy weight' may not in itself present a problem, as it may be possible to avoid such activities entirely. In contrast, difficulty with more complex and fundamental ADL activities, such as 'using the toilet' and 'getting dressed', represent far greater obstacles to independence. Additionally, difficulty with complex activities such as 'taking a bath' or 'getting in and out of bed' are unlikely to develop in isolation. To examine how particular difficulties may be associated with more or less complex needs, Table 17 shows the average number of difficulties reported by individuals with each individual Mobility, ADL or IADL item.

Table 17 shows that, on average individuals experience 3.3 difficulties, and this increases with age. A relatively modest increase in number of difficulties occurs early on, and a more marked increase from age 80 onwards, both overall and for each type of difficulty. Used in this way, the mean number of difficulties may be used to summarize the relative complexity of needs associated with each difficulty. High numbers of difficulties reflect those experienced by those with complex needs. Conversely, low numbers reflect difficulties that are common for those with few needs. As such, the needs of those having difficulty with ADL items wroom, eat and toilet, and IADL items meal and medic, are likely to be complex. Those with the least complex needs are likely to have difficulty with Mobility items stairs and stoop.

A point illustrated by Table 17 is that younger respondents who have difficulty with ADL items wroom and bath are likely to have more advanced needs than someone much older with the same difficulty. While these particular difficulties are more common in very old age, the same difficulties reflect uncommonly high dependency needs at younger ages. As such, understanding that particular difficulties may be indicative of more complex needs at younger than older

			Mean	number of	f difficultie	s by AGE G	ROUP		
		60-64	65-69	70-74	75-79	80-84	85-89	90+	ALL
ALL		2.3	2.6	3.1	3.7	4.8	6.2	8.8	3.3
With 1+ diffi	culties	4.4	4.4	4.7	5.1	6.0	7.1	9.7	5.1
With individ	ual difficulty:								
Mobility	100yds	10.6	10.5	10.1	10.1	10.7	11.3	12.9	10.7
	sit2hrs	7.8	7.7	8.4	8.7	9.6	10.9	14.3	8.5
	getup	6.8	6.8	7.0	7.2	8.5	9.6	12.5	7.5
	stairs	5.9	5.8	5.9	6.4	7.4	8.3	10.8	6.5
	stair	9.9	9.2	9.1	9.4	9.8	10.6	12.9	9.8
	stoop	5.8	5.8	6.0	6.4	7.4	8.8	11.1	6.5
	extend	8.4	8.3	9.0	9.4	10.1	11.6	13.9	9.4
	pull	9.0	8.8	8.8	9.2	9.6	10.5	12.7	9.4
	weights	7.6	7.6	7.7	7.7	8.5	9.0	11.3	8.1
	coin	9.4	9.5	9.8	9.8	10.7	11.6	15.2	10.3
ADL	dress	9.4	9.2	9.0	9.2	10.5	11.8	14.4	9.8
	wroom	14.9	14.6	14.2	14.5	14.4	14.9	16.9	14.8
	bath	11.1	10.4	9.8	9.8	10.3	11.3	13.0	10.5
	eat	13.5	13.3	12.8	13.5	14.5	15.4	17.7	14.2
	bed	11.9	12.4	12.0	12.6	13.0	14.3	17.5	12.8
	toilet	13.5	12.8	12.8	13.3	13.7	14.5	17.9	13.6
IADL	map	7.9	8.6	9.4	9.3	10.8	11.5	14.4	10.1
	meal	13.9	13.4	13.9	13.6	13.3	13.4	15.0	13.7
	shop	11.7	11.7	12.0	11.5	11.3	11.5	13.0	11.7
	phone	10.0	10.6	11.3	10.1	11.4	13.2	16.5	11.8
	medic	11.5	12.6	13.2	13.7	14.0	14.7	16.5	13.7
	hwork	10.0	9.8	9.5	9.3	9.7	10.3	12.7	9.9
	money	10.6	12.0	11.4	12.1	13.0	13.2	14.7	12.6

Table 17. Mean number of difficulties for respondents with individual Mobility, ADL or IADL items, by age group

Note: full label descriptions in Table 3

Source: ELSA, waves 1-4

ages may complicate the interpretation of the effects of ageing on dependency when exploring the effects of both factors on the receipt of care.

By considering the number of difficulties commonly experienced by individuals with different difficulties, the dynamics of dependency in later life are more easily identified. Although this provides an understanding of the relative complexity of needs in later life, it does not identify the way more (and less) complex needs are the result of particular combinations of difficulties. To expand on the analysis in Table 17, Table 18 presents the average number of Mobility, ADL and IADL difficulties experienced by people experiencing each difficulty, to help further disentangle the composition of dependency. Owing to the volume and complexity of data shown, a 4-band categorical age variable is used.

Although Table 17 showed that particular difficulties are experienced by people with the most

	Mean Mobility difficulties				Mean ADL difficulties				Mean IADL difficulties				
Domain and difficulty		60-64	65-74	75-84	85+	60-64	65-74	75-84	85+	60-64	65-74	75-84	85+
Mobility	100vds	6.9	6.7	6.6	6.8	2.0	1.8	1.8	2.1	1.7	1.8	2.0	3.0
	sit2hrs	5.5	5.7	6.2	7.3	1.2	1.3	1.4	2.1	1.0	1.1	1.5	2.5
	getup	4.8	4.9	5.3	6.2	1.1	1.1	1.3	1.8	0.9	0.9	1.3	2.4
	stairs	4.3	4.2	4.7	5.4	0.9	0.8	1.0	1.4	0.8	0.8	1.1	2.2
	stair	6.6	6.2	6.2	6.6	1.8	1.5	1.6	1.9	1.5	1.5	1.7	2.8
	stoop	4.2	4.2	4.6	5.7	0.9	0.9	1.0	1.5	0.7	0.8	1.1	2.2
	extend	5.8	5.9	6.4	7.2	1.5	1.5	1.7	2.3	1.2	1.4	1.7	3.0
	pull	6.1	6.0	6.1	6.5	1.5	1.4	1.5	1.9	1.4	1.4	1.7	2.8
	weights	5.3	5.3	5.4	5.8	1.2	1.1	1.2	1.5	1.1	1.2	1.4	2.4
	coin	6.2	6.3	6.5	7.2	1.7	1.7	1.8	2.4	1.5	1.6	2.0	3.2
ADL	dress	5.7	5.4	5.6	6.4	2.3	2.2	2.3	3.0	1.4	1.5	1.8	3.2
	wroom	8.0	7.6	7.5	7.6	4.1	3.8	3.8	4.0	2.9	3.0	3.2	4.1
	bath	6.5	5.9	5.8	6.2	2.8	2.4	2.3	2.6	1.8	1.8	2.0	3.1
	eat	7.0	6.5	6.8	7.4	3.8	3.5	3.7	4.1	2.7	3.0	3.5	5.0
	bed	6.9	6.8	6.8	7.5	3.1	3.2	3.4	4.0	1.9	2.2	2.6	3.8
	toilet	7.4	6.8	6.8	7.3	3.8	3.7	3.7	4.4	2.3	2.3	2.9	4.1
IADL	map	4.4	4.8	5.2	6.1	1.2	1.5	1.6	2.2	2.3	2.7	3.3	4.3
	meal	7.4	6.9	6.5	6.6	3.1	3.0	2.8	2.7	3.4	3.7	4.2	4.7
	shop	6.7	6.7	6.3	6.3	2.3	2.3	2.1	2.1	2.7	2.9	3.0	3.7
	phone	4.9	5.2	5.0	6.4	1.9	2.1	2.0	2.9	3.2	3.8	3.8	5.2
	medic	5.9	6.2	6.0	6.4	2.2	2.5	2.8	3.2	3.4	4.3	5.0	5.8
	hwork	6.1	5.8	5.7	6.0	1.8	1.7	1.6	1.9	2.0	2.1	2.3	3.2
	money	5.4	5.6	5.8	6.3	1.9	2.1	2.3	2.6	3.3	4.0	4.4	5.0

Table 18. Mean number of domain-specific difficulties reported, by 4-band categorical age

*Note: full label descriptions in Table 3.* Source: ELSA, waves 1-4

complex and often by those with these difficulties at the oldest ages, Table 18 demonstrates the variability in the composition of needs associated with the 23 different items. Turning to consider the type and complexity of needs associated with each difficulty in more detail, Figure 15 shows the average complexity of Mobility needs associated with having a given difficulty. For the purposes of showing differences in the progressive nature of dependency for those with different needs, the figure highlights results for the youngest (aged 60-64) and oldest (85+) respondents, alongside the highest and lowest number across all 4 age groups.

Figure 15 identifies that for the majority of difficulties – for example, Mobility items sit2hrs and stoop, ADL dress and IADLs map and phone – younger people who have these difficulties have less complex Mobility needs than older people with the same difficulty. This pattern will be referred to as Pattern 1 for the remainder of this section, and reflects the progressive development of more complex needs in the course of 'natural ageing'. This pattern describes 15 difficulties (8 Mobility, 3 ADL and 4 IADL).

Figure 15. Mean number of Mobility difficulties for ages '60-64', '85+' and including minimum and maximum number of difficulties across all age groups, by individual difficulty



Source: ELSA, waves 1-4 (from Table 18)

Figure 15 also suggests another pattern, whereby younger people who have particular difficulties have a broadly similar level of Mobility needs as older people experiencing the same difficulty. This pattern – referred to as pattern 2 for the rest of this section – is reflected by 4 difficulties: Mobility items *100yds* and *stair*, ADL *toilet* and IADL *hwork*. People experiencing these difficulties are likely to have complex Mobility needs, regardless of their age.

Finally, Figure 15 indicates a third pattern – which will be known as pattern 3 – whereby, younger people experiencing certain difficulties have more complex Mobility needs than the oldest with the same difficulty. The difficulties reflecting pattern 3 are ADLs *wroom* and *bath*, and IADLs *meal* and *shop*.

Next, Figure 16 shows information on the average complexity of ADL needs associated with each item.

From Figure 16, the majority of difficulties follow pattern 1, whereby younger people who have these difficulties experience less complex ADL needs than older groups with the same difficulty. The items described by pattern 1 are the same items as with Mobility needs, but additionally include ADL toilet. Pattern 2 describes 4 items – Mobility items 100yds and stair, ADL wroom and Figure 16. Mean number of ADL difficulties for ages '60-64', '85+' and including minimum and maximum mean number of difficulties across all age categories, by individual difficulty



Source: ELSA, waves 1-4 (from Table 18)

IADL hwork – whereby experiencing these difficulties at younger ages is associated with having complex ADL needs, similar to the ADL needs of someone aged 85+. Finally, the remaining items – ADL *bath* and IADLs *meal* and *shop* – follow pattern 3, with younger people with these difficulties having more complex ADL needs than the oldest old with the same difficulty. The patterns are broadly the same for relative complexity of ADL and Mobility needs, and only ADLs *wroom* and *toilet* reflect different patterns.

Finally, turning to the relative complexity of IADL needs associated with individual difficulties, Figure 17 completes charting the information from Table 18.

Unlike Mobility and ADL domain difficulties, all IADL items follow pattern 1, whereby the youngest respondents with each difficulty have less complex needs than those in older age groups. This suggests IADL needs are likely to be less complex in early old age, and increasingly complex later on, regardless of the specific difficulty experienced.

While the complexity of IADL needs follows a consistent pattern, the pattern of Mobility and ADL needs are more variable and may disrupt assumptions about the linear progression of dependency in later life. While individual difficulties become more common as age advances,

Figure 17. Mean number of IADL difficulties for ages '60-64', '85+' and including minimum and maximum mean number of difficulties across all age categories, by individual difficulty



Source: ELSA, waves 1-4 (from Table 18)

this section suggests that attempting to summarise the development of dependency in later life is more complex. This exploratory analysis confirms that, although quantifying need generally in binary terms may be more parsimonious, such approaches remain restricted in what they are able to tell us about the underlying dynamics of dependency for older people.

In particular, difficulty walking short distances, climbing several flights of stairs, taking a bath, or doing domestic tasks like preparing a meal, doing shopping or housework at younger ages is associated with uncommonly complex needs.

The analysis presented helps to identify the specific complexity and types of need associated with different Mobility, ADL and IADL difficulties, and at different points of later life. To expand on this further, it is of interest to understand how particular difficulties are most commonly experienced in later life by those with lesser or greater dependency needs. In order to unpick this analysis further, a cross-tabulation was initially undertaken to show the number of difficulties reported by individuals reporting each of the 23 primary difficulties. For example, any person who has difficulty walking 100 yards can potentially experience a total number of difficulties ranging between 1 and 23. On average, someone with this difficulty has 10.7 difficulties (from Table 17). The cross-tabulation produces a high dimension 23 x 23 table, and to
enable easier interpretation, a simpler 5-item categorical version of the number of difficulties measure is used (as used in Figure 11). Figure 18 shows the proportion in each 'complexity of needs' group who experience each individual difficulty.



Figure 18. Proportion with low / high level needs who experience primary difficulties

Figure 18 shows, across the 23 items there is a range in the relative complexity of needs associated with experiencing different difficulties and particular items are common when the number of difficulties is low while others are likely to occur only amongst those with complex needs. For example, around 20% of those having difficulty with less than 19 items experiences the 3 least common difficulties (ADL *eat* and IADLs *phone* and *medi*), while more than 70% of those with 19+ difficulties experience these difficulties. By comparison, more than 80% of the sample reporting less than 9 difficulties experiences the 2 most common items (Mobility items 'stairs' and 'stoop'). In this way, Figure 18 helps to identify the types of difficulties experienced by those in low and high need groups, and Figure 19 demonstrates this more clearly by showing the same data ordered by prevalence from most common to least common item.

Figure 19 shows the shift in needs from low to high, with particular items being experienced by a progressively smaller proportion of those with less complex needs. It is clear that certain items

Note: full label descriptions in Table 3 Source: ELSA, waves 1-4



Figure 19. Proportion with low / high level needs who experience primary difficulties, ranked by prevalence

Note: full label descriptions in Table 3 Source: ELSA, waves 1-4

across all domains share similar patterns. For example, similar proportions of people with low and high needs experience difficulty performing many of the common Mobility difficulties as experience more common IADL and ADL items (e.g. *shop*, *hwork*, *bath* and *dress*). This suggests that conflating ADL and IADL difficulties into binary measures which aim to measure need in these dimensions may restrict the understanding of how needs occur in reality, and may limit the understanding of care as it responds to the needs of older people. Figure 20 shows the breakdown of those reporting each difficulty by the proportion in each of the low to high needs groups.

Considered in this way, Figure 20 further emphasises the great variation in the distribution of needs for those experiencing these difficulties. For example, a large proportion of those reporting Mobility items getup, stairs, and stoop have few difficulties: between 25% and 33% of those with these difficulties have the least complex needs (1-3 difficulties), 63% report less than 9 difficulties, and less than 3% have the most complex needs (19-23 difficulties). By contrast, less than 2% of those who have difficulty with ADLs wroom, bed, and IADL meal have relatively few difficulties, while between 12% and 19% have the most complex needs. In this way,



Figure 20. Complexity of needs by count of difficulties for respondents reporting difficulty with individual items

Note: full label descriptions in Table 3 Source: ELSA, waves 1-4

it should not be assumed that uniformity exists in the prevalence or complexity of needs associated with the range of items which are often used to measure the existence of need.

### 3.2.1.2. Exploring the accumulation of need

In later life, some people will experience dependency as a result of multiple difficulties, and needs are likely to become increasingly complex as people age. To explore the process by which needs accumulate, this section presents an examination of how particular difficulties occur in combination, as needs develop and become increasingly complex. Firstly, for each person reporting a given Mobility, ADL and IADL difficulty – here termed the *primary* difficulty – the proportion of respondents having difficulty with each of the remaining dependency items – termed *secondary* difficulties – was determined. Each item is then ranked ordinally from the most to the least commonly occurring difficulty in combination with each primary difficulty. The mean was calculated from these ranking scores for each item, producing an ordinal summary of difficulties most commonly occurring in later life.

Figure 21 shows the final ordinal ranking for the 23 items, as specified by the overall mean rank. The range in ranking scores for each item is shown by minimum and maximum rank achieved for

Figure 21. Mean item-specific secondary difficulty prevalence ranking with min/max ranking range for those reporting each Mobility, ADL and IADL difficulty



Note: full label descriptions in Table 3 Source: ELSA, waves 1-4

each item as a secondary difficulty. The ranking of items with a narrow range are more stable, while items with wider minimum and maximum values are ranked less consistently in the range. As confirmed in Table 17, the average number of difficulties for those aged 60+ is 3.3 and 5.1 for the sub-sample with 1+ difficulty. Figure 21 shows on average, 3 Mobility items are consistently the most commonly reported secondary difficulties suggesting that these difficulties are most likely to develop before any other. When different needs are conflated to binary or count-based approaches, large numbers of people with low level needs may obscure the range of difficulties underlying more complex needs. For example, Figure 22 and Figure 23 show the proportion of respondents reporting cumulative difficulties and discrete numbers of difficulties.

Figure 22 and Figure 23 show that conflating different needs to summary measures, the prevalence of specific difficulties becomes harder to identify due to large numbers of cases with low numbers of difficulties. For example, while around half of those in the range of 1-5 difficulties report Mobility items stairs and stoop (Figure 22), disaggregating this group shows around 80% of those with 5 difficulties have difficulty with this item (Figure 23). In Figure 23, it is easier to identify the difficulties that the majority of older people with low level need





Note: full label descriptions in Table 3 Source: ELSA, waves 1-4

experience, while revealing the contribution that less common difficulties make in more complex

patterns of need.



Figure 23. Proportion of respondents with discrete number of difficulties reporting individual primary difficulties

*Note: full label descriptions in Table 3* Source: ELSA, waves 1-4

### 3.3. Summary of chapter

In summary, this chapter introduced ELSA as a key resource for exploring different aspects of need as it is occurs in later life. The chapter described the key ELSA variables that will be used for

the purpose of constructing measures of need and dependency throughout this study. Analysis of the 23 Mobility, ADL and IADL difficulties was conducted to explore the distribution of individual difficulties, and to unpick the characteristics of more complex needs occurring from combinations of Mobility, ADL and IADL difficulties.

The initial exploratory analysis found that certain difficulties are reported consistently in later life by those with any needs, regardless of other underlying difficulties. Further, the analysis found that particular difficulties are only likely to occur at younger ages when needs are already complex. This analysis suggests that the prevalence of different difficulties, varies both within and between domains, and it is therefore important to be conscious that when conflating difficulties to summary measures of need, the impact of different Mobility, ADL and IADL needs on the receipt of care are equally unlikely to be uniform.

The next chapter presents logistic regression analysis to explore the relationship between dependency and care receipt in later life, focusing on the way Mobility, ADL and IADL difficulties can be used to capture dependency.

### **Chapter 4**

# 4. <u>Exploratory analysis of self-reported difficulties and their</u> relation to receipt of care

This chapter uses logistic regression to examine the effects of different Mobility, ADL and IADL difficulties on the likelihood of receiving informal, formal, and private care, as well as the receipt of care from any source. As outlined in section 2.8, the sample is restricted to respondents with one or more difficulties of any type to consider the effect of each difficulty on care receipt, for those who may potentially receive care. Table 19 shows the number of cases in the sample receiving help with a difficulty from each of the 4 sources.

Table 19. Care received by source of care, proportion of sample with 1+ difficulties

Source of care	Count	%
Any source	7,901	45.1
Partner or Child	6,051	34.5
Formal	603	3.4
Private	955	5.5
Number with 1+ difficulty	17,518	100.0

Source: ELSA, waves 1-4 (sample: with 1+ difficulties)

The explanatory variables in the models presented in this chapter include gender, familial characteristics (has children; lives with partner), age (categorical), and SES measured by highest educational qualification.

## 4.1. Controlling for needs by individual difficulties

For these models, need for care is measured based on whether an individual confirms difficulty performing each of 23 individual actions and activities with each difficulty considered as having a separate and independent effect.

# 4.1.1. Modelling receipt of care controlling for individual Mobility, ADL and IADL difficulties

Table 20 shows 4 sets of logistic regression results for the effects of explanatory factors including whether an individual reports each of the 23 difficulties on whether or not care is received from any source, from a partner or child, from a formal source, and from privately arranged sources (all taken separately as 0/1 events).

Table 20. Logistic regression - receipt of care from 4 sources using the 23 individual Mobility, ADL and IADL difficulties

	Dependent variable –			- receives care from source:				
	1. Any		2. Partner or child		3. Formal		4. Private	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Female <sup>1</sup>	1.53***	1.35 - 1.73	1.29***	1.12 - 1.49	0.86	0.61 - 1.20	2.52***	1.94 - 3.26
Coniugal family								
Lives with a partner <sup>2</sup>	1.91***	1.68 - 2.18			0.26***	0.18 - 0.39	0.58***	0.45 - 0.75
Has any children <sup>3</sup>	1.46***	1.27 - 1.69			1.07	0.78 - 1.48	0.80	0.63 - 1.02
Partner only <sup>4</sup>			0.74 <sup>*</sup>	0.56 - 0.98				
Child only <sup>4</sup>			0.33***	0.29 - 0.39				
Age group <sup>5</sup>								
65-69	1 01	0 86 - 1 18	0.91	0 77 - 1 08	2 81**	1 43 - 5 53	2.08**	1 30 - 3 34
70-74	1.09	0.93 - 1.29	0.94	0.79 - 1.13	2.72**	1.36 - 5.41	4.37***	2.78 - 6.89
75-79	1.42***	1.19 - 1.68	1.19	0.99 - 1.44	4.51***	2.29 - 8.87	5.54***	3.52 - 8.72
80-84	1.91***	1.58 - 2.31	1.39**	1.12 - 1.72	9.72***	4.99 - 18.92	11.81***	7.49 - 18.63
85-89	2.77***	2.17 - 3.53	1.44**	1.10 - 1.89	11.45***	5.73 - 22.89	17.09***	10.54 - 27.71
90+	3.75***	2.42 - 5.81	1.89**	1.19 - 2.99	11.95	5.49 - 26.02	17.27***	9.67 - 30.86
Education <sup>6</sup>			•		•			
A-level	1.34 <sup>*</sup>	1.06 - 1.71	1.37 <sup>*</sup>	1.04 - 1.80	1.63	0.76 - 3.48	0.80	0.52 - 1.25
O-level	1.22	0.98 - 1.53	1.42**	1.10 - 1.83	0.95	0.46 - 1.95	0.49**	0.32 - 0.75
None	1.64***	1.32 - 2.03	2.29***	1.79 - 2.92	1.28	0.66 - 2.49	0.33***	0.23 - 0.50
Mobility <sup>7</sup>			•		•		•	
Walk 100 yards	1.63***	1.39 - 1.92	1.32**	1.11 - 1.57	1.65**	1.16 - 2.33	0.97	0.76 - 1.25
Sit 2 hours	1.01	0.88 - 1.16	1.02	0.88 - 1.18	0.86	0.63 - 1.17	0.87	0.69 - 1.09
Get up	1.03	0.92 - 1.15	1.07	0.95 - 1.22	0.65**	0.47 - 0.89	1.18	0.95 - 1.47
Climb stairs	1.04	0.93 - 1.17	1.37***	1.21 - 1.56	1.00	0.64 - 1.57	1.27	0.96 - 1.67
Climb stair	1.32***	1.15 - 1.52	1.22 <sup>*</sup>	1.05 - 1.42	1.99 <sup>***</sup>	1.39 - 2.86	1.18	0.92 - 1.50
Stoop, etc	1.19**	1.06 - 1.32	1.21**	1.07 - 1.37	0.94	0.63 - 1.39	1.03	0.80 - 1.33
Extend arms	1.34	1.16 - 1.55	1.31**	1.12 - 1.53	1.18	0.87 - 1.59	0.98	0.78 - 1.24
Pull/push	2.00	1.75 - 2.28	1.82	1.58 - 2.11	1.27	0.88 - 1.85	1.34	1.05 - 1.72
Lift weights	2.74	2.43 - 3.09	2.75	2.40 - 3.15	1.32	0.87 - 2.01	1.32	1.02 - 1.72
Pick up coin	1.29	1.06 - 1.57	1.25	1.02 - 1.53	0.98	0.70 - 1.38	1.18	0.90 - 1.55
ADL <sup>7</sup>								
Get dressed	1.28	1.10 - 1.47	1.40	1.20 - 1.63	1.15	0.84 - 1.59	0.96	0.76 - 1.22
Walk across a room	0.84	0.59 - 1.19	0.62	0.45 - 0.86	1.45	1.00 - 2.09	1.28	0.92 - 1.77
Bath/shower	1.41	1.21 - 1.65	1.59	1.34 - 1.87	4.15	2.97 - 5.81	0.82	0.65 - 1.04
Eat food	1.39	0.93 - 2.08	1.36	0.92 - 2.02	0.78	0.50 - 1.21	1.00	0.67 - 1.50
Get in/out bed	0.68	0.54 - 0.85	0.88	0.70 - 1.11	0.94	0.65 - 1.35	0.91	0.68 - 1.23
Use toilet	0.89	0.67 - 1.19	0.90	0.67 - 1.19	1.14	0.77 - 1.67	0.96	0.69 - 1.35
			•		•		•	
Use map	1.64***	1.34 - 2.00	1.34**	1.08 - 1.65	1.38	0.98 - 1.95	0.65**	0.48 - 0.88
Prepare hot meal	2.04	1.46 - 2.86	1.39	1.03 - 1.88	2.69	1.88 - 3.83	0.78	0.57 - 1.07
Shop for groceries	3.38	2.74 - 4.16	2.60	2.13 - 3.19	2.19	1.55 - 3.08	0.83	0.65 - 1.06
Make phone calls	4.24	3.01 - 5.97	3.60	2.50 - 5.18	0.60	0.37 - 0.97	0.65	0.41 - 1.03
Take medication	3.27	2.02 - 5.28	3.02	1.85 - 4.91	0.82	0.50 - 1.33	1.06	0.66 - 1.69
Do housework	5.49	4.75 - 6.34	3.06	2.63 - 3.56	2.83	1.95 - 4.09	20.40	15.45 - 26.93
Manage money	8.21	5.56 - 12.12	7.24	4.99 - 10.49	1.08	0.72 - 1.62	0.56	0.38 - 0.83
Ν	16,725		13,722		16,725		16,725	
N_g	7,338		6,387		7,338		7,338	
rho	0.33		0.37		0.56		0.44	
BIC	15,081		13,117		3,471		5,295	
Pseudo R2	0.34		0.28		0.35		0.28	

Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001Reference categories: <sup>1</sup> men; <sup>2</sup> does not live with a partner; <sup>3</sup> has no children; <sup>4</sup> lives with a partner and has children; <sup>5</sup> 60-64; <sup>6</sup> Degree; <sup>7</sup> does not report this difficulty

Source: ELSA, waves 1-4 (Sample: with 1+ difficulties)

### 4.1.1.1. Model diagnostics

Models presented in sections 4.1, 4.2 and 4.3 include the same sample and control for the same explanatory variables. To enable an understanding of the relative improvement gained from adopting each approach considered in these sections, reduced models were initially run using the same sample and controlling for the same explanatory variables but excluding controls for dependency. Analysis from the reduced models is not shown due to space limitations, but can be provided on request. This allows the benefit of each approach to measuring dependency to be directly compared, based on the change in BIC and pseudo r<sup>2</sup> values.

Compared to the reduced model not controlling for dependency, all full models had lower BIC values. Differences in BIC value from the reduced model in all cases was >10, suggesting that additional controls for dependency, in this case using multiple binary measures for individual difficulties, improve the model. Additionally, comparing between the pseudo  $r^2$  values in the reduced and full models, models explained a minimum of an additional 14% (model 4) and a maximum of 29% (model 1) of variance in the relevant dependent variable.

#### 4.1.1.2. Discussion of results

Beginning with the effects of the explanatory variables, women are more likely to receive care, and are over 2.5 times as likely to receive private care as men, although there is no significant difference in the likelihood of formal care receipt compared to men. Older people who live with a partner are the most likely to receive care, holding other factors constant, although living with a partner are the most likely to receive care, holding other factors constant, although living with a partner lowers the chance of both formal and private care, emphasizing the integral role that care from a partner plays in supporting older people. Although those with children have a greater chance of receiving care, this is likely to be informal support and this is predominately more often received from a partner than from children. However, there is no statistically significant effect on the likelihood of receiving formal or private care if someone has children and this might suggest that, unlike living with a partner, having children does not stop people from receiving care from these sources. This could be interpreted as confirmation that care

provided by children may potentially be supported by other forms of care, whereas care from a partner precludes a need for other care for most people.

As expected, the oldest old have the greatest chance of receiving care, and those in their 80s being far more likely to receive formal and private care than those in the reference group, aged 60-64. However, the ageing effect appears less pronounced in explaining whether someone receives informal care. This could be explained by the significance of Mobility difficulties in model 2, which directly capture aspects of dependency that can be supported by informal help, thus reducing the effects of ageing on care receipt. Further, it is likely that age is not a factor in decisions about caring made between partners or their children, but may be a determining factor in eligibility for other sorts of support including formal services. Compared to those with a degree, older people without educational qualifications are more likely to receive informal care, and have a lower chance of receiving private care. There is no significant difference by education level on receiving formal care when holding other factors constant.

Turning to consider the 23 measures of dependency, having difficulty with 7 Mobility, 2 ADL, and all 7 IADL items increases the likelihood of receiving care, while difficulty with ADL item 'getting in/out bed' lowers the likelihood of receiving care, holding other factors constant. Of the 16 items which increase the chances of care being received, having difficulty with housework, making telephone calls, shopping, and taking medication markedly increase the likelihood of care receipt when also controlling for the effects of other IADL, ADL and Mobility difficulties.

When the type of care being received is broken down, IADL difficulties are significant in increasing the likelihood of informal family care, but there appears to be task-specificity in the types of activity associated with formal and private care separately. For example, formal care is associated predominately with help preparing hot meals, domestic tasks, and personal care, while private care seems almost exclusively associated with housework. This confirms that unpaid care is able to meet a broader range of needs than either formal or private care, which are both directed to support very specific aspects of dependency.

In terms of understanding how formal and private care services may be able to provide support to those with other needs, Table 20 shows that IADL difficulties falling outside the realm of domestic tasks do not affect the receipt of formal or private care and indeed may actually lower the likelihood of receiving care from these sources. For example, those having difficulty 'making phone calls' have a lower chance of receiving formal care. This could potentially identify an area of concern, if this reflects barriers to accessing formal services for these who are unable to make contact.

Of the 6 ADL activities, difficulty getting dressed increases the likelihood of help from within the family, and older people with difficulty bathing have an increased chance of formal care and unpaid care. Having difficulty getting in and out of bed actually lowers the likelihood of care, which does not translate directly into lower chances of informal, formal or private care. This may identify another area of concern, whereby older people with very limited mobility are unable to get support, even from informal sources.

While difficulty eating food, getting in and out of bed and using the toilet are all very important activities, it is uncovered that all 3 items are not found to be significant in predicting care receipt from informal, formal and private sources. This should be understood in light of the models controlling for ADL and Mobility needs simultaneously, where the physical aspects of ADL dependency may potentially captured directly through the ADL items themselves and indirectly by different Mobility items. Mobility items therefore could be considered as indirect measures of dependency, similarly to age, allowing for additional measures of impairment alongside disability to control for aspects of need that may otherwise not be picked up using purely ADL and IADL-based measures of need.

In this way, it might be assumed that without controlling for Mobility impairments, the effects of other ADL and IADL difficulties may become significant. In order to verify this, analysis was conducted by running 3 models exploring whether someone receives any care with separate models for Mobility domain items, ADL domain items, and IADL items (not shown). This analysis confirmed that when each set of domain-specific items were entered together in separate

models all items were significant and increased the likelihood of receiving care. When modelling Mobility needs in this way, one item (difficulty 'sitting for 2 hours') was not significant. In the model controlling only for IADL items, the single strongest predictor of care receipt was difficulty with housework rather than managing money. This might suggest that in the absence of controls for Mobility limitations, the effect of physical tasks are measured more directly. Further, when controlling only for ADL activities, difficulty walking across a room and eating food are the strongest predictors of care receipt, where these items are not significant in the full models. As such, it is important to be aware of the direct and indirect effects of dependency when interpreting the effects of difficulty performing ADL and IADL tasks.

Finally, while there are large statistically significant odds ratios for the private care model, this is likely due to a relatively small number of cases (955) receiving this type of care, and 86% of people aged 80+ receiving private care have this difficulty.

### 4.1.2. Summary of section 4.1

Using individual Mobility, ADL and IADL difficulties as indicators of need allows a detailed understanding of the association between specific Mobility, ADL and IADL difficulties, and the receipt of different types of care. This demonstrates the variation in dependency needs for those using each type of care. By considering these 23 items simultaneously in this way, it was shown that Mobility needs may indirectly capture aspects of dependency which more direct measurements of disability in relation to specific ADL and IADL activities may not be captured. One issue with entering all 23 items as independent measures is that variation in the likelihood of care receipt resulting from multiple ADL, IADL limitations and Mobility impairments is not

of care receipt resulting from multiple ADL, IADL limitations and Mobility impairments is not captured. Care is likely to target wider aspects of dependency than single isolated difficulties, and supporting someone with ADL tasks, such as getting out of bed or using the toilet, may involve other aspects of support, whether these are physical, emotional or psychological, which may not be captured by the specification of single isolated activities (Artaud et al, 2013).

To consider this further, data from waves 3 and 4 of ELSA collects information on help received with 14 specific Mobility, ADL and IADL activities, classified into 6 types of activity. Exploring how different types of care provide particular types of support, Figure 24 shows proportions of people receiving care with each type of difficulty from each source, alongside the number of sources of care providing help with each type of difficulty.





Source: ELSA, waves 3 and 4

Figure 24 shows that around 70% of people receiving other informal and private care get help with only one type of activity, mostly domestic tasks or movement around the house. Around 60% of people receiving formal care get help with more than one type of activity, predominately washing and dressing, and moving around the house. Half of those receiving care from partners and children get help with more than one task, with similar the most common tasks being domestic chores and general mobility, with around 35% receiving help with washing and dressing. Although this data has only been collected from wave 3 onwards, it provides a useful way to consider how different types of care are utilized.

As Figure 24 shows, supporting individuals with more advanced needs may involve dealing with different aspects of care, and care responsibilities may overlap when more than one care provider is involved. Modelling dependency as isolated difficulties, while showing how particular needs are more likely to be met by certain types of care, does not capture the impact of advanced needs on care receipt. For example, in providing care to meet the needs of an individual experiencing difficulty performing x, y and z activities, it would be unproductive to designate separate services to meet each individual need. Instead, it would be expected that support from one service, whether this be provided formally, privately or informally, would provide support with different needs, where this is manageable and appropriate. As such, the next section considers the impact of greater dependency on care provision, using a cumulative count of the number of Mobility limitations, ADL and IADL difficulties that are experienced.

### 4.2. Controlling for needs by total number of difficulties

As discussed, the first approach does not allow for the impact of more advanced needs resulting from multiple Mobility, ADL and IADL difficulties to be understood. To expand on the previous analysis, this section adopts a summary measure of relative dependency using a count of the number of difficulties an individual experiences. The new variable follows a simple metric interval scale, ranging from 1 (least complex needs) to 23 (most complex needs). Figure 25 shows the cumulative proportion of respondents reporting between 1 and 23 difficulties by age group.

Half of the sample has difficulty with less than 4 items, and needs become increasingly complex in later life. 59% of the youngest group have 1-3 difficulties compared to 16% of the oldest group, while 3.5% of the youngest and 21% of the oldest have more than 13 difficulties. Focusing on a specific number of difficulties is descriptively complex when attempting to understand needs on a relative scale, and a 'simplified' 5-category measure is also considered to allow the relative differences between low and high needs to be contrasted. The new categorical measure

Figure 25. Number of difficulties (cumulative percentage by age)



Source: ELSA, waves 1-4 (Sample: with 1+ difficulties)

defines low needs as 1-3 difficulties (coded 1), the next group includes those with 4-8 difficulties (coded 2), and the numbers of difficulties increase by 5 for each of the remaining groups, with the most complex needs including those with 19-23 difficulties (coded 5). Figure 26 shows the proportion of each age group defined by the relative complexity of their needs using the new measure.



Figure 26. Banded number of difficulties (percentage of age category) – all ELSA respondents with a difficulty

Source: ELSA, waves 1-4 (sample: with 1+ difficulties)

Taking the 5 bands as an indicator of relative complexity of needs, 84% of people aged 60-64 experience less than 9 difficulties and this proportion remains stable until ages 80+ with 27% of those aged 80-84 and 53% of the oldest group having difficulty with more than 8 items. Similarly only a small proportion of those aged below 80 – around 1% – have the most complex needs with 2% of those 80-84 rising to almost 10% of those aged 90+ having more than 18 difficulties. The above only allows for an understanding of the development of complex needs as age increases and the next section undertakes logistic regression analysis using the continuous variable 'number of difficulties experienced' to explore the effect of increasingly complex needs on receipt of care.

# 4.2.1. Modelling care sources separately for number of difficulties experienced (entered continuously)

Table 21 shows logistic regression results for the 4 models in turn.

### 4.2.1.1. Model diagnostics

Compared to the previous models in Table 20, the models all have higher BIC values, indicating a worse model fit when the continuous measure of dependency is used. The pseudo r2 suggests that the models explain between around 5% (models 1-3) and 12% (model 4) less of the variance in the relevant dependent variable. As such, the loss of information from reducing the parameters down to a single measure provides no statistical benefit. Additionally, the rho value suggest that variance in the responses from the same individual explain almost 60% of the overall variance in receipt of formal care, which suggests that changes within individuals are likely to explain most of this care outcome. This might confirm that changes in a person's circumstances and needs may explain the receipt of formal care.

### 4.2.1.2. Model discussion

Entering the number of difficulties as a continuous measure, the odds ratios, sign and effects sizes of the other independent variables are broadly the same as in the earlier models (shown in Table 20). This is reassuring since the models in Table 21 are more parsimonious, with fewer

	Table 21. Logistic regression –	· receipt of care from 4	4 sources using 'number o	of difficulties experienced
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	_		Depender		eceives car	e nom source	•	
	1.	Any	2. Partr	ner/Child	<b>3.</b> Fe	ormal	4.	Private
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Female <sup>1</sup>	1.63***	1.44 - 1.84	1.45***	1.27 - 1.67	0.96	0.69 - 1.33	2.59 <sup>****</sup>	2.02 - 3.32
Conjugal family								
Lives with a partner <sup>2</sup>	1.60***	1.41 - 1.82			0.26***	0.18 - 0.37	0.57***	0.45 - 0.73
Has any children <sup>3</sup>	1.47***	1.28 - 1.69			1.18	0.86 - 1.62	0.94	0.75 - 1.19
Partner only <sup>4</sup>			0.71 <sup>*</sup>	0.54 - 0.95				
Children only <sup>4</sup>			0.38 <sup>***</sup>	0.33 - 0.44				
Age group <sup>5</sup>								
65-69	0.99	0.85 - 1.16	0.92	0.77 - 1.09	3.01**	1.55 - 5.84	1.98 <sup>**</sup>	1.25 - 3.12
70-74	1.11	0.94 - 1.31	0.99	0.83 - 1.18	3.02**	1.54 - 5.93	4.41***	2.84 - 6.83
75-79	1.53 <sup>***</sup>	1.29 - 1.82	1.32**	1.09 - 1.59	5.24***	2.71 - 10.15	$6.15^{***}$	3.97 - 9.54
80-84	2.34 <sup>***</sup>	1.93 - 2.82	1.71 <sup>***</sup>	1.38 - 2.11	11.22***	5.87 - 21.52	12.62***	8.12 - 19.61
85-89	3.87 <sup>***</sup>	3.04 - 4.89	2.05	1.57 - 2.67	15.67***	8.00 - 30.73	18.63	11.69 - 29.67
90+	5.75	3.79 - 8.72	3.38 <sup>***</sup>	2.18 - 5.25	18.69	8.76 - 39.86	13.62***	7.77 - 23.85
Education <sup>6</sup>								
A-level	1.32 <sup>*</sup>	1.04 - 1.68	1.40 <sup>*</sup>	1.07 - 1.85	1.39	0.66 - 2.94	0.81	0.52 - 1.25
O-level	1.19	0.95 - 1.48	1.45**	1.12 - 1.87	0.96	0.48 - 1.95	0.50 <sup>**</sup>	0.33 - 0.75
None	1.64 <sup>***</sup>	1.32 - 2.03	2.38 <sup>***</sup>	1.86 - 3.05	1.29	0.67 - 2.48	0.33 <sup>***</sup>	0.22 - 0.49
Number of difficulties	1.61***	1.58 - 1.64	1.52***	1.49 - 1.56	1.37***	1.33 - 1.41	1.18 <sup>***</sup>	1.15 - 1.20
Ν	16,725		13,722		16,725		16,725	
N_g	7,338		6,387		7,338		7,338	
rho	0.37		0.40		0.58		0.50	
BIC	15,999		13,513		3,486		5,804	
Pseudo R2	0.29		0.24		0.29		0.16	

Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001

Reference categories: <sup>1</sup> male; <sup>2</sup> does not live with a partner; <sup>3</sup> has no children; <sup>4</sup> Lives with a partner and has children; <sup>5</sup> 60-64; <sup>6</sup> Degree

Source: ELSA, waves 1-4 (Sample: with 1+ difficulties)

parameters to be estimated. However, the odds ratios of the age variable increase when entering the number of difficulties as a continuous measure. This might suggest that without fully accounting for the characteristics of individual difficulties (Table 20), differences in the likelihood of receiving care would be attributed to age rather than specific needs. As in the discussion of , allowing a parameter for each individual difficulty helps explain the impact that ageing has on the likelihood of receiving care. However, the continuous measure does not provide an easily interpretable understanding of the differences in the chances of receiving care between those with the least and most complex needs. For example, the cumulative impact of each additional difficulty on the likelihood of receiving informal, formal and private care is consistent whether the difference is between 1-2 difficulties, 10-11 difficulties or 22-23 difficulties. However, experiencing an additional Mobility difficulty for those with relatively low needs is unlikely to have the same effect on the likelihood of receiving care as an additional ADL difficulty, for those with complex needs. As such, it would be expected that the impact of 'one more difficulty' will vary according to whether needs are relatively minor or more complex.

# 4.2.2. Modelling care sources separately for number of difficulties reported (entered categorically)

In order to enable easier interpretation of how increasingly complex needs may affect the likelihood of receiving different types of care, the analysis in this section adopts a 5-item categorical measure of relative need. Table 22 shows the logistic regression results. From exploratory investigations of needs in the previous chapters, there was no overall patterning of all forms of need by age, hence non-linear relationships are not considered and a categorical measure seems the most appropriate approach.

### 4.2.2.1. Model diagnostics

Compared to the fit in models in Table 20, these models again have higher BIC values, although the difference is less severe. Changes in pseudo r<sup>2</sup> range from between 5% and 9%, suggesting while worse than the models in Table 20 this is an improvement over models controlling for dependency using a purely continuous scale. This provides evidence for the analytic benefits of more nuanced measures of dependency.

### 4.2.2.2. Model discussion

Using the new measure of relative need, there is little variation in effect sizes of the other independent measures and – by operationalizing needs using the categorical indicator – the dramatic impact of more complex needs on the likelihood of care receipt can be seen. The extremely high odds ratios associated with experiencing high numbers of difficulties is due to almost all cases with complex needs – 96% of those with 14-18 difficulties and 99.1% of those with 19-23 difficulties – receiving some form of care. As such, having 19+ difficulties

Table 22. Logistic regression	- receipt of care from	4 sources using 'number of	difficulties' (categorical)
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			Dependent	variable – rec	eives care f	rom source:		
	1.	Any	2. Partr	ner/Child	3. F	ormal	4. Pr	ivate
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Female <sup>1</sup>	1.61***	1.4 - 1.8	1.44***	1.3 - 1.6	0.92	0.7 - 1.3	2.42****	1.9 - 3.1
Conjugal family								
Lives with a partner <sup>2</sup>	1.48***	1.3 - 1.7			0.24***	0.2 - 0.3	0.57***	0.4 - 0.7
Has any children <sup>3</sup>	1.47***	1.3 - 1.7			1.10	0.8 - 1.5	0.89	0.7 - 1.1
Partner only <sup>4</sup>			0.70 <sup>*</sup>	0.5 - 0.9				
Child only <sup>4</sup>			0.41***	0.4 - 0.5				
Age group <sup>5</sup>								
65-69	0.98	0.8 - 1.1	0.91	0.8 - 1.1	2.99**	1.6 - 5.7	1.98**	1.3 - 3.1
70-74	1.11	0.9 - 1.3	0.99	0.8 - 1.2	2.89 <sup>**</sup>	1.5 - 5.6	4.22***	2.7 - 6.5
75-79	1.52***	1.3 - 1.8	1.29**	1.1 - 1.6	4.98***	2.6 - 9.5	5.48***	3.6 - 8.5
80-84	2.35	2.0 - 2.8	1.68***	1.4 - 2.1	10.20***	5.4 - 19.3	11.15	7.2 - 17.2
85-89	3.97***	3.1 - 5.0	2.09***	1.6 - 2.7	14.65	7.6 - 28.4	16.46***	10.4 - 26.0
90+	6.08 <sup>***</sup>	4.1 - 9.1	3.70 <sup>****</sup>	2.4 - 5.6	18.38***	8.8 - 38.6	14.05	8.1 - 24.3
Education <sup>6</sup>								
A-level	1.33 <sup>*</sup>	1.0 - 1.7	1.38 <sup>*</sup>	1.1 - 1.8	1.35	0.6 - 2.8	0.77	0.5 - 1.2
O-level	1.23	1.0 - 1.5	1.43**	1.1 - 1.8	0.91	0.5 - 1.8	0.46***	0.3 - 0.7
None	1.68 <sup>***</sup>	1.4 - 2.1	2.34***	1.8 - 3.0	1.19	0.6 - 2.3	0.30***	0.2 - 0.4
Number of difficulties <sup>7</sup>								
4–8	7.29***	6.5 - 8.2	7.35***	6.4 - 8.4	9.94***	5.5 - 17.8	6.06***	4.6 - 7.9
9–13	48.00***	39.7 - 58.1	37.35***	30.6 - 45.6	61.98***	34.1 - 112.5	14.25****	10.5 - 19.3
14–18	263.56***	172.5 - 402.7	110.29***	78.1 - 155.7	206.53***	108.3 - 394.0	12.52***	8.6 - 18.2
19–23	1,311.4***	302 - 5,703	228.57***	94.4 - 553.7	256.87***	120.0 - 549.8	6.19 <sup>***</sup>	3.2 - 11.8
Ν	16,725		13,722		16,725		16,725	
N_g	7,338		6,387		7,338		7,338	
rho	0.36		0.38		0.57		0.46	
BIC	16,466		13,787		3,492		5,690	
Pseudo R2	0.27		0.23		0.30		0.19	

Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001Reference categories: <sup>1</sup> men; <sup>2</sup> does not live with a partner; <sup>3</sup> has no children; <sup>4</sup> Lives with partner and has children; <sup>5</sup> 60-*64;* <sup>6</sup> *Degree;* <sup>7</sup> 1-3 *difficulties* 

Source: ELSA, waves 1-4 (Sample: with 1+ difficulties)

almost completely predicts receipt of some form of care. The only type of care where those experiencing the most complex needs do not have the greatest chance of receiving care is when modelling receipt of private care, reflected in the OR of 6.19. Here, those with the most complex needs have a lower chance of receiving private care than those with fewer difficulties, suggesting private care is unlikely to be employed to support people with the most severe dependency needs.

### 4.2.3. Summary of section 4.2

This section introduced an approach to measuring the complexity of needs by using a metric (categorical) count of the number of Mobility, ADL and IADL difficulties people experience. The initial approach, using a continuous variable, proved to be limiting when attempting to understand the relative differences in care receipt between those with minor and more complex needs. To enable a clearer interpretation of the impact of experiencing greater needs, an alternative approach was adopted using a categorical version of the same measure. Analysis conducted with the categorical measure showed that those experiencing complex needs due to large numbers of Mobility, ADL, and IADL difficulties are disproportionately more likely to receive care when compared to those with relatively few difficulties.

This approach usefully allows an understanding of how different types of care are employed to meet increasingly complex needs. However, the boundaries used to differentiate between relatively minor or more complex needs are arbitrarily assigned and conclusions about the effect of different needs on particular types of care are limited to general statements. Further, quantifying the relative complexity of the needs people experience in this way may fundamentally restrict the degree to which qualitative differences affecting care receipt can be controlled. As such, this approach does not capture how different domains of need intersect with the receipt of care. In order to allow for the particular effects of different types of need to be considered, the next section introduces a third approach using a count of domain-specific difficulties.

### 4.3. Controlling for needs by number of domain-specific difficulties

This section adopts an approach grouping the Mobility, ADL and IADL items together as collective domains and the number of difficulties experienced within each domain is used to measure the relative complexity of needs in each domain simultaneously. This will provide a way to explore how increasingly complex needs in a given domain may affect the receipt of different types of care. Figure 27 shows the breakdown of the count of domain-specific difficulties by age.

Taking 1+ difficulties as an indicator of having at least some domain-specific needs, across all age groups 64% of the sample experience Mobility needs, 24% have ADL needs and 25% IADL needs. The overall number of domain-specific difficulties increases with age while the proportion of people with relatively complex needs also increases with age in all 3 domains. In the Mobility domain there are more people with low needs compared to high needs until ages 80+. In the ADL and IADL domains, the majority of people have only 1 or 2 domain-specific difficulties except at 90+ when there are a greater proportion of people with more than 3+ IADL difficulties. The relatively high number of people with complex Mobility needs is in part be due to this domain being composed of a greater number of items relating to smaller-scale 'impairments' rather than more complex ADL and IADL activities. It may simply be easier to evaluate whether difficulty is experienced 'lifting their arms above shoulder height' or 'picking up a coin from a table' than to provide self-assessed evaluations of whether their experience performing more complicated activities such as 'using the toilet' or 'taking a bath or shower' qualifies as having difficulty or not. The interpretation of the question may be partly informed by an individual's own expectation of what the person asking the question regards as a difficulty.

Further, reducing self-reported responses to potentially complex questions on the health of individuals to binary responses does not allow for information regarding the degree of difficulty experienced to be identified. As such there may be measurement error due to interpretation and assessment inherent in subjective assessments of personal health and capacity to perform personal care tasks. However, ELSA represents a unique source of information on the health of older people, and in spite of these concerns, the ELSA data on Mobility, ADL and IADL needs provides a beneficial resource to analyse the needs of older people.

The next section explores the relationship between relative need for care and patterns of care receipt, using the count of domain-specific difficulties.



Figure 27. Number of domain-specific (i) Mobility, (ii) ADL and (iii) IADL difficulties, by age (N=26,722)





Table Lot Logictic regression receipt of care month roources asing counter of administration	Table 23.	Logistic regression -	<ul> <li>receipt of care from</li> </ul>	4 sources using count of	domain-specific difficultie
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			Depende	nt variable –	receives car	e from source:		
	1. /	Any	2. Partr	ner/Child	3. F	ormal	4. I	Private
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Female <sup>1</sup>	1.61 ***	1.43 - 1.82	1.40***	1.22 - 1.60	1.00	0.72 - 1.39	2.42***	1.89 - 3.11
<b>Conjugal family</b> Lives with a partner <sup>2</sup> Has any children <sup>3</sup> Partner only <sup>4</sup> Children only <sup>4</sup>	1.75 <sup>***</sup> 1.48 <sup>***</sup>	1.54 - 1.99 1.28 - 1.71	0.73 <sup>*</sup> 0.36 <sup>****</sup>	0.55 - 0.96 0.31 - 0.42	0.26 <sup>***</sup> 1.22	0.18 - 0.38 0.89 - 1.67	0.58 <sup>***</sup> 0.92	0.45 - 0.74 0.73 - 1.16
Age group <sup>5</sup> 65-69 70-74 75-79 80-84 85-89 90+	1.01 1.13 1.49*** 2.07*** 3.06*** 4.28***	0.87 - 1.18 0.97 - 1.33 1.26 - 1.76 1.71 - 2.50 2.41 - 3.90 2.78 - 6.61	0.92 0.99 1.28 <sup>*</sup> 1.53 <sup>***</sup> 1.63 <sup>****</sup> 2.29 <sup>****</sup>	0.78 - 1.09 0.83 - 1.19 1.06 - 1.54 1.24 - 1.89 1.25 - 2.13 1.45 - 3.61	2.95** 2.96** 5.11*** 10.80*** 14.38*** 16.69***	1.52 - 5.73 1.51 - 5.83 2.63 - 9.91 5.62 - 20.76 7.29 - 28.36 7.74 - 35.98	1.95** 4.35*** 6.02*** 12.07*** 17.68*** 12.88***	1.23 - 3.07 2.81 - 6.74 3.88 - 9.34 7.78 - 18.74 11.10 - 28.15 7.33 - 22.61
<b>Education<sup>6</sup></b> Edu: A-level Edu: O-level Edu: None	1.33 <sup>*</sup> 1.22 1.66 <sup>****</sup>	1.05 - 1.69 0.98 - 1.53 1.34 - 2.06	1.40 <sup>*</sup> 1.46 <sup>**</sup> 2.39 <sup>***</sup>	1.06 - 1.84 1.13 - 1.88 1.87 - 3.06	1.43 0.99 1.35	0.68 - 3.02 0.49 - 2.01 0.70 - 2.60	0.79 0.48 <sup>****</sup> 0.31 <sup>****</sup>	0.51 - 1.22 0.32 - 0.72 0.21 - 0.45
Number of difficulties <sup>7</sup> Mobility ADL IADL	1.44 <sup>***</sup> 1.10 <sup>**</sup> 3.92 <sup>***</sup>	1.40 - 1.48 1.03 - 1.18 3.61 - 4.26	1.42 <sup>***</sup> 1.13 <sup>***</sup> 2.67 <sup>***</sup>	1.37 - 1.47 1.06 - 1.21 2.47 - 2.88	1.28 <sup>***</sup> 1.38 <sup>***</sup> 1.50 <sup>***</sup>	1.19 - 1.37 1.25 - 1.53 1.37 - 1.64	1.31 <sup>***</sup> 0.91 <sup>*</sup> 1.24 <sup>***</sup>	1.25 - 1.38 0.84 - 0.99 1.15 - 1.34
N N_g rho BIC Pseudo R2	16,725 7,338 0.34 15,343 0.32		13,722 6,387 0.38 13,260 0.26		16,725 7,338 0.59 3,498 0.29		16,725 7,338 0.50 5,782 0.17	

Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001 Reference categories: <sup>1</sup> men; <sup>2</sup> does not live with a partner; <sup>3</sup> has no children; <sup>4</sup> 60-64; <sup>5</sup> Degree; <sup>6</sup> no domain-specific difficulties

Source: ELSA, waves 1-4

#### 4.3.1.1. Model diagnostics

Comparing again to models in Table 20, representing the optimal approach so far considered to controlling for dependency when modelling receipt of care, these models again have higher (ie worse) BIC values, but these are better than the previous 2 sets of models, with the pseudo r<sup>2</sup> identifying the difference being between 2% (model 2) and 11% (model 4). The rho values are all around 30 that suggest that differences between individuals explain the majority of variation in the receipt of each type of care.

#### 4.3.1.2. Model discussion

Model results are again broadly similar to the other models. However, constructing 'domainspecific level of need' indicators allows the variable effect of more complex needs in different domains on receipt of care to be identified. Of the 3 domains, an additional IADL difficulty has a greater effect on whether someone receives care, including both informal and formal care, than an additional difficulty in the Mobility or ADL domains. Reporting IADL difficulties also increases the likelihood of receiving private care although experiencing Mobility difficulties has a marginally larger effect. This may appear to be counter-intuitive, as the analysis shown in Table 20 identified that difficulty with IADL item 'doing work around the house' dramatically increased the likelihood of receiving private care. However, by conflating the 7 IADL items into a single IADL domain measure, the impact of a single item - 'doing housework' - becomes reduced hidden as a result of measuring the total effect from other items in the same domain. Instead, difficulties relating to housework may be captured more accurately by multiple Mobility domainspecific difficulties. Reporting Mobility difficulties increases the chances of receiving care from all sources while ADL needs increase the chances of receiving informal and formal care. It was shown in Table 18 that those with ADL difficulties are likely to experience more Mobility difficulties, and the negative effect of ADL dependency may therefore moderate the overall increase in likelihood of receiving private care associated with multiple Mobility difficulties alongside other IADL needs. This also supports the analysis in Table 22, suggesting private care is less likely to be received by those with very complex needs.

### 4.3.2. Summary

Measuring needs using the number of domain-specific difficulties experienced enables an understanding of how levels of need across different domains can contribute to the types of care that people receive. As when considering need purely as a count of the total number of difficulties, this approach describes a linear relationship between increasingly complex needs and the type of care received and does not clearly identify the cumulative effect of experiencing greater numbers of difficulties, associated with increasingly complex needs. Further, direct

comparison between the effects of experiencing need in different domains is made problematic since the number of constituent items summarised by each domain is not the same, and it isn't possible to easily compare patterns of care receipt for those with the greatest need in each domain. In order to enable comparison between those with high and low levels of dependency, chapter 5 considers approaches to handling the dimensionality of the data using 2 original approaches. Firstly, using the Indicator of Relative Need (IoRN) as a framework for measuring different types and levels of need simultaneously; Secondly, by developing summary measures of need using principal components analysis (PCA), a data reduction and classification method. This chapter continues by moving beyond the approaches considered so far, which do not explicitly account for the way that needs develop across time. The next section utilizes lagged variables to explore how changes in the status of ADL difficulties can affect the chances of care being initially received.

### 4.4. Exploring the effects of difficulty status on initial care receipt

Care is employed to meet specific needs. The point at which care is first employed will therefore be directly related to how needs develop, and how particular needs impact on how a person is able to live and function independently. The needs that people experience are not stable, and while certain needs may develop and become progressively more complex, other needs may become less severe. For example, someone experiencing difficulty walking across a room following an operation may recover from this and no longer experience this difficulty. Further, adaptations to the home may reduce the impact of particular difficulties, such as moving around the home and taking a shower, and can reduce the amount of formal care received (Agree and Freedman, 2000; Agree et al, 2005; Allen, Foster and Berg, 2001). In this way, the care that a person receives is also likely to change dynamically as needs and dependencies change.

When considering the different types of care that are available, depending on the type and complexity of needs people experience, care from a single source may be sufficient to meet their needs. Some studies suggest care from any source indicates that needs are being met (e.g.

Gannon and Davin, 2010). However, although any type of care received is likely to meet at least some aspects of need, it may be that other needs remain unmet and this is evidenced by some people receiving care from multiple sources concurrently. As such, understanding how different types of care meet particular needs requires further investigation. When needs are relatively low, it can be assumed that care from any source may negate the need for care from other sources completely. For example, someone with low levels of need may receive care from a partner, and this is likely to decrease the likelihood of receiving care from other informal or formal sources. In this example, the point at which informal care starts will be dependent on the type and complexity of needs being met as well as the availability of family or friends with the capacity and willingness to provide unpaid care. As needs become more complex, a partner or child may become increasingly less able to meet the demands of more complex needs involving more intensive care. In this situation, other sources of care may potentially be sought to supplement the unpaid care. This may involve seeking support from formal or private care services to provide support that is otherwise beyond the means of a partner or child to supply. Understanding that the needs people have and the care they receive are connected dynamically therefore requires moving to an approach explicitly operationalizing the longitudinal aspects of the ELSA data.

To expand on this, analysis was conducted to identify how change or stability in the experience of particular difficulties over time may affect the start of care. The sample in the section is restricted to only respondents who are present in 2 consecutive waves, and who were not receiving care from any source in the first of these 2 consecutive waves (baseline). This design allows for an exploration of how changing needs affect the likelihood of care starting in the next consecutive wave (follow-up).

For a given pair of consecutive waves, a person may report difficulty with any of the 23 Mobility, ADL and IADL items as follows: in neither wave, at baseline wave only, at follow-up wave only, or in both waves. Similarly, across each pair of consecutive waves an individual may receive care from any of the specified sources and for each type of care they may receive care: in neither

wave, at baseline wave only, at follow-up wave only, or in both waves. Having information on how the status of needs and care receipt vary across waves allows analysis of how change in the status of needs affects how care receipt may begin, continue or end. The dynamic status of both needs and care across 2 consecutive waves is specified in Table 24, where the first wave is identified as 'baseline' and the second wave is identified as 'follow-up'.

	At baseline	At follow-up	Consecutive wave status at follow-up
Difficulty	Difficulty not experienced	Difficulty not experienced	Difficulty status – neither
	Difficulty not experienced	Difficulty experienced	Difficulty status – newly reported
	Difficulty experienced	Difficulty experienced	Difficulty status – ongoing
	Difficulty experienced	Difficulty not experienced	Difficulty status – stopped
Care	Care not received	Care not received	Care status – none received
	Care not received	Care received	Care status – started receiving
	Care received	Care received	Care status – continued receiving
	Care received	Care not received	Care status – stopped receiving

Table 24. Permutations and specification of 'Difficulty status' and 'Care status' across 2 consecutive waves

Using this approach to operationalizing change or stability in the needs that people experience and how care is received allows a way to understand how the development of different needs may dynamically intersect with the receipt care. Using the new measures, Figure 28 through Figure 31 show whether or not care is received at baseline and follow-up for those with each difficulty: (i) in neither wave; (ii) newly reported at follow-up; (iii) ongoing at follow-up; (iv) stopped at follow-up.

The majority of people in the sample who are present in 2 consecutive waves (n=15,243) do not experience any difficulties (n=10,360). Figure 28 shows more than 60% of people who do not experience a given difficulty do not receive care from any source in either wave. From Figure 29, the number of people newly reporting a difficulty at follow-up varies, with as few as 295 people newly reporting difficulty 'eating food' while more than 1,000 people newly report difficulty with 9 of the 10 Mobility domain items. More than 30% of people newly reporting one of the IADL difficulties at follow-up have started to receive care in this wave. These IADL difficulties represent the items most commonly newly reported in combination with care starting. In



Figure 28. Any care received status for individual domain difficulties (i) experienced in neither wave

Source: ELSA, waves 1-4 (Sample: those in 2 consecutive waves)



Figure 29. Any care received status for individual domain difficulties (ii) newly reported in wave 2

particular, 44% of those newly reporting difficulty 'doing housework' at follow-up begin to receive care in the same wave suggesting that care most commonly begins with help of this nature. In the ADL domain, more than half of those newly experiencing difficulty 'walking across a room', 'eating food', 'using the toilet' and 'getting in and out of bed' were receiving care at baseline before these difficulties developed. This confirms that some form of care is likely already in place prior to developing the majority of ADL difficulties although over half of those

Source: ELSA, waves 1-4 (Sample: those in 2 consecutive waves)

newly reporting difficulty 'getting dressed' and 'taking a bath or shower' were not already receiving care in the previous wave.



Figure 30. Any care received status for individual domain difficulties (iii) ongoing in wave 2

Source: ELSA, waves 1-4 (Sample: those in 2 consecutive waves)

Figure 30 shows, with the exception of items 'using a map' and 'doing housework', 9-out-of-10 people reporting ongoing IADL difficulties at follow-up received care in both consecutive waves. Similarly, more than 80% of those reporting ongoing difficulty with 4 of the 6 ADL items received care at baseline and follow-up. Only a small proportion – less than 10% – of those reporting ongoing difficulty with all 7 IADL items and all ADL items except 1 received care in neither wave. By comparison, more than 20% of those reporting ongoing difficulty with 4 of the Mobility items did not receive care in either wave. Further, more than 10% of people experiencing ongoing difficulty with all but one of the Mobility items started to receive care at follow-up compared to less than 5% of those experiencing ongoing difficulty with 2 ADL and 4 IADL items who began receiving care at follow-up. This suggests that there is greater likelihood of care starting due to ongoing difficulty with Mobility items whereas those with longer-term ADL and IADL difficulties are likely to have already been receiving care.



Figure 31. Any care received status for individual domain difficulties (iv) stopped in wave 2

Source: ELSA, waves 1-4 (Sample: those in 2 consecutive waves)

Turning to consider how care is affected by particular needs ending, Figure 31 shows that care is more likely to cease in response to certain difficulties ending than others. For example, more than 40% of those who had difficulty 'climbing flights of stairs', 'stooping, etc.', 'lifting weights' and 'doing housework' who were also receiving care at baseline but did not report the difficulty at follow-up also stopped receiving care. This compares to less than 20% of those reporting difficulty with 4 ADL and 6 IADL items who no longer receive any care at follow-up when these difficulties cease. This shows that in the majority of cases when particular difficulties are no longer experienced care is likely to continue and this is supported by the fact that more than half of those no longer reporting a given difficulty at follow-up who were receiving care at baseline continued to receive care at follow-up. This is more evident when looking at ADL and IADL difficulties: with the exception of the item 'doing housework', more than 70% of cases where a previous ADL or IADL difficulty ended the person continued to receive care at follow-up.

Summarising the patterns of care receipt in response to changes in the status of Mobility, ADL and IADL difficulties is helpful to understand the impact that particular difficulties may have on how care may start or end. However, before turning to consider how the status of these needs may affect the type of care that people receive it is necessary to make several points clear. Primarily it should be acknowledged that attempting to build a model to explore how changes in the status of 23 difficulties may affect the type of care received would involve an overly complex model to account for the 4 possible states of each individual difficulty. As such, a more parsimonious approach would be to focus on the impact of a few key difficulties to see how they may affect the types of care received. For the purposes of the following analysis the status of individual difficulties are assumed to occur independently of each other. However, changes in the status of care received from different sources cannot be assumed similarly independent. As discussed, receiving one type of care at baseline is likely to have a direct impact on whether or not an individual continues to receive care and whether they begin receiving care from another source. As such, attempting to unpick how different types of care may dynamically change in response to the development or improvement of needs becomes problematic.

The only point at which the care receipt can be assumed to occur independently of pre-existing care from another source is the point at which care initially begins. By restricting analysis in this way, it is assumed that any care received is a direct outcome of the particular needs being experienced, when other background characteristics are also taken into account. Considering these issues, the analysis focuses on whether or not care is received at follow-up by those who did not receive care at baseline. Since the majority of care received is provided informally, this section expands the sources of care considered in the previous approaches to include an additional source of care, classified as unpaid care from a person other than a partner or child, which can include other family members, friends or neighbours. In order to maintain a parsimonious model, the number of difficulties controlled for will be restricted to 5 IADL difficulties and 2 Mobility difficulties which were shown in Figure 29 to be the items most commonly associated with care starting for those newly reporting a difficulty at follow-up. By focusing on these items, the analysis should be able to identify how new or ongoing difficulties may affect the receipt of different types of care. It should be noted, further analysis could consider the impact of experiencing other ADL and Mobility needs using a similar approach but, due to limitations of space, these are not considered here.

Figure 32 summarises the sample of around 11,000 cases, showing the proportion of cases receiving no care at baseline that began receiving care at follow-up by the status of each of the 7 difficulties.



Figure 32. Proportion of sample initially receiving care at follow-up, by individual difficulty status

Although there is variation across individual items, it is clear that there is consistency across the 7 items with a high proportion of cases newly reporting, or with ongoing difficulty with a given item, starting to receive care at follow-up. It should be noted that when the sample is restricted in this way – i.e. including only individuals who did not receive care at baseline – that certain combinations of need status and care status have small numbers of cases. In particular, there are less than 20 cases with ongoing difficulty 'using the telephone', 'taking medication' and 'managing money' who did not already receive care in the previous wave. Of the 10,999 cases without care at baseline, only 1,808 (16%) start receiving care at follow up, of which 88% receive care from a partner or child, 6% receive other informal, 4% receive private care, and just 2% start to receive formal care. Combined with the small numbers of cases for particular categories of IADL difficulties, for example, private care beginning for those with ongoing difficulty taking medication and making telephone calls (8 and 11 cases, respectively) makes modelling formal and private care initiation using this approach problematic. Although it may be productive to

Source: ELSA, waves 1-4 (Sample: in 2 consecutive waves and not receiving care at baseline)

look at the relationship between other difficulties and formal and private care starting, due to the limitations of space the analysis focuses on initial receipt of informal care exclusively.

# 4.4.1. Modelling care receipt across consecutive waves for 7 key Mobility and IADL difficulties

This section undertakes logistic regression analysis to explore how care first initiates in response to particular needs, and the sample under analysis is therefore restricted to respondents in 2 consecutive waves who did not receive care in the prior wave (see Figure 32). By restricting the analysis to those who were not previously receiving care, this approach will provide an understanding of the dynamic impact that new, ongoing or previous needs have on care beginning. As discussed, due to small numbers of cases that receive private and formal care at follow up, this analysis considers only informal care. Therefore, this section expands on the previous analysis, by additionally considering unpaid care from sources other than partners and children. The models presented examine the effects of changes in the status of 7 difficulties, alongside background demographic and socio-economic characteristics, on initial receipt of care from any source, unpaid care from a partner or child, and care from any other informal source. Additionally, the age variable has been simplified to a 4-item measure in order to limit the complexity of the model, and to enable the effects of ageing – across early, mid and late old age – to be more easily interpretable. Table 25 presents results from the logistic regression analysis for the 3 models.

Holding other explanatory variables constant, women are more likely to receive care at follow up than men are; older people living with a partner are less likely to receive other types of unpaid care, while having children lowers the chance of care from other unpaid sources beginning. The likelihood of care starting at follow-up increases with age, and the oldest group are around 3 times as likely to begin receiving any care and care from other informal sources, holding other factors constant. The least educated group are most likely to start to receive care, and are more than twice as likely as the most educated to receive care from a partner or child, although in terms of other unpaid care the effect of education is not significant.

Table 25. Logistic regression results	dependent variable: care	received at follow up
---------------------------------------	--------------------------	-----------------------

		om source:	rce:				
Care source	1. An	y source	2. Part	ner/Child	3. Other informal		
	OR	95% CI	OR	95% CI	OR	95% CI	
Female <sup>1</sup>	1.68***	1.42 - 2.00	1.69***	1.36 - 2.11	1.49 <sup>*</sup>	1.03 - 2.14	
Conjugal family	***		1		***		
Lives with a partner <sup>2</sup>	2.49	2.04 - 3.04			0.28	0.18 - 0.44	
Has any children <sup>°</sup>	0.80	0.65 - 0.98			0.66	0.46 - 0.94	
Partner only			0.89	0.57 - 1.37			
Children only			0.19	0.14 - 0.26			
Age group <sup>5</sup>			_	_			
65-74	1.24	0.98 - 1.56	1.21	0.92 - 1.60	1.28	0.72 - 2.28	
75-84	2.18	1.68 - 2.82	1.97	1.44 - 2.69	2.03	1.13 - 3.63	
85+	3.36	2.31 - 4.89	2.03	1.22 - 3.36	2.75	1.36 - 5.54	
Education <sup>6</sup>				_			
A-level	1.49 ้	1.09 - 2.03	1.82**	1.22 - 2.72	1.24	0.64 - 2.41	
O-level	1.44	1.07 - 1.94	1.73	1.18 - 2.53	0.91	0.48 - 1.72	
None	1.69	1.27 - 2.24	2.38	1.64 - 3.45	0.99	0.55 - 1.79	
Pull/push objects <sup>7</sup>	***						
Started	3.20	2.47 - 4.13	3.05	2.21 - 4.21	2.14	1.36 - 3.36	
Continued	2.40	1.66 - 3.46	1.59	0.98 - 2.56	1.96	1.09 - 3.54	
Stopped	1.75	1.21 - 2.53	2.37	1.48 - 3.78	2.28	1.21 - 4.32	
Lifting heavy weights <sup>7</sup>				_			
Started	6.33	4.97 - 8.06	7.12****	5.20 - 9.74	4.39	2.73 - 7.08	
Continued	3.74 ***	2.74 - 5.09	3.90 ***	2.63 - 5.78	3.90 ***	2.23 - 6.81	
Stopped	1.89	1.38 - 2.58	1.86	1.24 - 2.81	3.38	1.85 - 6.17	
Shopping for groceries <sup>7</sup>				_			
Started	8.14***	5.16 - 12.83	6.14	3.68 - 10.24	2.77****	1.68 - 4.54	
Continued	2.72	1.07 - 6.91	1.29	0.36 - 4.56	2.03	0.70 - 5.94	
Stopped	1.88	0.96 - 3.68	2.05	0.85 - 4.94	1.46	0.52 - 4.04	
Using the telephone <sup>7</sup>	***			_			
Started	13.07 ***	7.27 - 23.50	23.48 <sup>***</sup>	11.26 - 48.97	0.62	0.25 - 1.58	
Continued	10.80	1.73 - 67.51	5.27	0.54 - 51.87	21.71	2.96 - 159.08	
Stopped	0.71	0.23 - 2.19	1.20	0.29 - 4.95	0.39	0.05 - 3.09	
Taking medication <sup>7</sup>	***			_			
Started	13.69	5.23 - 35.83	4.84	1.69 - 13.87	1.61	0.67 - 3.90	
Continued	1.80	0.02 - 172.39	0.68	0.00 - 807.21	3.12	0.08 - 121.73	
Stopped	1.24	0.31 - 5.02	2.20	0.41 - 11.88	2.86	0.48 - 16.93	
Doing housework <sup>7</sup>	***			_			
Started	11.20****	8.48 - 14.78	6.54	4.69 - 9.12	6.18***	3.92 - 9.74	
Continued	7.99	4.86 - 13.14	9.39	5.06 - 17.42	6.89	3.39 - 14.04	
Stopped	1.64	1.05 - 2.57	1.49	0.82 - 2.71	1.78	0.80 - 3.97	
Managing money <sup>7</sup>	***						
Started	27.26	13.72 - 54.14	22.22	9.63 - 51.32	0.63	0.28 - 1.45	
Continued	6.32	0.34 - 116.10	8.66	0.20 - 371.69	2.08	0.07 - 58.57	
Stopped	0.83	0.22 - 3.18	0.67	0.10 - 4.39	0.15	0.01 - 2.25	
Ν	10,979		8,951		10,979		
N_g	5,485		4,656		5 <i>,</i> 485		
rho	0.30		0.39		0.49		
BIC Decude D2	6,705		5,015		2,405		
Pseudo R2	0.34		0.27	l	0.28	I	

Significance values: \* p < 0.05; \*\* p < 0.01; \*\*\* p < 0.001Reference categories: <sup>1</sup> men; <sup>2</sup> does not live with a partner; <sup>3</sup> no children; <sup>4</sup> Lives with a partner and has children; <sup>5</sup> 60-64; <sup>6</sup> Degree; <sup>7</sup> difficulty in neither wave

Source: ELSA, waves 1-4 (Sample: present in 2 consecutive waves without care at baseline)

Newly reporting each of the 7 items increases the chance of care beginning, holding other factors constant, although there are clear differences in how some needs are met by different types of informal care. While help with domestic tasks, such as shopping and housework may be met soon after the difficulty develops, from outside the family if necessary, help with some difficulties, such as taking medication and managing money, is likely to come exclusively from a partner or child. This is confirmation that these IADL activities reflect characteristically different needs, where intimate and personal tasks are a domain in which the type of support supplied from within the family unit is unlikely to come from elsewhere. In particular, the nature of tasks such as dealing with money necessitates a caregiver-receiver relationship based on trust, while support with phone calls requires a level of proximity and availability that formal and private care arrangements are commonly unable to provide. In the particular case of difficulty using the telephone, it is clear that those not receiving support from their family will ultimately need to find support from elsewhere in their social circle. With tasks of this nature, it is unclear how older people cope in the absence of a willing family member, friend or neighbour.

### 4.4.2. Summary of section 4.4

This approach allows an understanding of the way in which the development or change in the status of different difficulties can affect care at the point it is first received. As discussed, this approach restricts the sample under analysis to only respondents in 2 consecutive waves who were not receiving care at baseline. Since the majority of all care received is provided by partners/children, the analysis identified issues when attempting to model first receipt of formal and private care by those experiencing ongoing needs using this approach since care from informal sources will almost always precede the receipt of formal or private care. However, this approach allows an understanding of the dynamic impact of 7 key Mobility and IADL difficulties. It may be possible in future analysis to consider how changes in needs may affect the receipt of care at follow-up for those already receiving care at baseline. However, without accounting for endogeneity in factors underlying decisions about who provides care (see section 1.5; Bolin,

Lindgren and Lundborg, 2008; Bonsang, 2009; Gannon and Davin, 2010; Van Houtven and Norton, 2004) assumptions regarding the independent effect of pre-existing care on newlyreceived care become problematic. Within the scope of the current thesis, the data available in ELSA is not adequate for exploring these questions further.

### 4.5. Summary of chapter

This chapter adopted a number of exploratory approaches to consider how different needs may affect the likelihood of receiving care from a range of sources. The analysis has shown that it is necessary to take account of differences in the characteristics of different Mobility, ADL, and IADL difficulties in order that the effects of different needs are not obscured. The approaches presented in the chapter have focused on unpicking how mobility, ADL and IADL difficulties collectively affect the likelihood of care receipt. The approaches adopted in this chapter explored the independent effects of different mobility, ADL and IADL difficulties, exploring how different needs may vary in their impact on care receipt, before offering 2 simple approaches to reflect relative dependency. The first, by disregarding the differences between mobility, ADL and IADL needs, then by controlling for relative needs in each domain simultaneously. The chapter closed with a consideration of how the status of particular difficulties may determine the transition into receiving care.

The next chapter builds on the previous analysis, by developing a measure of dependency that allows for the differences in type and level of dependency to be controlled for, by applying a preexisting framework – the Indicator of Relative Need (IoRN) – to the ELSA data.
## **Chapter 5**

## 5. <u>Measuring levels of need across different domains</u> <u>simultaneously</u>

As discussed, approaches to understanding the relationship between the need-for-care and the care received from formal, private and informal sources commonly rely upon the use of health and disability indicators such as activities of daily living. As outlined in section 1.3, the supply of formal care in England is currently dependent on assessment processes and eligibility criteria which are likely to be regionally-specific. However, reducing the diversity of needs in research to single binary measures - for example, dichotomising the existence of 'need' as the presence of any ADL difficulties, regardless of the difficulty or if someone has only one or multiple difficulties, does not reflect the more multifaceted aspects of need as it occurs as a result of combinations of different difficulties. Similarly, the type of care that people receive is likely to vary according to the complexity and nature of their individual needs. Further, approaches to exploring the relationship between the need for care and care receipt using overly simplistic measures of need may fail to engage with formal care assessment procedures, which may prioritise particular dependencies above others. In the context of formal service provision there is a tradition of developing frameworks and assessment procedures for determining how formal care services are allocated. The Indicator of Relative Need (IoRN) is a questionnaire-based tool implemented as a non-compulsory aspect of the single shared-assessment policy within the Scottish health and social care sector.

The IoRN tool determines need-for-care by measuring level of dependency within specific dimensions of physical and mental health. The IoRN tool replaces the previous Resource Use Measure (RUM), originally developed as a tool to determine eligibility for free nursing care prior to the expansion of free personal and nursing care to all older people in Scotland (Scottish Government, 2003). The application of the IoRN is not a requirement of the assessment process but may be optionally implemented by individual LA within Scotland. For a LA opting to use the IoRN within their assessment procedures, the tool may provide a complement to current

statutory systems and processes for determining eligibility for care services at an individual level, supporting decision-making processes with respect to the allocation of care resources and planning for the provision of future care services (Scottish Executive, 2004).

The development of the original RUM questionnaire involved close consultation with expert reference groups in order that the RUM would include the types of needs, including clinical and mental health needs, which could be expected to be supported by existing health and social care services in Scotland. A pilot-study collected detailed information on the costs associated with providing health and social care services including hours of care provided across the range of available care services, unpaid informal care, equipment and adaptations and estimated unmet need (ISD Scotland, 2002). Using this data a framework was developed based on multiple questions which were refined and validated as the most statistically effective in predicting the estimated overall cost of providing the range of formal and informal care required to meet all identified dimensions of need. The IoRN questionnaire was developed from the original RUM model and is completed based on an objective assessment of a health professional providing responses to 17 individual questions framed within 4 dimensions of dependency:

- dependency in 3 core ADLs (such as moving about the house) to differentiate between the 6 items within ELSA previously specified as ADL these 3 items are collectively referred to from here onwards as IoRN-ADL
- 2. dependency in 7 personal care (IoRN-PC) tasks (such as washing and dressing)
- 3. dependency across aspects of mental health and wellbeing (IoRN-MHW) (due to conditions such as depression, dementia or Alzheimer's disease)
- 4. dependency in bowel management (IoRN-BM)

Responses to individual questions within each dimension are scored according to the degree to which an individual is independent in performing individual activities or exhibits specific behaviours. Scores are summed for each dimension and scores for each dimension are used to assign individuals to groups based on their overall relative level of need. The next section will outline how each of the 4 dimensions of need is assessed.

## 5.1. The IoRN framework for assessing need-for-care

The IoRN questionnaire is divided into 4 sections with responses within each section providing a 'within-category' score. The 4 within-category scores are then used to assign an individual to one of 9 groups (A - I) which are ordered according to relative needs - group A being most independent and group I being most dependent (see Figure 33). The 4 dimensions of need and within-category scores are outlined in more detail in this section.

#### 5.1.1. IoRN: activities of daily living

The IoRN assesses an individual's relative dependence in this area by their ability to perform 3 activities:

Eating a meal

Transferring from bed to a chair or wheelchair

Using the toilet

Relative dependency in each item is measured using 6 response categories [score for each response in brackets]:

Α.	Without assistance/performs task independently	[1]
В.	Without assistance using equipment or adaptations	[1]
C.	Needs assistance of one person	[2]
D.	Requires prompting/supervision [of one person]	[2]
E.	Requires complete assistance [of more than one person]	[3]
F.	Cannot/does not perform task	[3]

The scores for each question are totalled to produce a summary score ranging from 3 (least dependent) to 9 (most dependent).

#### 5.1.2. IoRN: personal care

The IoRN assesses an individual's dependence in this category by whether they are able to perform 7 activities:

Washing hands and face Having a complete wash, bath or shower Washing own hair Dressing/undressing Preparing and serving a main meal

Preparing a light snack

Preparing a hot drink

Relative dependency in each item is measured using 5 response categories [score for each response in brackets]:

Α.	Without difficulty	[1]
В.	Without difficulty using equipment or adaptations	[2]
C.	With difficulty using equipment or adaptations	[3]
D.	Requires prompting/supervision	[4]
E.	Cannot do without assistance from others	[5]

The scores for each question are totalled to produce a summary score ranging from 7 (least dependent) to 35 (most dependent).

## 5.1.3. IoRN: mental health and wellbeing

The IoRN assesses an individual's recent mental wellbeing and behaviour based on how often they have exhibited 6 specific behaviours in the previous 4 weeks. This section is included to capture

'the behavioural signs and symptoms of mental health problems such as dementia (or other signs of cognitive impairment), anxiety, depression, schizophrenia ... [and also covers] behavioural problems which may result from alcohol or drug dependencies, or acquired brain injury'

('SSA-IoRN general guidelines', Scottish Executive, 2004)

The 6 behaviours cover:

- Agitation or restlessness
- Disturbance or disruption
- Verbal aggression
- Resistiveness
- Difficulty with key relationships
- Behaviour constituting a risk to themselves

The first 3 items (agitation, disturbance, and verbal aggression) are assessed using 2 response categories [score for each response in brackets]:

Α.	Never, or less than three times in the last 4 weeks	[1]
----	---	-----

B. Three times or more in the last 4 weeks [2]

The next 3 behaviours (resistiveness, difficulty with relationships, and behaviour constituting a risk) are assessed according to whether the behaviour has been exhibited at all in the past 4 weeks with 2 response categories:

A.	No	[1]
B.	Yes	[2]

The scores for each question are again totalled to produce a summary score ranging from 6 (least dependent) to 12 (most dependent).

## 5.1.4. IoRN: bowel management

In the assessment of assistance or supervision with treatments relating to bowel management, rather than assign a score individuals are assigned to either low or high dependency group according to whether they require supervision more than once per week, as below:

Α.	Never, or less than once a week	[Low]
В.	More than once a week	[High]

## 5.1.5. Determining a hierarchy of need

Once the IoRN questionnaire is completed, the scores for the 4 dimensions are used to determine a relative dependency level within each domain and Table 26 shows how the levels are calculated.

Table 26. IoRN within-category scoring and relative dependency categorisation

Dimension of need	Domain score	Dependency class
IoRN activities of daily living (IoRN-ADL)	3 4 5-9	Low Medium High
IoRN personal care (IoRN-PC)	7-14 15-27 28-35	Low Medium High
IoRN mental health and wellbeing (IoRN-MHW)	6 7-9 10-12	Low Medium High
IoRN bowel management (IoRN-BM)		Low High

Source: Scottish Executive (2005)

Finally the relative level of dependency in each dimension is used to determine a final IoRN group where these groups are ranked according to average cost of providing care to meet the type and level of needs described by each group. The framework for determining the final relative need group is shown in Figure 33.



Figure 33. IoRN relative need-for-care grouping by within-category dependency level

In this way, the IoRN questionnaire represents an approach to assessing needs in a number of different domains simultaneously which allows for the impact of different types of need on the overall receipt of care regardless of the source providing the care. Considered hierarchically, the IoRN model prioritises IoRN-ADL domain needs as the first order by which overall level of dependency can be differentiated, followed by IoRN-PC, IoRN-MHW and IoRN-BM. In this way the IoRN represents a useful framework for understanding how different dimensions of need may operate together to place greater or lesser pressure on the provision of care.

#### 5.1.6. Summary of the IoRN

As discussed in section 1.7, previous approaches using secondary data to explore the relationship between needs and patterns of care receipt have commonly adopted simplified

*Note: full label descriptions in* Table 26 Source: reproduced from Scottish Executive (2005)

frameworks based on the presence or absence of 1 or more ADL and/or IADL difficulties. By conflating the characteristics of a range of potentially diverse difficulties into simplified measures of need such approaches do not allow for an understanding of the way different ADL or IADL difficulties may affect dependency and care differently. Further, it would be beneficial to develop a 'holistic' approach to capturing needs which allows a more complete understanding of how needs are experienced in order to better understand how different needs relate to the receipt of care in later life.

Adopting an approach allowing for the complexity of need to be summarised may help to move beyond the dichotomisation of needs, enabling a more accurate picture of dependency in later life to be considered. As with the Netten and Forder (2007) study, the IoRN model is additionally able to summarise the relative costs of a combination of formal and informal care and conceptually accounts for the impact of having needs left unmet.

As such, the existing framework of the IoRN provides a useful structural foundation to explore the impact of needs on the receipt of care allowing for different levels of need across a range of domains to be measured simultaneously. Further, the IoRN represents a validated tool for assessing relative levels of need and the IoRN framework can potentially be applied to existing secondary data on older people to explore the key research questions regarding how particular aspects of need may affect the type of care that older people receive.

#### 5.2. Developing an IoRN measure using ELSA

As discussed, the Scottish IoRN has been designed and validated as a tool to estimate the level of care necessary to meet a given combination of needs identified. The framework is based on an objective assessment of dependency levels across 4 domains – Activities of Daily Living (IoRN-ADL), Personal Care (IoRN-PC), Mental Health and Wellbeing (IoRN-MHW), and Bowel Management (IoRN-BM). Using the IoRN as a framework to objectively assess levels of need across each domain relies on determining the degree of dependency an individual experiences with each component activity. However, ELSA collects only self-reported measures of whether or not a person has difficulty with each activity and whether any help is received. ELSA cannot

therefore be used to determine the relative *degree* of difficulty a person may experience with any individual item or how reliant on the help they receive they are. Nonetheless, it can be assumed that applying the IoRN framework using ELSA data will reflect a similarly structured overall hierarchy of needs captured in the IoRN despite the measures of dependency being less precise. As such, this section will focus on developing a single indicator summarising combinations of different needs replicating the domains of dependency used in the IoRN framework to expand on the previous analysis to allow the structure of more complex needs to be considered. Further, although ELSA collects information on many broadly similar items to those used to assess dependency in the IoRN, there are particular IoRN domain items which have no direct equivalent in ELSA. The next section outlines how ELSA will be used to construct measures of domain-specific needs following the IoRN framework.

#### 5.2.1. Constructing comparable IoRN indicators of need using ELSA

This section outlines the construction of equivalent IoRN indicators of need using ELSA. As detailed in section 5.1, the IoRN framework is based on responses to 17 questions covering level of dependency in different domains of need. The first 2 domains – IoRN-ADL and IoRN-PC – assess dependency in 10 key activities covering self-care. The next domain – IoRN-MHW – considers current and recent behaviours to assess the presence of underlying mental conditions including depression. The last domain – IoRN-BM – assesses individuals' self-management in continence. As discussed, not all items specified in the IoRN are captured in ELSA and the equivalent domains will not be identical. In order to differentiate between the domains specified by the IoRN and the domains generated using ELSA the collective term Array of Need (AoN) will be used when referring to the ELSA-generated summary measure. In this way, the different collective domains will be referred to as AoN-ADL, AoN-PC, AoN-MHW and AoN-BM. The first section discusses using ELSA to construct indicators of need comparable to the IoRN domains IoRN-ADL and IoRN-PC.

#### 5.2.1.1. IORN-ADL and IORN-PC

The first 2 IoRN domains assess dependency in performing 10 activities and Table 27 shows the

comparable items provided in ELSA.

Group	IoRN items	Equivalent ELSA items			
IoRN-ADL	<ol> <li>eat a meal</li> <li>transfer from bed to a chair or wheelchair</li> <li>use the toilet</li> </ol>	'difficulty eating' 'difficulty getting in and out of bed' 'difficulty using the toilet'			
IORN-PC	<ol> <li>wash hands and face</li> <li>give a complete wash, a bath or a shower</li> <li>wash his / her own hair</li> <li>dress/undress</li> <li>prepare, cook and serve a main meal</li> <li>prepare a light snack (e.g. sandwich)</li> <li>prepare a hot drink (e.g. cup of tea)</li> </ol>	- 'difficulty bathing or showering' - 'difficulty dressing' 'difficulty preparing a hot meal' - -			

Table 27. IoRN IoRN-ADL and IoRN-PC activities and comparable ELSA items

Table 27 shows the IoRN-ADL domain is constituted by 3 items and all have comparable measures in ELSA. The IoRN-PC domain is constituted by 7 items of which 3 have a broadly comparable measure in ELSA. While difficulty in performing 4 of these items is not directly captured in ELSA, these items can be seen to reflect component tasks across two broader aspects of self-care, namely (a) washing and (b) preparing food. Difficulty with these aspects of self-care are broadly summarised by the 2 items 'difficulty bathing or showering' and 'difficulty preparing a hot meal'. While being able to take a bath or shower without difficulty would suggest that an individual is able to both 'wash face and hands' and 'wash own hair' they cover slightly different and more specific aspects of a wider regime of self-care. Older people who have difficulty taking a bath or shower may otherwise potentially be able to wash their hands and face or wash their own hair representing a capacity to perform more independently than knowing only whether difficulty is experienced taking a bath or shower might suggest. Similarly, those who report difficulty preparing a hot meal may otherwise be able to prepare a light snack or make a cup of tea which captures a degree of capacity to perform some tasks which would not be captured by considering only difficulty with 'preparing a hot meal'. While using fewer items in the AoN-PC domain does not provide as detailed a picture of dependency compared to the IoRN-PC domain it does broadly capture dependency in this particular area of self-care.

In this way, there are 3 matching ELSA items for each of the IoRN-ADL and IoRN-PC domains which can be used to provide broadly equivalent summary measures of need. Following the IoRN-framework, the 3 items in each ELSA-specified domain are scored and scores for each domain are summed to give a summary measure of relative need in each domain. While the scores in the IoRN framework rely on the independent assessment of relative dependency for each item provided by a health professional. The component ELSA items do not identify the *degree* of dependency as the items are self-reported binary measures reflecting only whether an individual experiences a given difficulty.

Sections 5.1.1 and 5.1.2 showed the scores for responses in the IoRN-ADL and IoRN-PC domains. Although ELSA provides information on whether individuals report that they receive care or help from a range of sources it is not possible to determine whether the help they receive is a necessary factor in performing a given task. As such it cannot be used to differentiate between response categories identifying that an individual receives rather than requires assistance with a given task. Responses to items in the IoRN-ADL domain reflect 3 states of relative dependency: 'without assistance', 'requires assistance', and 'cannot perform task'. The equivalent items in the AoN-ADL domain reflect only that a person has a difficulty. However, in reflecting difficulty rather than *dependency* those reporting a given item are categorising themselves as being dependent, although their degree of dependency remains unknown. Following the scoring frame in section 5.1.1, respondents reporting difficulty with an item in the AoN-ADL domain are scored 2 while those who do not report difficulty with an item are scored 1. Summing scores for responses to items in the AoN-ADL domain gives an overall score between 3 and 6 while overall domain scores in the IoRN-ADL domain range between 3 and 9. Responses to items in the IoRN-PC domain within the IoRN framework reflect 4 states of relative dependency: 'without difficulty', 'without difficulty (using equipment)', 'with difficulty (using equipment')', and 'requires assistance'. Although ELSA asks questions regarding whether adaptations or equipment are used there is no way to determine whether individuals use particular equipment or adaptations with respect to a given difficulty and therefore no scores of 2 are given. Since the

equivalent items in ELSA reflect only that a difficulty exists, when using the scoring frame in section 5.1.2 respondents are scored 1 if they report no difficulty and 3 if they report difficulty for each item in the AoN-PC domain. Summing scores for responses to items in this domain gives an overall domain score in the AoN-PC domain between 3 and 9 while scores in the IoRN-PC domain range between 7 and 35. Using this method to score the 6 individual items in ELSA produces summary scores for the 2 new AoN-ADL and AoN-PC domains and Figure 34 shows the mean scores for men and women in the 2 new domains.





Average scores for both domains increase with age for both men and women and the increase is most marked for the AoN-PC domain although the range of scores is greater in this domain. Scores appear relatively similar but women have slightly higher average scores compared to men, most notable in the oldest ages.

The summary scores for each domain are used to determine a relative dependency class ('low', 'medium' and 'high') for each domain. In order to operationalise for the research it has been necessary to adapt the IoRN framework in order to retain the same grouping due to summary scores in the AoN-PC domain generated from 3 rather than 7 items. The adapted relative dependency groupings alongside summary scores are shown in Table 28.

Source: ELSA, waves 1-4

Table 28. IoRN domain scoring scheme and adapted AoN scoring scheme

IoRN	ELSA	Relative dependency level
IoRN-ADL score	AoN-ADL score	
3	3	Low
4	4	Medium
5-9	5-6	High
IoRN-PC score	AoN-PC score	
7 – 14	3-6	Low
15 – 27	7–9	Medium
28 – 35	-	High

Source: Scottish Executive (2005) and ELSA

Due to the differences in scoring ELSA items, there are no cases with a score greater than 9 for the AoN-PC domain, and no cases can be assigned a 'high' relative dependency using this approach. To explore the new coding framework, the distribution of respondents for each domain is shown in Table 29 by age group.

	60-64	65-69	70-74	75-79	80-84	85-89	90+	Total
AoN-ADL <sup>a</sup>								
Low	92.7	92.7	91.1	89.7	86.7	81.9	75.2	90.4
Medium	5.0	5.1	6.4	7.1	8.8	12.0	11.7	6.5
High	2.4	2.2	2.5	3.2	4.5	6.2	13.1	3.1
AoN-PC <sup>b</sup>								
Low	94.1	92.9	91.4	89.3	85.4	77.3	61.6	90.2
Medium	5.9	7.1	8.6	10.7	14.6	22.7	38.4	9.8
Total	6.820	5.912	5.343	3,977	2,756	1.412	495	26,715

Table 29. Relative need in AoN-ADL and AoN-PC domains

<sup>a</sup> chi<sup>2</sup> (12df) = 443.0, p<0.001; <sup>2</sup> chi<sup>2</sup>(6df) = 974.6, p<0.001 Source: ELSA, waves 1-4

From Table 29, there is a statistically significant association between age and dependency in both domains (p<0.001). Without being able to classify those with high AoN-PC needs, the medium group for this domain includes respondents with high levels of dependency who cannot otherwise be identified. Around 90% of the sample is classified with low AoN-ADL and low AoN-PC needs. Dependency increases with age, with more than 13% in the sample aged 80+ having medium or high AoN-ADL needs, and over 20% having medium or greater AoN-PC needs. The next section outlines the construction of comparative indicators for the loRN-MHW domain.

#### 5.2.1.2. IORN-MHW

The IoRN questionnaire includes questions relating to recent mental wellbeing and behaviour to determine dependency needs relating to underlying mental health problems such as depression, anxiety, and forms of cognitive impairment including dementia. Dependency is assessed based on whether/how often an individual has exhibited 6 specific behaviours:

- 1. Agitation/restlessness
- 2. Disturbance/disruption
- 3. Verbal aggression
- 4. Resistiveness
- 5. Relationship difficulties
- 6. Behaviour constituting a risk

ELSA contains no directly comparable information relating to respondents *current* mental health state, although respondents are asked whether they have previously been diagnosed with a number of specific mental health problems including anxiety, depression, emotional problems, and mood swings. However, this information only confirms if these problems have been experienced in the previous 2 years and it is therefore not possible to identify whether these mental health problems were experienced recently. As the IoRN criteria assesses current mental health factors and behaviours it was decided to exclude these particular measures from the proposed ELSA-based mental wellbeing domain. Without directly equivalent measures to capture the IoRN-MHW domain in ELSA it was necessary to consider alternative approaches to determining a similar indicator for dependency resulting from mental health factors.

ELSA collects data regarding symptoms of depression using a revised 8-item Center for Epidemiologic Studies Depression Scale (CES-D) which was specifically developed as a tool for assessing depression in older people (Turvey, Wallace and Herzog, 1999). The full CES-D (Radloff, 1977) is a self-reported measure based on responses to 20 questions relating to different feelings and behaviours experienced over the previous week with response categories relating to how often a respondent experienced the relevant feeling or behaviour. The abbreviated eightitem version of the CES-D was developed as a tool for assessing depressive symptoms in older

people for whom the full CES-D may be too demanding due to physical and mental frailty (Turvey, Wallace and Herzog, 1999). The revised CES-D has been validated to capture both 'self-report of physician diagnosis and psychiatric treatment ... [and] higher rates of antidepressant use' (Turvey, Wallace and Herzog, 1999:139). As such, the revised CES-D used in ELSA captures similar feelings and behaviours to the questions used in the IoRN and which indicate symptoms of depression in older people. The 8 questions used in the ELSA CES-D are shown in Table 30.

#### Table 30. ELSA CES-D scale of depression questions

Much of the time during the past week:	<ol> <li>have you felt depressed?</li> <li>have you felt that everything you did was an effort?</li> <li>has your sleep been restless?</li> <li>were you happy?</li> <li>have you felt lonely?</li> <li>have you enjoyed life?</li> <li>have you felt sad?</li> <li>could you not get going?</li> </ol>
--	---

Source: ELSA

Responses to these questions in ELSA have binary 'yes'/'no' responses and are scored 1 for 'yes' and 0 for 'no' with the exception of questions 4 and 6 which are reverse coded (1 for 'no' and 0 for 'yes') and scores across all 8 questions are then summed to give a total CES-D score ranging from 0 to 8. Figure 35 shows mean CES-D scores by sex and age.





Source: ELSA, waves 1-4

There is a clear difference between men and women, with women reporting higher CES-D scores than men on average in all age groups except ages 90+. For men, average CES-D scores are lower and stable at younger ages but increase from age 75 onwards. Women aged 60-64 have higher CES-D scores on average than men aged 80-84, suggesting clear differences between men and women on this dimension.

Turvey, Wallace and Herzog (1999) suggest that a score of 6 or more on the 8-item scale is the cut-point signifying depressive symptoms. For the purposes of this study, a score of 6 or higher on the ELSA CES-D scale will similarly reflect a cut-off point for signifying depressive symptoms. Table 31 shows the mean CES-D score and the proportion exhibiting depressive symptoms by age.

	60-64	65-69	70-74	75-79	80-84	85-89	90+	Total
CES-D score 6+								
Men <sup>ª</sup>	4.2	4.0	3.3	3.7	4.6	6.0	9.1	4.1
Total	<b>3,216</b>	<b>2,790</b>	<b>2,484</b>	<b>1,791</b>	<b>1,135</b>	<b>520</b>	<b>164</b>	<b>12,100</b>
Women <sup>b</sup>	6.7	7.0	7.0	9.7	9.3	9.8	6.3	7.7
Total	<b>3,604</b>	<b>3,122</b>	<b>2,859</b>	<b>2,186</b>	<b>1,621</b>	<b>892</b>	<b>331</b>	<b>14,615</b>
ALL <sup>c</sup>	5.6	5.6	5.3	7.0	7.3	8.4	7.3	6.1
TOTAL	<b>6,820</b>	<b>5,912</b>	<b>5,343</b>	<b>3,977</b>	<b>2,756</b>	<b>1,412</b>	<b>495</b>	<b>26,715</b>

<sup>a</sup> chi<sup>2</sup>(6df) = 20.5, p<0.01; <sup>a</sup> chi<sup>2</sup>(6df) = 33.4, p<0.001; <sup>a</sup> chi<sup>2</sup>(6df) = 39.5, p<0.001 Source: ELSA, waves 1-4

There is a significant association between depressive symptoms and age for both men (p<0.01) and women (p<0.001). Depressive symptoms are increasingly common among older women, except for those aged 90+ who are less likely to report depressive symptoms than those aged 60-64. For men the pattern is less clear, with depressive symptoms being more common in younger members of the sample and at ages 80+.

The revised CES-D reflects one aspect of mental wellbeing, and the IoRN additionally assesses behaviours reflecting other underlying mental health conditions. Although there is no directly equivalent information available in ELSA, respondents are asked about previously diagnosed chronic conditions, including Alzheimer's disease and dementia. Bakker et al (2013) found care for people with dementia is likely to be predominately informal, as formal care services were considered more appropriate to meet physical rather than mental health issues, although formal care increased with the severity of dementia. As such, using a binary measure for dementia might limit the identification of the impact of behavioural difficulties due to greater disease severity. Respondents who confirm previous diagnosis with these conditions are asked to confirm whether they currently experience the condition. To allow consideration of other mental health conditions, this study assumes that respondents reporting a current diagnosis of dementia or Alzheimer's disease have greater mental health needs than those not experiencing these conditions. Since there is no way of determining to what degree these conditions currently affect respondents, this assumption may overestimate mental health difficulties due to these conditions, although they are ongoing conditions which are associated with progressive decline in mental capacity and those reporting these conditions are likely to experience higher degrees of dependency either currently or in the future. Table 32 shows the proportion of each age group confirming diagnosis of either dementia or Alzheimer's.

		60-64	65-69	70-74	75-79	80-84	85-89	90+	Total
Men	Dementia <sup>ª</sup>	0.6	0.6	1.0	1.1	2.5	4.6	3.0	1.1
	Alzheimer's <sup>b</sup>	0.0	0.1	0.0	0.3	0.6	1.9	1.8	0.2
	Total	3,216	2,790	2,484	1,791	1,135	520	164	12,100
Women	Dementia <sup>c</sup>	0.1	0.2	0.2	0.3	2.2	4.5	6.0	0.8
	Alzheimer's <sup>d</sup>	0.1	0.1	0.1	0.3	0.5	1.0	3.6	0.3
	Total	3,604	3,122	2,859	2,186	1,621	892	331	14,615
All	Dementia <sup>e</sup>	0.3	0.4	0.6	0.7	2.3	4.5	5.1	1.0
	Alzheimer's <sup>f</sup>	0.1	0.1	0.1	0.3	0.5	1.3	3.0	0.3
	Total	6,820	5,912	5,343	3,977	2,756	1,412	495	26,715

Table 32. Proportion of respondents confirming diagnosis of Alzheimer's disease and dementia, by age and gender

<sup>a</sup> chi<sup>2</sup>(6df) = 95.5, p<0.001; <sup>b</sup> chi<sup>2</sup>(6df) = 94.5, p<0.001; <sup>c</sup> chi<sup>2</sup>(6df) = 361.5, p<0.001; <sup>d</sup> chi<sup>2</sup>(6df) = 139.1, p<0.001; <sup>e</sup> chi<sup>2</sup>(6df) = 392.3, p<0.001; <sup>f</sup> chi<sup>2</sup>(6df) = 214.75, p<0.001 Source: ELSA, waves 1-4

From Table 32, there is a significant association between these conditions and age for both men and women (p<0.001). There is a higher prevalence of dementia than Alzheimer's at all ages, and a higher prevalence of dementia among men, except in the oldest group. For both conditions, the number of cases is very small. As shown in section 5.1.3, the IoRN-MHW domain classifies people into 3 relative dependency groups based on the assessment of 6 items. Identifying mental health conditions is more limited in ELSA, so respondents are categorised into only 2

groups in the AoN-MHW domain, as shown in Table 33.

AoN-MHW level	CES-D score				
Low	1-5	and neither	Alzheimer's	nor	dementia
High	>5	or either	Alzheimer's	or	dementia

#### Table 33. ELSA classification for dependency in the AoN-MHW domain

Table 34 shows the distribution of cases for the new ELSA-based IoRN-MHW variable.

	60-64	65-69	70-74	75-79	80-84	85-89	90+
AoN-MHW <sup>a</sup>							
Low	94.1	94.0	94.1	92.1	90.1	86.5	85.5
High	5.9	6.0	5.9	7.9	9.9	13.5	14.5

5,343

3,977

2,756

1,412

495

Total

92.8 7.2

26,715

#### Table 34. Relative dependency in the AoN-MHW domain

6,820

5,912

<sup>a</sup> chi<sup>2</sup>(6df) = 198.8, p<0.001;

Total

Source: ELSA, waves 1-4

From Table 34, there is a significant association between dependency in the mental health and wellbeing domain and age. Mental health needs increase most notably from ages 75 onwards, and around 15% of the oldest group having high mental health needs. Although the AoN-MHW domain does not cover the full range of underlying conditions measured by the IoRN, it differentiates those with some of the mental health conditions that the IoRN identifies as signifying greater dependence. Because the ELSA model only captures depression, dementia and Alzheimer's disease, other mental health needs are likely to be under-represented by adopting this approach.

#### 5.2.1.3. IORN-BM

The bowel management dimension of the IoRN is used to differentiate amongst those with high dependency needs. However, ELSA does not collect information on this aspect of dependency, and it was necessary to exclude this dimension from the ELSA framework. As the IoRN tool includes this domain in order to differentiate amongst the most dependent older care clients with very high ADL dependency needs (shown in Figure 33), this group is likely to be very small and constitute a very small subset of the 827 cases with high ADL needs in ELSA (Table 29). Further, the ELSA data collection procedure is unlikely to accommodate those with high dependency needs measured against formally-defined social care assessment criteria, and those in the high ADL needs group are likely to be representative of the most dependent older population who are able to remain living at home despite their high needs.

#### 5.2.2. The ELSA-based Array of Need (AoN) measure of relative dependency

Using the 3 dimensions of dependency identified in the previous section (AoN-ADL, AoN-PC and AoN-MHW), respondents are assigned to one of several dependency groups based on the type and complexity of their needs. Due to the lack of the AoN-PC 'high needs' category, the reduction of the AoN-MHW domain from 3 to 2 categories, and the exclusion of the IoRN-BM domain, the classification system has been simplified from 9 groups in the original IoRN, to 5 in the new Array of Need (AoN) measure of relative dependency. The original hierarchical IoRN framework, and the adapted AoN measure of relative dependency are shown in Figure 36.





Note: full label descriptions in Table 26

As discussed, IoRN groups D and E are not captured due to limited classification of the AoN-PC and AoN-MHW domains. Further, groups F, H and I in the original IoRN are not differentiated

due to the lack of information to define the AoN-BM domain. As such, all respondents classified high AoN-ADL needs are assigned into the same group, AoN5. While the ELSA-based measure is less refined due to the limitations of certain equivalent measures being unavailable, it represents a comparable model for determining a hierarchy of relative need, with groups classified following structurally similar domains and maintaining the hierarchical structure of the IoRNframework. The new AoN measure classifies needs following similar criteria as used in formal assessments for social care in Scotland, classifying people to one of 5 groups based on type and complexity of needs. In this framework, those classified with AoN1 have the least complex needs (low ADL and personal care needs) the AoN5 group are the most dependent (high ADL needs). Following the IoRN-framework, the AoN measure prioritises AoN-ADL needs as the main factor identifying low, medium or high levels of dependency without taking account of other dimensions of dependency. Table 35 shows the number of cases within each subsection classification.

AoN-ADL	# cases	AoN-PC	# cases	AoN-MHW	# cases	AoN	To be referred to throughout as
Low	24,150	Low Medium	23,025 1,125			1 2	AoN1 AoN2
Medium	1,738			Low High	1,424 314	3 4	AoN3 AoN4
High	827					5	AoN5

Table 35. Sample distribution by ELSA-based AoN needs type

Source: ELSA, waves 1-4

In order to explore how different domains of need impact on patterns of care for older people, the newly derived ELSA-based AoN measure is used in logistic regression analysis presented in section 6.1.

#### 5.2.3. The Array of Need

The key driver of care is the level of dependency that individuals experience. The AoN measure developed in section 5.2.1 will be used to allow for different needs across the AoN-ADL, AoN-PC and AoN-MHW domains to be explored simultaneously. Table 36 shows the distribution of cases

across the AoN groups, by age as a proportion of the whole sample and for those reporting any type of difficulty (i.e. any Mobility, ADL, or IADL difficulty).

	60-64	65-74	75-84	85+	Total
All respondents					
AoN1	90.7	88.6	82.9	67.4	86.2
AoN2	1.9	3.3	5.6	12.7	4.2
AoN3	4.0	4.9	6.4	9.1	5.3
AoN4	0.9	0.9	1.4	2.8	1.2
AoN5	2.4	2.3	3.8	8.0	3.1
Total	6,823	11,255	6,736	1,908	26,722
With a difficulty					
AoN1	82.6	81.8	77.6	63.1	78.9
AoN2	3.6	5.3	7.3	14.4	6.4
AoN3	7.6	7.8	8.3	10.3	8.1
AoN4	1.8	1.4	1.9	3.2	1.8
AoN5	4.4	3.7	4.9	9.0	4.7
Total	3,646	7,036	5,153	1,686	17,521

#### Table 36. AoN by age

Source: ELSA, waves 1-4

Table 36 shows that 86% of the ELSA sample aged 60+ is classified with AoN1 having the least dependency needs and represents 79% of those who report a difficulty. 3% of those aged 60+ are classified with AoN5, representing almost 5% of those with any type of difficulty.

Excluding those who do not report any difficulties – and as such cannot potentially be receiving care – the impact each AoN on care receipt is made clear in Figure 37, showing the proportion of the sample who have a difficulty (i.e. any number or combination of Mobility, ADL or IADL difficulties) who receive care by AoN group and age.

A lower proportion of those in AoN1 receive care than in all other AoN groups reflecting differences in dependency captured by the AoN measure. While around 36% in AoN1 receive care this compares to 72% in AoN3, 81% in AoN2 and AoN4 and 91% in AoN5. The combination of age and dependency can be seen to impact care with the oldest old in each AoN group the most likely to receive care with 60% of the oldest old in AoN1 and more than 90% of the oldest old in AoN2, AoN4 and AoN5 receiving care.

However, while 60% of the oldest old in AoN1 receive care this compares to more than 65% of the youngest in all other AoN groups who receive care. The increase in care with advancing age

Figure 37. Proportion with needs receiving care by AoN and age



Source: ELSA, waves 1-4 (AoN groupings shown Figure 36)

is not consistent across all groups. For example, 75% of the youngest in AoN2 and 87% in AoN5 receive care but there is no consistent increase in care receipt until 85+. The proportion receiving care increases more consistently with age in AoN3 and AoN4.

This suggests that following the IoRN-framework and measuring dependency across different domains simultaneously allows the AoN measure to capture aspects of need which may not be identified by binary or metric measures of need such as those considered in chapter 4 which do not allow the genuine complexity of needs to be considered. In this context, the AoN approach represents a way to capture the broader dimensionality of needs beyond other approaches that are restricted to considering only ADL or IADL difficulties.

### 5.3. Summary of chapter

This chapter has outlined the IoRN as a framework for measuring different domains of need simultaneously, which was operationalized using equivalent measures in ELSA to produce the AoN measure. The chapter suggested that using the AoN measure provides a more detailed summary of needs as they are experienced in later life. The next chapter will utilise the AoN (based on the IoRN-framework) with other explanatory variables in logistic regression analysis, to explore the key drivers of care from the 4 main sources.

## Chapter 6

# 6. <u>Exploring receipt of care using multi-domain measures of</u> <u>need</u>

This chapter begins by adopting logistic regression analysis using the AoN measure developed in the previous chapter to explore the relationship between relative levels of need across different domains simultaneously. The chapter continues by expanding on the IoRN-based approach to measuring multi-domain needs by using principal components analysis (PCA) to develop a broader multi-domain approach to measuring relative needs across alternative domains of need.

## 6.1. Controlling for need by AoN dependency in 3 different domains simultaneously

This section uses logistic regression analysis to explore the effects of explanatory factors on receipt of *any* care, as well as care from different sources. When modelling the receipt of care, the effects of relative need in different domains are controlled for using the newly defined AoN measure of dependency. As in chapter 4, explanatory variables include age, gender, conjugal family structure, and socioeconomic status. The models in this chapter control for socioeconomic status (SES) using education and introduce controls for wealth. The combination of these 2 measures provides control for early life social status (education) and accumulated advantage/ disadvantage over the life course (wealth) to consider how different controls of socioeconomic status influence care receipt in old age.

Although the AoN measure classifies individuals to one of 5 groups (as presented in Table 35, the AoN1 group includes individuals without needs. Conceptually this group is not relevant to this study and as with all models in this thesis, the sample is again restricted to individuals with at least one difficulty, representing the section of the sample that may potentially receive care. The next section explores the impact of AoN dependency on whether *any* care is received.

#### 6.1.1. Modelling receipt of any care from AoN dependency

Model 0 presents the null model and performs a logistic regression on the dependent variable without any independent factors in order to evaluate models containing additional explanatory

factors. Model 1 includes demographic characteristics, conjugal family structure, and SES without controlling for needs and Model 2 introduces a control for dependency using the AoN measure developed in section 5.2.1.

Table 37 shows the results of logistic regression on the receipt of any care. All models include the same sample of ELSA respondents who have one or more difficulties, and the sample comprises 16,183 different observations from 7,122 unique individuals present on average in 2.3 of 4 waves. The chi-square test was significant (p<0.001) and confirmed an association between the dependent and independent variables in these models. The BIC values for models 1 and 2 show a large improvement, confirming that the model is improved by the additional explanatory variables (a change greater than 10 identifies a valid case for including additional variables in the model, as discussed in section 2.8.2.1).

In the models controlling for independent factors, females are twice as likely to receive care. Those living with a partner are more likely to receive care while having children lowers the chances of care being received. The appropriateness of 'having children' as a proxy for the availability of informal care is problematic compared to 'living with a partner' since this measure does not in itself capture how close children may live which is a likely to be a key factor in their potential for providing care. Those in older ages have a higher chance of receiving care with those aged 85+ being dramatically more likely to receive care. The ageing effect is moderated when needs are controlled for although there remains a marked age effect at ages 85+ beyond that captured by the AoN dependency measure. In particular, the 90+ group is smaller and based on only 447 cases of which 82% receive care while 65 cases in this group are classified with AoN5 dependency needs only 1 of which does not receive care which identifies the dramatic impact dependency needs have on the oldest old. Low wealth and no education increase the likelihood of care receipt, although the effects of SES are broadly the same, whether controlling for needs or not.

Turning to the effects of AoN dependency needs (see Figure 36 and Table 35 for the specification

	Model 0		Мо	del 1	Model 2	
Receives any care	OR	95% CI	OR	95% CI	OR	95% CI
Female <sup>1</sup>			1.92***	1.67 - 2.22	2.02***	1.77 - 2.30
<b>Conjugal family</b> Lives with a partner <sup>2</sup> Has any children <sup>3</sup>			1.58 <sup>****</sup> 0.61 <sup>****</sup>	1.36 - 1.84 0.52 - 0.70	1.71 <sup>****</sup> 0.68 <sup>****</sup>	1.49 - 1.97 0.59 - 0.79
Age group <sup>4</sup> 65-69 70-74 75-79 80-84 85-89 90+			1.02 1.20 <sup>*</sup> 1.94 <sup>***</sup> 3.80 <sup>***</sup> 8.26 <sup>***</sup> 23.40 <sup>***</sup>	0.87 - 1.21 1.01 - 1.43 1.61 - 2.35 3.08 - 4.69 6.34 - 10.76 15.05 - 36.38	1.04 1.20 <sup>*</sup> 1.86 <sup>****</sup> 3.26 <sup>****</sup> 6.32 <sup>****</sup> 13.99 <sup>****</sup>	0.89 - 1.22 1.01 - 1.41 1.56 - 2.22 2.68 - 3.97 4.93 - 8.09 9.19 - 21.31
Wealth quintile <sup>5</sup> WQ4 WQ3 WQ2 WQ1 (low)			1.19 1.50 <sup>****</sup> 2.27 <sup>***</sup> 2.90 <sup>***</sup>	0.98 - 1.44 1.23 - 1.84 1.85 - 2.80 2.33 - 3.60	1.15 1.37 <sup>***</sup> 1.98 2.23 <sup>***</sup>	0.96 - 1.38 1.13 - 1.65 1.63 - 2.40 1.82 - 2.73
<b>Education<sup>6</sup></b> A-level O-level None			1.38 <sup>*</sup> 1.28 2.17 <sup>****</sup>	1.04 - 1.84 0.98 - 1.67 1.67 - 2.82	1.33 <sup>*</sup> 1.22 1.86 <sup>****</sup>	1.03 - 1.73 0.96 - 1.56 1.47 - 2.36
Array of Need <sup>7</sup> AoN2 AoN3 AoN4 AoN5					9.64 <sup>***</sup> 6.31 <sup>***</sup> 11.05 <sup>***</sup> 28.49 <sup>***</sup>	7.68 - 12.11 5.23 - 7.61 7.23 - 16.88 20.35 - 39.89
N N_g rho BIC Pseudo R2	15,846 7,087 0.60 19,668		15,846 7,087 0.56 18,838 0.06		15,846 7,087 0.46 17,712 0.15	

Table 37. Logistic regression: modelling receipt of care from any source for AoN dependency (n=7,904 receiving any care)

Significance values: \* p < 0.05; \*\* p < 0.01; \*\*\* p < 0.001Reference categories: <sup>1</sup> male; <sup>2</sup> does not live with a partner; <sup>3</sup> has no children; <sup>4</sup> 60-64; <sup>5</sup> Wealth quintile 1; <sup>6</sup> Degree; <sup>7</sup> AoN1

Source: ELSA, waves 1-4

of the AoN measure) identifies clear differences in the likelihood of receiving care depending on relative level of dependency. All groups have a greater chance of receiving care when other factors are held constant. As expected, those with AoN5 are naturally the most likely to be receiving care as was shown in Figure 37. Compared to those in AoN1 having AoN3 - reflecting medium level AoN-ADL and low level AoN-MHW dependency needs - are 6 times as likely to receive care while those with AoN2 and AoN4 are around 10 times as likely to receive care. This confirms that by operationalizing dependency needs using the IoRN-framework-based AoN measure, the model is able to differentiate both type and level of needs across a number of dimensions and how these can affect the receipt of care.

This section explored how demographic characteristics, family structure, SES and dependency needs affect the likelihood of receiving care. The following 4 sections extend this analysis by applying the same modelling approach to consider how dependency and other background characteristics may affect the receipt of care from the 4 sources identified earlier.

#### 6.1.2. Modelling receipt of partner or child care from AoN dependency

As discussed in section 2.5 (Table 5), the majority of people who receive care are helped by a family member and around 35% of those experiencing any difficulty gets help from a partner or child. This section explores differences in the receipt of unpaid care from within the conjugal family in more detail by considering the effects of other explanatory factors. In the previous models (Table 37) the sample included only those who experience at least one Mobility, ADL or IADL difficulty. The analysis in this section will further restrict the sample to respondents who either live with a partner or have children, since respondents who have neither cannot receive this type of care. A new conjugal family structure indicator is used in the modelling specifying whether a person lives with a partner (but has no children), has children (but does not live with a partner), or lives with a partner *and* has children. Table 38 shows the family structure of the ELSA sample that experiences one or more difficulty, by age.

Conjugal family structure	60-64	65-74	75-84	85+	Total
Neither Pathor only	15.1	17.6	26.5	43.6	22.2
Child only	14.7	22.2	31.6	38.3	4.1 25.0
Both	64.5 3.646	56.0 7.036	38.5 5 151	16.4 1.685	48.8 17 518
10101	3,040	7,030	5,151	1,005	17,518

Table 38. New conjuga	I family structu	re indicator, b	y age
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Source: ELSA, waves 1-4

In the ELSA sample with a difficulty, the majority live with a partner and have children, with a relatively small proportion of those living with a partner having no children, and 25% of respondents with needs do not live with a partner but have children. More than 20% of the sample neither lives with a partner nor has any children, and the proportion increases with age. Older people with inadequate informal support networks are more likely to rely on formal

services (Chappell and Blandford, 1991; Coughlin et al, 1992) and care from children is more likely amongst those not living with a partner (Blomgren et al, 2012). The availability of a partner or child therefore plays a key role in determining whether care outside the informal network is accessed. The high proportion of the very old who have needs have neither a partner or child and this group are likely to require help from formal services when needs cannot be met from within their potentially limited social network. As with the previous section, 3 models are presented, and Table 39 shows OR and 95% confidence intervals (CI) for explanatory variable effects on care receipt from a partner or child.

Table 39. Logistic regression: modelling receipt of care from a partner or child for AoN dependency (n=6,502 receiving 'partner or child' care)

Receives any care:	Model 0	Mod	del 1	Model 2	
Partner or child	OR 95% CI	OR	95% CI	OR	95% CI
Female <sup>1</sup>		1.90***	1.62 - 2.22	2.01***	1.74 - 2.33
<b>Conjugal family<sup>2</sup></b> Partner only Child only		0.81 0.27 <sup>****</sup>	0.59 - 1.11 0.23 - 0.33	0.80 0.26 <sup>****</sup>	0.60 - 1.07 0.22 - 0.31
Age group <sup>3</sup> 65-69 70-74 75-79 80-84 85-89 90+		0.97 1.08 1.54 <sup>****</sup> 2.68 <sup>****</sup> 4.01 7.23 <sup>****</sup>	0.81 - 1.16 0.89 - 1.31 1.25 - 1.89 2.12 - 3.39 2.97 - 5.40 4.36 - 12.01	0.97 1.07 1.47 <sup>***</sup> 2.30 <sup>****</sup> 3.16 <sup>****</sup> 5.05 <sup>****</sup>	0.82 - 1.16 0.89 - 1.29 1.21 - 1.79 1.84 - 2.88 2.38 - 4.20 3.11 - 8.21
Wealth quintile <sup>4</sup> WQ4 WQ3 WQ2 WQ1 (low)		1.07 1.45 <sup>**</sup> 2.30 <sup>***</sup> 2.94 <sup>***</sup>	0.86 - 1.32 1.16 - 1.80 1.83 - 2.88 2.30 - 3.75	1.04 1.29 <sup>*</sup> 1.94 <sup>***</sup> 2.26 <sup>***</sup>	0.85 - 1.27 1.05 - 1.59 1.57 - 2.41 1.80 - 2.84
<b>Education<sup>5</sup></b> A-level O-level None		1.50 <sup>*</sup> 1.46 <sup>*</sup> 2.73 <sup>****</sup>	1.09 - 2.06 1.09 - 1.96 2.04 - 3.66	1.44 <sup>*</sup> 1.43 <sup>*</sup> 2.37 <sup>***</sup>	1.07 - 1.93 1.09 - 1.88 1.81 - 3.11
Array of Need <sup>6</sup> AoN2 AoN3 AoN4 AoN5				9.05 <sup>***</sup> 5.78 <sup>***</sup> 10.53 20.35 <sup>***</sup>	7.01 - 11.68 4.71 - 7.10 6.66 - 16.64 14.24 - 29.08
N N_g rho BIC Pseudo R2	12,488 5,994 0.58 15,035	12,488 5,994 0.54 14,605 0.05		12,488 5,994 0.45 13,815 0.12	

Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001

Reference categories: <sup>1</sup> male; <sup>2</sup> lives with a partner and has children; <sup>3</sup> 60-64; <sup>4</sup> Wealth quintile 1; <sup>5</sup> Degree; <sup>6</sup> AoN1 Source: ELSA, waves 1-4

The sample here comprises 12,488 different observations, from 5,994 unique individuals present on average in 2.1 of 4 waves. The probability of the model chi-square in all models is <0.001 and the null hypothesis is rejected, confirming a relationship between the dependent and independent variables. As would be expected, the introduction of additional explanatory variables reduces the BIC in successive models, with the change confirming that there is a valid case for including the additional variables. The pseudo r2 suggests that including the AoN measure explains around 7% more of the variation in the dependent variable than the restricted model. Further, the intra-class correlation (rho) is smaller in the full model, with a greater amount of the variation in the dependent variable being from variability between rather than within individuals.

The effects of explanatory factors other than conjugal family structure are broadly the same as in Table 37, although the effect of being in the oldest age group is less marked while having no education has a bigger effect on receiving care from a partner or child. Compared to those who live with a partner and have children – the reference category – there is no difference in the likelihood of receiving care for those living with a partner who do not have children but those with children who do not have a co-resident partner have a much lower chance of receiving care. This emphasizes the importance of partners in the supply of unpaid care and that for those not living with a partner, particularly for those in the oldest ages where living without a partner becomes more common, children may not present an available or reliable provider of help. This may be because of the dependency needs of the oldest old are too complex or demanding for informal support to meet. The effect of greater dependency needs using the AoN measure are similar for those with AoN2 and AoN4 with those with AoN3 having a lower likelihood of care while those with AoN5 having a far greater chance of receiving care from this source. As before, controlling for dependency needs moderates the effects of old age, low wealth and no qualifications but marginally increases the positive effect of being female. Additionally controlling for dependency needs does not change the effect of conjugal family structure.

The next section explores the effects of explanatory factors on the receipt of care from informal sources other than from partners and children.

#### 6.1.3. Modelling receipt of other informal care from AoN dependency

Other informal care is less common than help from a partner and children, but is received by a greater proportion of older people than formal or private care. From Table 5, 6% of ELSA respondents aged 60+ receives care from other informal sources, representing more than 20% of those who receive any care. Older people living alone or without children may rely on unpaid help with their needs from friends and other family. Table 40 presents results from logistic regression analysis including AoN dependency, on receipt of other informal care.

As with the previous models, the chi-square is significant, confirming an association between the independent and dependent variables. As with the other models presented, the BIC improves when adding explanatory variables. The model including the AoN dependency measure best measures differences in receipt of other informal care, and the pseudo r2 suggests that model 2 describes an additional 4% of variation in the model.

As with care from partners and children, women are more likely than men to receive unpaid care from other informal sources, and those not living with a partner are around 4 times as likely to receive this type of unpaid care. However, the likelihood of receiving care from this source is only slightly lower for those who have children, which has no significant effect when controlling for dependency. This suggests that, the presence of a co-resident partner directly influences the reliance on care from unpaid sources outside the conjugal family. Conversely, depending on circumstances and relative proximity, children are less likely to be able to provide care to a dependent parent directly, although children are often integral to the organisation of care from other sources for a parent, which may explain the large difference in the effect sizes of partners and children in these models.

Ageing increases the chances of care being received but the effect is only seen at ages 80+ and is less marked than in previous models. The effect of social disadvantage due to low wealth

Receives any care:	Moo	del 0 95% Cl	Mo	odel 1	Model 2	
	OK	35% CI	UK	3378 CI	OK	35% CI
Female <sup>1</sup>			1.64 <sup>***</sup>	1.37 - 1.97	1.67***	1.39 - 1.99
<b>Conjugal family</b> Lives with a partner <sup>2</sup> Has any children <sup>3</sup>			0.24 <sup>***</sup> 0.81 <sup>*</sup>	0.19 - 0.29 0.68 - 0.96	0.24 <sup>***</sup> 0.87	0.20 - 0.29 0.73 - 1.03
Age group <sup>4</sup> 65-69 70-74 75-79 80-84 85-89 90+			0.86 0.99 1.24 1.72 <sup>***</sup> 2.47 <sup>***</sup>	0.66 - 1.11 0.77 - 1.29 0.95 - 1.60 1.31 - 2.25 1.82 - 3.34	0.87 1.01 1.23 1.62 <sup>***</sup> 2.18 <sup>***</sup>	0.67 - 1.13 0.78 - 1.31 0.95 - 1.60 1.24 - 2.11 1.62 - 2.94
Wealth quintile <sup>5</sup> WQ4 WQ3 WQ2 WQ1 (low)			3.70 <sup>***</sup> 1.62 <sup>**</sup> 1.77 <sup>**</sup> 2.91 <sup>***</sup> 3.35 <sup>***</sup>	2.48 - 5.53 1.17 - 2.24 1.28 - 2.44 2.12 - 3.98 2.45 - 4.60	2.83 <sup>****</sup> 1.59 <sup>***</sup> 1.68 <sup>***</sup> 2.64 <sup>****</sup> 2.86 <sup>****</sup>	1.91 - 4.20 1.15 - 2.20 1.22 - 2.31 1.93 - 3.60 2.09 - 3.91
<b>Education<sup>6</sup></b> A-level O-level None			0.78 0.64 <sup>*</sup> 0.91	0.53 - 1.14 0.45 - 0.91 0.65 - 1.27	0.78 0.64 <sup>*</sup> 0.86	0.54 - 1.13 0.45 - 0.90 0.62 - 1.19
Array of Need <sup>7</sup> AoN2 AoN3 AoN4 AoN5 N N_g rho	15,846 7,087 0.54		15,846 7,087 0.43		3.27*** 2.93*** 3.58*** 4.79*** 15,846 7,087 0.40	2.61 - 4.12 2.35 - 3.65 2.43 - 5.26 3.66 - 6.27
BIC Pseudo R2	9,430		8,729 0.11		8,517 0.15	

Table 40. Logistic regression: modelling receipt of care from other informal sources for AoN dependency (n=1,628 receiving 'other informal' care)

Significance values: \* p < 0.05; \*\* p < 0.01; \*\*\* p < 0.001Reference categories: <sup>1</sup> male; <sup>2</sup> does not live with a partner; <sup>3</sup> has no children; <sup>4</sup> 60-64; <sup>5</sup> Wealth quintile 1; <sup>6</sup> Degree; <sup>7</sup> AoN1

Source: ELSA, waves 1-4

remains but the effect of having no qualifications is not significant. This suggests that the most economically disadvantaged older people are likely to be dependent on unpaid care from other family and friends when a co-resident partner is not present or unable to provide support. The support provided by this type of unpaid informal care is most likely to be help with routine domestic tasks and this is reflected by the effects of dependency being broadly the same regardless of increasingly complex AoN dependency.

The next section explores the effects of explanatory factors on the receipt of formal care.

### 6.1.4. Modelling receipt of formal care from AoN dependency

As has been shown, the majority of care received in later life is unpaid help, with the majority provided by partners and children. Older people may also be able to rely on unpaid support from other sources if help from within the family is not possible. However, for those with increasingly complex needs, the capacity and suitability of informal help to provide adequate support may become an issue. When needs can no longer be met by unpaid help alone, other types of care provision may become necessary, while informal help may continue in a supplementary or complementary role. In the context of increasing pressure within social care service provision to prioritize only those with more severe dependency needs, care services may focus resources on only those least able to manage their needs using unpaid help alone. In determining who is able to self-fund care and both factors are important in determining what care may be received. This section focuses on the receipt of formal care to explore the degree to which needs, financial circumstances and other background characteristics may contribute to the likelihood of receiving formal care.

The dependent variable in the models shown in Table 41 captures whether care is received from a local authority, social services or from services arranged by the health service, including from social or health workers or a district nurse (dependent on definition in any given ELSA wave). These models are based on the same sample as the models presented in Table 40. As with all models presented previously in this section, the model chi square in all models is <0.001 and the null hypothesis is rejected.

Turning to the effects of independent variables, unlike other types of care women have no greater chance of receiving formal care than men, which supports notions of equity in the provision of care by LA, social services and the health service. The availability of conjugal family is again significant with those not living with a partner being around 3 times as likely to receive formal care while those without children are around twice as likely to receive this type of care. This further evidences the fundamental role that unpaid care plays in providing support in later

Receives any care: Formal	Moo OR	del 0 95% Cl	OR M	lodel 1 95% Cl	Model 2 OR 95% Cl		
Female <sup>1</sup>			1.17	0.82 - 1.68	1.21	0.85 - 1.72	
<b>Conjugal family</b> Lives with a partner <sup>2</sup> Has any children <sup>3</sup>			0.28 <sup>***</sup> 0.43 <sup>***</sup>	0.19 - 0.43 0.31 - 0.59	0.31 <sup>***</sup> 0.52 <sup>***</sup>	0.20 - 0.47 0.38 - 0.71	
Age group <sup>4</sup> 65-69 70-74 75-79 80-84 85-89 90+			3.22** 3.20** 6.19*** 16.97*** 37.74 99.10***	1.62 - 6.40 1.58 - 6.47 3.07 - 12.48 8.37 - 34.39 17.72 - 80.39 41.38 - 237.35	3.60 <sup>***</sup> 3.57 <sup>**</sup> 6.37 <sup>***</sup> 16.22 <sup>****</sup> 31.23 <sup>****</sup> 55.75 <sup>***</sup>	1.77 - 7.33 1.72 - 7.39 3.10 - 13.07 7.94 - 33.10 14.72 - 66.25 23.77 - 130.79	
Wealth quintile <sup>5</sup> WQ4 WQ3 WQ2 WQ1 (low)			1.11 2.21 <sup>*</sup> 3.95 <sup>***</sup> 7.01 <sup>***</sup>	0.55 - 2.25 1.12 - 4.36 2.03 - 7.68 3.60 - 13.66	1.16 2.27 <sup>*</sup> 3.67 <sup>***</sup> 6.08 <sup>****</sup>	0.55 - 2.46 1.11 - 4.64 1.83 - 7.35 3.04 - 12.15	
<b>Education<sup>6</sup></b> A-level O-level None			1.44 0.79 1.02	0.64 - 3.24 0.37 - 1.72 0.49 - 2.12	1.46 0.77 0.89	0.64 - 3.31 0.35 - 1.68 0.42 - 1.86	
Array of Need <sup>7</sup> AoN2 AoN3 AoN4 AoN5					19.06 <sup>****</sup> 10.97 <sup>****</sup> 12.03 <sup>****</sup> 44.23 <sup>****</sup>	12.55 - 28.94 7.10 - 16.95 6.12 - 23.65 27.41 - 71.35	
N N_g rho BIC Pseudo R2	15,846 7,087 0.70 4,287		15,846 7,087 0.69 3,791 0.17		15,846 7,087 0.64 3,383 0.29		

Table 41. Logistic regression: modelling receipt of care from formal sources for AoN dependency (n=603 receiving 'formal' care)

Significance values: \* p < 0.05; \*\* p < 0.01; \*\*\* p < 0.001Reference categories: <sup>1</sup> male; <sup>2</sup> does not live with a partner; <sup>3</sup> has no children; <sup>4</sup> 60-64; <sup>5</sup> Wealth quintile 1; <sup>6</sup> Degree; <sup>7</sup> AoN1

Source: ELSA, waves 1-4

life, whereby older people without partners or children who develop dependency needs that might otherwise be met by support from within the family are likely to end up relying on other unpaid care if available. In this sense, formal care represents a final resort for dependent older people whose needs cannot be met by unpaid care alone.

Age has a marked effect on formal care receipt. Those aged 80+ are dramatically more likely to receive formal care, and the effect of age is broadly the same when additionally controlling for dependency, although the greater chance of receiving formal care for those aged 90+ is much less pronounced. This suggests that formal care becomes increasingly likely as age increases, although the effects of dependency become more important for the oldest old. Clearly, any increase in likelihood of formal care for older groups may reflect the greater likelihood of more complex needs amongst the very old. For example, only 9% of people aged 60-64 are classified with needs greater than AoN1, compared to 33% of those aged 85+ (shown in Table 36). However, this may also reflect a deficit in the availability of people to provide informal care, or that where unpaid care is available it may be unable to meet the greater levels of need experienced among the oldest old with care needs.

Similarly, SES measures reflect the social stratification of health and dependency, with greater dependency occurring amongst those with the least wealth. For example, 1.2% of the top wealth quintile is classified with the most complex needs (AoN5) compared to 4.9% of the bottom wealth quintile. As such, both age and wealth reflect the way formal care is likely to be targeted towards meeting the needs of the most vulnerable with the greatest needs, whether this disadvantage is reflected by a person's socio-economic circumstances or dependency itself.

Due to the difficulty in disentangling and interpreting the negative effects of factors such as age and social status on dependency and patterns of care receipt, the inclusion of an explicit measure of dependency provides a way to isolate the effect of differences by dependency. The most dependent group (AoN5) are consistently more likely to receive formal care, but the effects of less severe dependency are not consistent with earlier models looking at unpaid care. For example, those with AoN2 have a greater chance of receiving formal care than those in either AoN3 or AoN4, which share a similar effect. The increased chances of care for those with AoN2 and AoN5 suggests formal care is targeted towards helping those with greater AoN-ADL and AoN-PC needs. As such, those with less severe needs in these domains, as well as those experiencing additional mental health difficulties, appear to be less likely to be supported by formal care. That mental health issues may prevent someone from accessing the care services that they might otherwise be eligible for is of course concerning, particularly as this may be a particularly vulnerable group, and suggests that access to care services could be better targeted to those with mental health needs.

The next section explores the effects of explanatory factors on the receipt of privately arranged or privately paid for care services.

#### 6.1.5. Modelling receipt of private care from AoN dependency

In the range of care services provided to older people, informal and formal care encapsulate the majority of support and care services that are commonly available to older people living at home. However, some older people may be able to access additional support from privately paid services, although such services are necessarily only available to those who have adequate finances in place to pay for them. As discussed in section 1.5, while many previous studies have investigated the substitution effect between informal and formal/professional care services (e.g. Bolin, Lindgren and Lundborg, 2008; Gannon and Davin, 2010; Van Houtven and Norton, 2004), these studies do not differentiate between public and private sector care. Further, substitution itself cannot be assumed, since informal care has been found to have a complementary rather than a substitutive effect on professional/paid nursing care (Bonsang, 2009). Since the scale of ELSA is large enough to allow for care from state-funded services and privately-paid services to be analysed separately, it is useful to consider the effects of dependency on private care receipt. In the ELSA sample, a larger proportion of respondents with difficulties receive private care than receive formal care. From Table 5, 3.6% of respondents aged 60+ receive private care representing around 12% of those receiving care. Clearly, for some older people the ability to pay for additional help represents an avenue of support not available to many people otherwise reliant on informal care. As suggested in previous studies, private care services are commonly employed to provide help with specific activities, such as domestic help. Private care is therefore less adaptable to meeting needs that not are able to be scheduled or routinized. Litwak (1985) differentiates the types of support conventionally provided by formal or private care services from the care provided by a person's family or a close friend. For example, tasks that involve ongoing supervision or events that occur unexpectedly can be better supported by informal care, which can be more responsive due to closer proximity (Litwak, 1985). While it is easy to understand that those with greater dependency needs are more likely to receive care, exploring

the differences in the support different types of care provide can help to identify the scope of informal support and formal and private service provision. Further, further investigation may expose where deficits in the continuum of care exist for those without access to particular care resources.

The dependent variable in the models presented in Table 42 captures whether or not a respondent receives private care. The sample is unchanged from the models presented in Table 40 and Table 41. As in previous models in this section, the model chi square in all models is <0.001 and the null hypothesis is rejected.

Table 42. Logistic regression: modelling receipt of care from private sources for AoN dependency (n=955 receiving 'private' care)

Receives any care:	Model 0		Мо	del 1	Model 2		
Private	OR	95% CI	OR	95% CI	OR	95% CI	
Female <sup>1</sup>			2.70***	2.10 - 3.49	2.72***	2.11 - 3.49	
<b>Conjugal family</b> Lives with a partner <sup>2</sup> Has any children <sup>3</sup>			0.40 <sup>***</sup> 0.88	0.31 - 0.51 0.70 - 1.09	0.41 <sup>***</sup> 0.94	0.32 - 0.53 0.75 - 1.17	
Age group <sup>4</sup> 65-69 70-74 75-79 80-84 85-89 90+			1.83** 4.12*** 5.93*** 14.10*** 25.76*** 32.07***	1.16 - 2.87 2.66 - 6.36 3.83 - 9.18 9.06 - 21.94 16.06 - 41.31 18.08 - 56.91	1.84** 4.10 5.95*** 13.30*** 23.31*** 24.92***	1.17 - 2.90 2.65 - 6.32 3.85 - 9.19 8.57 - 20.63 14.60 - 37.23 14.10 - 44.03	
Wealth quintile <sup>5</sup> WQ4 WQ3 WQ2 WQ1 (low)			0.91 0.77 0.80 0.46 <sup>****</sup>	0.66 - 1.27 0.54 - 1.08 0.57 - 1.13 0.32 - 0.66	0.92 0.74 0.74 0.40****	0.66 - 1.27 0.53 - 1.04 0.53 - 1.04 0.28 - 0.58	
<b>Education<sup>6</sup></b> A-level O-level None			0.90 0.60 <sup>*</sup> 0.50 <sup>**</sup>	0.58 - 1.39 0.40 - 0.91 0.33 - 0.75	0.90 0.60 <sup>*</sup> 0.48 <sup>****</sup>	0.59 - 1.39 0.40 - 0.91 0.32 - 0.71	
Array of Need <sup>7</sup> AoN2 AoN3 AoN4 AoN5					2.68 <sup>****</sup> 2.96 <sup>****</sup> 2.67 <sup>**</sup> 3.90 <sup>****</sup>	1.99 - 3.60 2.22 - 3.94 1.51 - 4.73 2.74 - 5.56	
N N_g rho BIC Pseudo R2	15,846 7,087 0.61 6,399		15,846 7,087 0.52 5,881 0.13		15,846 7,087 0.49 5,807 0.15		

Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001

Reference categories: <sup>1</sup> male; <sup>2</sup> does not live with a partner; <sup>3</sup> has no children; <sup>4</sup> 60-64; <sup>5</sup> Wealth quintile 1; <sup>6</sup> Degree; <sup>7</sup> AoN1

Source: ELSA, waves 1-4

Turning to the effects of independent variables, the direction and size of each factor effect is similar to those in Table 40 modelling receipt of other informal care. Briefly summarising the main effects, women are more likely to receive private care, and not living with a partner more than doubles the likelihood that private care is received. This analysis also highlights a limitation in adopting the binary measure 'has any children' as a proxy for availability of unpaid care, since there is no information on the geographical proximity and financial resources of children, which are central factors determining the availability of children to care themselves or to potentially arrange and pay for care instead. In this context, it is understandable that knowing only that someone has any children has no significant effect on the likelihood of private care being received.

As with previous models, the oldest group have the greatest chance of receiving private care, but as with formal care, the effect of old age is less pronounced at ages 85+ when controlling for AoN dependency. SES factors are significant, with the wealthiest and degree educated being twice as likely to receive private care compared to their reference categories, holding other factors stable. However, these 2 measures are likely reflecting similar aspects of social status. In order to evaluate the effects of social status more clearly, models were run including each SES measure in turn (analysis not shown). This analysis showed that both SES measures captured a broadly similar effect with those in the most disadvantaged group being around a third as likely to receive private care compared to the most advantaged group.

Those with high dependency needs are more likely to receive this type of care, but the difference between different AoN groups is less marked than for formal care and care from a partner or child. Although the differences between AoN groups are slight, there is an increase as AoN-ADL needs increase from none (AoN2) to low (AoN3) to high (AoN5), although the addition of mental health difficulties (AoN4) actually lowers the chances of private care being received. This suggests that those with more complex AoN-ADL needs are more likely to receive private care, while the increase between AoN2 and AoN5 is small and may suggest that the people pay

for help with the same types of activities regardless of whether needs are moderate or more complex.

## 6.1.6. Modelling receipt of different types of care from AoN domain-specific dependency level

Being able to simultaneously control for dependency across 3 domains allows a direct understanding of the degree to which high levels of dependency can affect the type care received. However, this does not identify how particular needs may be more likely to be met by one type of care than another. In order to consider this further, this section adopts an alternative approach using 3 separate domain-specific dependency measures – AoN-ADL, AoN-PC and AoN-MHW (as defined in chapter 5) – to explore how dependency in each individual domain affects the receipt of the 4 types of care. Logistic regression models are run exploring the independent effects of dependency in each domain on receipt of care, from any source and from each of the key sources. These models are based on the same sample, including the same explanatory variables used to model care receipt in Table 39 to Table 42 (model 2), with the exception of the measures of dependency, which are entered as separate domains, and the effects of other explanatory variables remain broadly the same. Table 43 shows only the effects of dependency using the original AoN measure (for comparison) and the 3 separate domain measures, along with the model fit (BIC) for each model.

All models are improved by controlling for dependency using the 3 domain-specific dependency measures, except when modelling private care receipt where the single summary AoN measure is preferable, although there is very little difference in the amount explained between the 2 models. By isolating the effects of dependency in each of the 3 domains separately, Table 43 shows that experiencing increased dependency in a single domain can have a dramatic effect on the care received depending on the type of needs experienced. Both types of informal care are more likely to be received by those with greater needs in all 3 domains but greater AoN-PC needs have a more marked effect than AoN-ADL needs and this pattern is more pronounced for care from a partner or child than for care from other informal sources. Formal care is more likely
	Any source Partner or Other informa child		Other informal	Formal	Private
	n = 7,904	n = 6,052	n = 1,628	n = 603	n = 955
Array of Need <sup>1</sup>					
AoN2 AoN3 AoN4 AoN5	9.64 <sup>***</sup> 6.31 <sup>***</sup> 11.05 <sup>***</sup> 28.49 <sup>***</sup>	9.05 <sup>***</sup> 5.78 <sup>***</sup> 10.53 <sup>***</sup> 20.35 <sup>***</sup>	3.27 <sup>***</sup> 2.93 <sup>***</sup> 3.58 <sup>***</sup> 4.79 <sup>***</sup>	19.06 <sup>***</sup> 10.97 <sup>***</sup> 12.03 <sup>***</sup> 44.23 <sup>***</sup>	2.68 <sup>***</sup> 2.96 <sup>***</sup> 2.67 <sup>**</sup> 3.90 <sup>***</sup>
BIC improvement <sup>#</sup>	1,126	790	212	408	74
Domain-specific dependency <sup>2</sup>					
AoN-ADL: AoN-ADL:	3.10 <sup>***</sup> 6.42 <sup>***</sup>	2.83 <sup>***</sup> 5.18 <sup>***</sup>	1.72 <sup>***</sup> 1.97 <sup>***</sup>	1.78 <sup>**</sup> 3.97 <sup>***</sup>	1.97 <sup>***</sup> 2.20 <sup>***</sup>
AoN-PC:	8.64***	7.21***	2.75	14.14***	1.88***
AoN-MHW: high	1.87***	1.87***	1.32**	1.42	1.17
BIC improvement <sup>#</sup>	1,321	900	232	449	61

Table 43. Logistic regression: comparison between independent variable effects – (1) AoN summary dependency and (2) individual AoN domain dependency measures – when modelling receipt of care from each source

Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001

<sup>#</sup> improvement in BIC from model 1 (excluding measures of dependency) Reference categories: <sup>1</sup> AoN1; <sup>2</sup> domain-specific dependency 'low'

Source: ELSA, waves 1-4

for those with high levels of AoN-ADL dependency, dramatically so for those with increased AoN-PC needs, but there is no significant effect from mental health difficulties when all other factor effects are held constant. This confirms informal care is able to provide classifiably different types of support to formal and private care, and may be the only avenue of support for those with mental health issues such as depression. Those with greater AoN-ADL and AoN-PC needs are more likely to receive private care, although the effect remains the same regardless of high or only moderate AoN-ADL needs.

#### 6.1.7. Summary of section 6.1

This section explored the impact of a range of respondent characteristics, including gender, family structure, age and SES, on receipt of informal, formal and private care, using 2 new approaches to controlling for different types of dependency needs. The first approach used the AoN summary measure of dependency to consider the effects of 3 different types of need simultaneously. The second approach considered domain effects separately, explicitly focusing the analysis on the effects of need in particular domains of dependency on different care outcomes. The analysis identified that the AoN summary measure of dependency, based on the

IoRN-framework, provides a way to understand how dependency measured as the overall product of particular ADL and IADL needs can identify differences in the receipt of different types of care. The analysis suggest that unpaid conjugal family care is likely to be the primary source of care for all types of need, and is adaptable enough to provide support for those with mental health issues, needs that are not met by formal and private care services.

It was shown that formal care is likely to meet the needs of those with high AoN-PC domain needs, and it should be noted that limitations in defining the AoN-PC domain in ELSA results in AoN dichotomising dependency in this domain to a binary high/low measure. Finally, private care was shown to meet the needs of those with high AoN-ADL and AoN-PC needs, but this effect was broadly the same regardless of the type or level of needs experienced, suggesting that private care supports the same needs regardless of other needs a person may have.

Using the IoRN tool as framework to develop a comparable measure, quantifying the level of dependency resulting from different domains of activity, enforces a constraint on the AoN measure that is unnecessary when using ELSA. Since ELSA includes information on more aspects of need than could be collected in the routine process of performing assessments for social care support (the context in which IoRN data is collected).

The ELSA sample includes a large sample of older people with a wide range of needs that the IoRN is not designed to measure. As such, the AoN measure may not be appropriate when attempting to classify the dependency needs of older people living at home, and a more appropriate and nuanced approach would incorporate a broader range of needs which are not relevant for the purposes of developing formal assessment tools such as the IoRN. The next section builds on the AoN measure, expanding the scope of dependency under consideration to include the full range of ADL, IADL and Mobility items available in ELSA to capture a broader spectrum of needs, better reflecting the older population living at home.

# 6.2. Developing an expanded multi-domain summary measure of dependency using ELSA

The IoRN provides one approach to summarising the needs of older people by operationalizing dependency across 4 specific domains. The IoRN questionnaire is designed for ease of assessment by care professionals, focusing on only the needs (described in chapter 5) that most affect older peoples' ability to remain independent. The AoN measure of dependency, based as it is on the IoRN-framework, captures broad differences in dependency resulting from greater or lesser need across different domains simultaneously. This measure is therefore highly suited to the process of assessing older people for social care services, but such assessments are likely to be undertaken at the point where unpaid care is no longer able to fully meet a person's needs. In attempting to understand the needs of the population of older people living at home, it may be more productive to explore how needs are met prior to seeking formal support. To explore this further, Figure 38 shows the proportion of people with each permutation of individual AoN-ADL and AoN-PC component difficulties in each AoN group receiving care from each source.

From Table 38, care varies within a given AoN group depending on the particular difficulties that are experienced. In particular, there is a marked difference in care receipt for those with and without AoN-PC needs but are classified within the lowest need group (AoN1). Further, those who experience difficulty preparing a meal and taking a bath who are specified as AoN2 have a greater chance of receiving care, particularly formal care, than those with greater dependency who are classified as AoN3 and AoN4, and those specified in AoN5 who do not have difficulty eating food and using the toilet. The limitations of applying such an approach to the population of older people living at home are apparent. Beyond the items used to define the AoN-ADL and AoN-PC domains, there are an additional 17 items collected in ELSA relating to other aspects ADL, IADL and Mobility dependency. In order to include these other dimensions of dependency, this section expands the range of needs under consideration using the full range of 23 items included in ELSA (detailed in section 2.4.1). By considering all ADL, IADL and Mobility items, it can be expected that less critical needs that are otherwise excluded from analysis focusing on the more severe ADL and IADL needs can be understood, and provide scope to explore how less critical aspects of dependency may affect care receipt in the home.



Figure 38. Proportion receiving care from each source by specific combination of AoN-ADL or AoN-PC items

and down AoN-PC labels 1 preparing a hot meal, 2 taking a bath or shower, 3 getting dressed including putting on shoes and socks Source: ELSA, waves 1-4 (note: sample including those with 1+ difficulties)

The aim of this section will be to expand upon the multi-domain approach of the AoN measure developed in section 5.2.1, to develop an alternative multi-domain approach to summarising older people's needs. Principal components analysis (PCA) will be used to identify, specify and derive summary measures of dependency as it occurs across the full range of Mobility, ADL and IADL dimensions of need. The next section introduces PCA and describes its implementation to ELSA to identify, qualify and generate more nuanced measures of dependency.

#### 6.2.1. Principal components analysis (PCA)

PCA is a data reduction method used to derive summary scores from multiple correlated variables. The process of PCA produces one or more variables (or components) which usefully describe linear relationships between ranges of component variables (Sharma, 1996). The PCA process determines multiple components equal to the number of input variables, cumulatively capturing 100% of the variation between the individual variables. The first component describes

the greatest proportion of variance with successive components describing the greater part of the remaining variation, while being uncorrelated with all other components. Each identified component has an eigenvalue describing the relative variance described by each successive component in turn, where the sum of all component eigenvalues is equal to the number of component items included in analysis. Following the Kaiser criterion (Kaiser, 1960), components with an eigenvalue greater than 1 are retained, identifying components usefully describing an underlying linear relationship between the entered variables. For retained components, scores for all entered variables give relative weights for each item. A summary score for each respondent may then be computed using the scores assigned to variables within each of the retained components. In this way, PCA is able to reduce a range of correlated variables to a smaller number of uncorrelated component scores, which summarize underlying patterns of association between the items according to patterns of variation between them.

#### 6.2.1.1. Application of PCA to categorical data

PCA is commonly associated with deriving summary measures using continuous variables, and there is debate around the application of PCA in the case of discrete categorical and dichotomous variables. Filmer and Pritchett (2001) apply PCA using a range of nominal categorical and binary indicators of asset ownership, deriving a summary index of SES as a proxy for long-run wealth in the absence of traditional continuous SES measurements such as income, wealth and expenditure. In their study, they argue that binary measures used in the PCA analysis, including indicators such as asset ownership and practical facilities, were conceptually ordinal in nature, whereby positive responses on the selected binary variables reflected improved social circumstances. To overcome the non-ordinal nature of multi-category nominal variables, such as source of drinking water and available toilet facilities, Filmer and Pritchett (2001) transformed the relevant variables into multiple dummy indicator variables.

Kolenikov and Angeles (2009) argue that applying PCA to nominal variables is fundamentally problematic, since the PCA method cannot differentiate between binary measures which

conceptually follow a similar ordinal structure (i.e. a positive reflecting ownership that conceptually reflect improved SES). Dummy variables derived from discrete multi-category nominal variables, which are not ordinal, would therefore confuse clear interpretation of PCAderived measures, which is potentially problematic (Kolenikov and Angeles, 2009). In spite of this, they argue binary measures may theoretically be used, where a positive on the input binary items conceptually share a matching directional change in the underlying dimension of interest. The 23 items in this study are all binary indicators, capturing difficulty performing specific actions and activities, and positive responses share a conceptual change towards greater dependency. Further, a previous study also applied PCA methods to ELSA, deriving an index of disability from the same set of ADL, IADL and Mobility items considered here (Nazroo, Zaninotto and Gjonça, 2008). In light of this, and following Kolenikov and Angeles (2009), PCA is considered conceptually appropriate in this context.

#### 6.2.1.2. Application of PCA to the ELSA data

It is necessary to outline the proposed approach to applying PCA methods to ELSA data, particularly since ELSA is longitudinal in nature and therefore contains repeated measures across multiple waves. PCA assesses variation in the outcomes of specific sets of items without consideration for any potential clustering effect associated with repeated measures by the same respondent (i.e. by not being able to consider the time of each response). As such, applying PCA to linked data from multiple waves of ELSA may incorrectly estimate the variation occurring between the component items being considered, since an individual present in 4 waves will contribute a greater effect to overall variation between items being considered and may skew results. In this way, it was considered necessary to perform PCA for each wave independently, thus basing the PCA on the true within-wave variation.

Weights produced by PCA in a given wave are relative to the range of variation described at each wave. As such, the range and scale of wave-specific scores are relative only to the number and distribution of cases used to derive the weighted scores, and as these vary from one wave to the

next, the scores produced are not comparable across waves. One approach initially considered to enable cross-wave comparability was standardizing the wave-specific scores for each domain, in order that domain scores captured across multiple waves be on equivalent scales. Analysis was initially conducted and standardized wave specific scores were generated by subtracting the mean and dividing by the standard deviation to produce scores with a mean of 0 and a standard deviation of 1 (UCLA, 2014) following Equation 2.

#### Equation 2

## x\* = (x-m)/sd

where **m** is the mean of **x**, and **sd** is the standard deviation (UCLA, 2014)

However, attempting to interpret the relative effect of a domain was problematic when using standardized scores that had no conceptual meaning, only that an increase in the standardized scores conceptually related to an increase in the degree of difficulty within a particular domain. On undertaking regression analysis, entering the multiple PCA-derived components simultaneously became unnecessarily complicated and difficult to interpret, undermining the purpose of the analysis. In light of this, an alternative approach was sought to allow for consistency across waves, to enable direct comparison between the relative effects of dependency in the newly identified dimensions.

With this in mind, the PCA-derived base scores for each domain were transformed into categorical variables. Taking each component in turn, the summary scores of those reporting at least some level of difficulty were transformed into tertiles, reflecting distinctions in the relative degree of difficulty experienced in each domain. The remaining respondents who do not report difficulty with any items were coded into a single category (0). Those reporting difficulties were thus classified into categories 1-3 reflecting 'low', 'medium' or 'high' dependency for each specified component. In this way, the complexity of needs as described by the PCA-derived components are able to be used in regression analysis, allowing an understanding of the impact of different components, summarising particular aspects of dependency, on care receipt.

#### 6.2.2. Using PCA to construct alternative domains of need in ELSA

PCA will be applied to the 23 items measuring whether individuals have difficulty performing Mobility, ADL and IADL items, expanding upon the AoN measure developed in section 5.2.1. All 23 items are considered using PCA and analysis will confirm underlying patterns of association between these items. Items are initially checked to confirm between-item correlations and their suitability for this approach. After performing this check, PCA will be used to test and identify suitable components. Following the selection of components, PCA methods are used to produce component summary scores, which are then standardized by transforming scores for cases with a difficulty into tertiles to produce a measure that can be compared relative to the other components and across waves. The final 4-item categorical measure for each specified component captures relative level of dependency, as shown in Table 44.

Table 44. Coding frame for new domain-specific relative level of need

Relative level of need	Conditions for classification	Variable coded
None	without domain-specific difficulties	0
Low	with 1+ difficulties, component score in 1st tertile	1
Medium	with 1+ difficulties, component score in 2 <sup>nd</sup> tertile	2
High	with 1+ difficulties, component score in 3rd tertile	3

#### 6.2.3. Undertaking PCA on 23 Mobility, ADL and IADL items

This section considers patterns of underlying association between the 23 items, which are collectively grouped within ELSA across 3 domains of need: Mobility, ADL and IADL. Spearman's rank correlations were initially employed as an exploratory checking measure. Due to the large number of items being considered and the longitudinal design of ELSA, Table 45 shows the average correlation between all items, along with the average and lowest correlation between each item and items in the 3 domains. The lowest correlation reflects the single lowest item-to-item correlation value between an item and the other 22 items, and with items from each ELSA-specified domain group, from any wave.

Table 45 confirms the average correlation between the 23 items ranges from 0.21 to 0.39, and

ELSA-specified domain:	Mobility							
Item:	100yds	sitting	getup	stairs	stair	stoop	extend	pull
Average corr MOB items	0.40	0.30	0.37	0.38	0.41	0.37	0.30	0.43
Lowest corr MOB items	0.24	0.19	0.22	0.19	0.24	0.21	0.22	0.25
Average corr ADL items	0.38	0.22	0.30	0.25	0.35	0.26	0.27	0.34
Lowest corr ADL items	0.19	0.09	0.13	0.13	0.17	0.13	0.19	0.18
Average corr IADL items	0.33	0.16	0.21	0.23	0.31	0.21	0.22	0.32
Lowest corr IADL items	0.11	0.05	0.09	0.10	0.10	0.09	0.09	0.12
Average corr ALL items	0.37	0.23	0.30	0.30	0.36	0.29	0.27	0.37
ELSA-specified domain:	Mobility		ADL					
Item:	lift	pick	eat	wroom	bed	toilet	bath	dress
Average corr MOD items	0.42	0.25	0.20	0.20	0.21	0.24	0.27	0.26
Average corr. MOB items	0.42	0.25	0.20	0.28	0.51	0.24	0.37	0.50
Average corr ADL items	0.22	0.19	0.09	0.17	0.22	0.17	0.24	0.24
Lowest corr - ADL items	0.30	0.24	0.20	0.38	0.40	0.37	0.38	0.40
Average corr - IADL items	0.17	0.10	0.21	0.21	0.21	0.25	0.21	0.23
Lowest corr - IADL items	0.29	0.21	0.23	0.31	0.20	0.20	0.34	0.23
Lowest cont. TADE items	0.10	0.11	0.15	0.10	0.11	0.10	0.15	0.15
Average corr ALL items	0.35	0.23	0.25	0.31	0.32	0.28	0.36	0.34
ELSA-specified domain:	IADL							
Item:	meal	shop	hwork	map	tele	medi	money	
Average corr MOB items	0.28	0.37	0.42	0.19	0.14	0.16	0.18	
Lowest corr MOB items	0.17	0.21	0.25	0.11	0.05	0.09	0.09	
Average corr ADL items	0.39	0.39	0.38	0.21	0.21	0.24	0.24	
Lowest corr ADL items	0.29	0.26	0.22	0.12	0.10	0.15	0.12	
Average corr IADL items	0.42	0.40	0.33	0.33	0.31	0.36	0.40	
Lowest corr IADL items	0.24	0.17	0.13	0.19	0.13	0.19	0.24	
Average corr ALL items	0.35	0.39	0.38	0.24	0.21	0.24	0.26	

Table 45. Spearman rank correlations (average and lowest) for all items (across 4 waves)

Note: full label descriptions in Table 3

Source: ELSA, waves 1-4

the majority of items have stronger correlations with items within the same domain. The item sitting has lower correlations with IADL items, in particular the items tele, medi and money, than other Mobility items across all waves. These 3 items suggest that difficulty sitting is less likely to be associated with difficulty performing activities involving mental capacity than physical mobility. While the correlations between items remain broadly consistent across all 4 waves for the majority of items, the lower average correlation between IADL item *tele* and other items (average correlation of 0.21) appears to be due to correlations between this and other items being notably lower in wave 1. For example, the average correlation between *tele* and all other items was 0.12 in wave 1, rising to 0.17 in wave 2 and 0.22 in wave 4. This suggests there may be some measurement error associated with this particular item in wave 1. Apart from a few

particular cases, correlations between the 23 items are considered sufficient to consider all items for PCA.

In order to determine whether there are a suitable number of cases to apply PCA methods to the 23 items, the KMO measure of sampling adequacy was adopted. The KMO test identifies items that should be excluded from PCA due to an insufficient number of cases, where values near to 0 indicate that PCA is not appropriate and should not be used. KMO values for all items are consistently 0.85 or greater and remain stable across waves. As such, all items are suitable for PCA analysis.

Performing PCA on the 23 items simultaneously and following the Kaiser criterion, only components with and an eigenvalue less than 1 are retained and the relevant retained eigenvalues are shown in Table 46.

Component	Eigenvalue	Difference	Proportion	Cumulative
Component 1				
min	6.36	4.63	0.28	0.28
max	7.12	5.03	0.31	0.31
Component 2				
min	1.73	0.46	0.08	0.35
max	2.09	0.87	0.09	0.40
Component 3				
min	1.22	0.14	0.05	0.41
max	1.28	0.23	0.06	0.45
Component 4				
min	1.05	0.08	0.05	0.45
max	1.08	0.17	0.05	0.50

Table 46. PCA component eigenvalues (range across 4 wave
--

Source: ELSA, waves 1-4

Components 1 to 4 are retained, which together describe between 45% and 50% of the overall variance between these 23 items. Table 47 presents the range of individual loadings for each of the 23 items across all 4 waves in relation to components 1 to 4.

Due to the large number of items included in the analysis, unpicking the relatively complex patterns captured by the specific weights for individual component items, as shown in Table 47, requires identifying the characteristics shared by items that make the most significant contribution within any given component.

	Co	omponen	t 1	C	Component 2		C	omponen	t 3	Component 4		
	Min	Max	Range	Min	Max	Range	Min	Max	Range	Min	Max	Range
100vds	0.25	0.28	0.03	-0.18	-0 10	0.08	-0 14	-0 11	0.03	-0 14	-0.07	0.08
sitting	0.12	0.15	0.03	-0.23	-0.18	0.05	0.11	0.32	0.00	0.39	0.47	0.08
getun	0.16	0.18	0.02	-0.25	-0.19	0.06	0.18	0.28	0.11	0.15	0.46	0.31
stairs	0.14	0.16	0.03	-0.20	-0.17	0.03	-0.34	-0.31	0.03	-0.12	-0.08	0.04
stair	0.23	0.26	0.03	-0.19	-0.17	0.02	-0.22	-0.15	0.06	-0.11	-0.08	0.04
stoop	0.12	0.16	0.04	-0.20	-0.19	0.01	0.03	0.17	0.14	0.10	0.40	0.30
extend	0.16	0.19	0.03	-0.14	-0.05	0.09	0.06	0.10	0.03	0.08	0.32	0.23
pull	0.24	0.26	0.03	-0.21	-0.15	0.06	-0.29	-0.22	0.07	0.00	0.22	0.22
lift	0.21	0.23	0.02	-0.22	-0.16	0.06	-0.35	-0.31	0.05	-0.02	0.22	0.24
pick	0.15	0.15	0.00	0.01	0.10	0.09	0.13	0.27	0.14	0.16	0.43	0.27
•												
eat	0.15	0.20	0.05	0.19	0.26	0.07	0.16	0.29	0.12	-0.11	0.10	0.21
wroom	0.23	0.24	0.01	0.02	0.07	0.04	0.15	0.23	0.07	-0.34	-0.29	0.05
bed	0.22	0.24	0.01	-0.08	-0.04	0.04	0.29	0.38	0.09	-0.26	-0.08	0.18
toilet	0.20	0.21	0.02	0.02	0.06	0.04	0.30	0.39	0.09	-0.36	-0.15	0.20
bath	0.24	0.26	0.01	-0.06	-0.04	0.02	0.02	0.09	0.07	-0.18	-0.08	0.10
dress	0.22	0.23	0.01	-0.11	-0.06	0.04	0.20	0.28	0.08	-0.15	0.06	0.21
meal	0.24	0.26	0.02	0.23	0.28	0.05	-0.05	0.04	0.09	-0.19	-0.06	0.14
shop	0.27	0.28	0.01	0.02	0.08	0.06	-0.20	-0.14	0.05	-0.19	-0.05	0.14
hwork	0.25	0.28	0.03	-0.13	-0.06	0.08	-0.19	-0.14	0.05	-0.09	-0.06	0.04
map	0.12	0.17	0.05	0.29	0.32	0.03	-0.25	-0.16	0.10	0.17	0.19	0.03
tele	0.09	0.17	0.09	0.37	0.38	0.01	-0.09	0.03	0.12	0.12	0.28	0.16
medi	0.12	0.20	0.07	0.38	0.41	0.03	-0.09	0.00	0.09	0.10	0.15	0.05
money	0.13	0.21	0.07	0.37	0.42	0.05	-0.22	-0.11	0.10	0.09	0.16	0.07

Table 47. Individual item weights from PCA components 1 to 4 (range across 4 waves)

*Note: full label descriptions in Table 3* Source: ELSA, waves 1-4

**Component 1** appears to describe physical activities, with the strongest factors being Mobility items 100yds, pull and lift, predominately physical ADL items such as wroom, bed and bath, and IADL items meal, shop and hwork. This suggests that difficulty with these activities is likely to increase collectively. Notably, the more cognitive IADL items contribute little to this component. This component can therefore be considered a summary measure of physical dependency. **Component 2** appears to describe the cognitive aspects of the IADL domain, with items map, tele, medi and money being dominant factors in this domain. Although less pronounced, ADL and IADL activities involving a cognitive dimension, namely items eat and meal, contribute to this component. This component can therefore be considered a summary of cognitive dependency.

**Component 3** appears to describe a relationship between difficulties relating to getting around the house, namely ADL items *bed* and *toilet*, which are offset by dependency in Mobility items *stairs* and *lift*. This component can therefore be considered a summary of mobility.

**Component 4** appears predominately to relate to a single aspect of dependency, namely difficulty with Mobility item *sitting*, which is offset by ADL difficulty *wroom*. It should be noted that loadings for some items in this component are less consistent from one wave to the next, with some items such as Mobility items *stoop* and *extend* contributing strongly in some but not all waves. Since the loadings for items in component 4 are inconsistent between waves, it was considered problematic to include component 4 for the purposes of undertaking longitudinal analysis and only components 1 to 3 are considered. Although this restricts the degree to which all identified dimensions of dependency summarised across the 23 items are considered, component 4 captures only 0.05% of the overall variance between the 23 items and more than 40% of the overall variance is still described by the first 3 retained components.

Throughout the rest of this chapter, the 3 components under consideration will be referred to as follows:

Component 1: Physical Component 2: Cognitive

#### **Component 3**: *Mobility*

Alongside confirming underlying patterns of association between the 23 items, the purpose of PCA in this application is also to reduce the dimensionality of the data, transforming a large number of binary measures to a set of summary scores. These are then operationalized for the research as low, medium and high levels dependency within specific domains of need. Following the PCA stage, item weights generated for components 1 to 3 were used to calculate component summary scores at each wave, reflecting relative level of dependency in the Physical, Cognitive and Mobility dimensions described by components 1 to 3. As described earlier, these summary scores were split then into 3 groups (tertiles) with a final 4-category summary measure of dependency in each dimension generated, following the classification outlined in Table 44. The distribution of the new measures is presented in Table 48, across age groups to show transitions in Physical, Cognitive and Mobility dependency with increasing age.

Level of need	60-64 (%)	65-69 (%)	70-74 (%)	75-79 (%)	80-84 (%)	85-89 (%)	90+ (%)	Total (%)
No dependency	46.6	41.2	33.3	26.5	19.2	12.3	9.7	34.4
Comp 1: Physical dep.								
Low Medium High	23.2 16.2 14.0	23.6 19.8 15.4	24.0 23.1 19.6	21.5 27.7 24.4	19.2 26.5 35.1	13.0 27.7 47.0	7.7 18.6 64.0	22.0 21.8 21.8
Comp 2: Cognitive dep.								
Low Medium High	17.7 19.1 16.7	18.8 21.4 18.6	22.1 24.2 20.4	24.1 26.1 23.3	28.8 24.9 27.1	30.7 26.2 30.8	34.9 21.0 34.3	21.9 22.7 21.0
Comp 3: Mobility dep.								
Low Medium High	15.0 18.4 20.0	17.6 20.8 20.4	22.6 22.5 21.6	27.6 24.4 21.4	35.0 24.5 21.4	46.0 22.8 18.9	54.1 18.0 18.2	23.4 21.5 20.7
Total	6,823	5,912	5,343	3,978	2,756	1,412	495	26,719

Table 48. Distribution of PCA-derived Physical, Cognitive and Mobility dimensions of dependency, by age

Source: ELSA, waves 1-4

Experiencing dependency is increasingly common at older ages, and less than 10% of those aged 90+ do not report a difficulty. High dependency in the physical and cognitive dimensions increases consistently from youngest to oldest, while high mobility dependency remains broadly consistent at around 20% in all age groups. These differences in relative dependency across the 3 dimensions are shown more clearly in Figure 39 (shown as the proportion of those in each age group reporting difficulties).



Figure 39. Distribution of relative dependency for those with any difficulty, by age

Source: ELSA, waves 1-4

Figure 39 shows a broadly similar proportion of people have low, mid and high dependency needs across all ages except for those aged 85+, where over half experience high physical dependency and low mobility dependency. Figure 40 shows the proportion of people receiving care from each of the 4 different sources who have low, mid and high dependency needs in each dimension.



Figure 40. Relative level of need across 3 PCA-derived dimensions of dependency for those receiving care across 3 PCA-derived dimensions of dependency

Of those receiving care from any source, around 60% have high physical dependency, 37% have high cognitive dependency and around 25% have high mobility dependency. The distribution of those receiving each type of care is different however with those receiving formal care being likely to have low mobility dependency (over 50%) and dramatically more likely to have high physical dependency (around 94%). While only a small proportion (around 10%) of those receiving any care experience low physical dependency, a far greater proportion who receive care have either low cognitive dependency (38%) or low mobility dependency (48%). The very high likelihood of care for those in the high physical dependency needs group, where over 80% receive care of some sort, suggests that these needs are key in determining the receipt of care. Undertaking regression analysis will help to unpick how these different dimensions of

Source: ELSA, waves 1-4

dependency operate simultaneously alongside other background characteristics to determine if care is received and from where.

#### 6.2.4. Summary of section 6.2

dependency on patterns of care receipt in later life.

This section applied PCA to the 23 Mobility, ADL and IADL items collected in ELSA. The items were initially tested for suitability for further PCA analysis and preliminary analysis checked for underlying patterns of association. The analysis identified 4 components capturing underlying and uncorrelated patterns of variance. The item weights for components 1 to 3 were seen to remain broadly stable across all 4 waves of ELSA. Weights for individual items specified within component 4 were seen to be inconsistent and vary across the 4 waves and it was decided to exclude component 4 from further consideration in the following longitudinal analysis. PCA methods were used to generate summary scores for each of the 3 dimensions - physical, cognitive and mobility dependency – at each wave and these scores were split into 3 groups (tertiles) which were combined with the group 'has no difficulties' to produce a 4-category measure of relative dependency. The 4 new measures identify relative level of dependency in each of dimension. Adopting an approach to capturing relative dependency, encompassing the full range of dependency items, provides an understanding of dependency in later life that is more nuanced, allowing for a picture of dependency in old age that potentially better reflects the experience of a wider range of older people, particularly those with less severe needs. The next section uses the new measures in logistic regression analysis to explore the effects of

## 6.3. Controlling for need by PCA-derived dimensions of dependency

Following the analysis presented in section 6.1 considering the Array of Need measure as a means to operationalize relative dependency across 3 domains of need simultaneously, this section undertakes logistic regression analysis to explore broader dimensions of dependency. The analysis focuses on the new PCA-derived measure of dependency developed in section 6.2, summary measure of dependency across 3 domains – physical, cognitive and mobility. As before,

explanatory variables control for background demographic and socio-economic characteristics (described in section 2.6). The dependent variables considered in the following analysis are the same outlined in section 2.5, indicating whether a person receives care from any source, from a partner or child and other types of informal care, and from formal and private care. The next section presents results of the logistic regression analysis of patterns of care receipt from each source in turn.

## 6.3.1. Logistic regression: Modelling receipt of care from different sources of care for PCA-derived dimensions of dependency

This section explores the effects of explanatory factors on receipt of care, focusing on the effects of relative dependency across 3 PCA-derived dimensions of dependency. Four regression models are run, and dependent variables capture receipt of the following types of care:

Model 1: Receives care from a partner or child

Model 2: Receives care from any other informal source

Model 3: Receives care from any formal source

Model 4: Receives care from private sources.

Each model includes the independent variables listed in section 2.6, additionally including the 3 PCA-derived dimensions of dependency measures.

It should be noted that, undertaking initial analysis and entering the dependency measures using reference category 'low dependency' as the reference category produced extremely high odds ratios for those with high dependency, particularly the effects of high physical dependency on the receipt of formal care. In light of this issue, the 'mid dependency' group in each dimension of dependency is used as the reference category instead, since this will enable an understanding of how the care for those with high and low needs compares to those with moderate needs, where the comparison could be expected to be less dramatic.

As stated, the sample is restricted to respondents with any difficulty. Model 1 is additionally restricted to respondents with a partner or child, using a single conjugal family indicator (co-

resident partner and children; co-resident partner and no children; children and no co-resident

partner). The 4 models are presented in Table 49.

	Dependent variable – receives care from source:									
	1. Partn	er or child	2. Other	r informal	3. I	ormal	4. P	rivate		
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI		
Female <sup>1</sup>	1.61***	1.40 - 1.86	1.48***	1.24 - 1.77	1.01	0.71 - 1.44	2.33***	1.82 - 3.00		
<b>Conjugal family</b> Lives with partner <sup>2</sup> Has any children <sup>3</sup>	0.79 0.21 <sup>****</sup>	0.59 - 1.05 0.18 - 0.25			0.31 <sup>***</sup> 0.53 <sup>***</sup>	0.21 - 0.48 0.39 - 0.73	0.44 <sup>***</sup> 0.99	0.34 - 0.56 0.79 - 1.24		
Partner only <sup>4</sup> Children only <sup>4</sup>			0.24 <sup>***</sup> 0.92	0.20 - 0.30 0.78 - 1.08						
Age group <sup>5</sup> 65-69 70-74 75-79 80-84 85-89 90+	0.91 0.91 1.11 1.50 <sup>***</sup> 1.52 <sup>**</sup> 2.07 <sup>**</sup>	0.77 - 1.09 0.76 - 1.10 0.91 - 1.35 1.20 - 1.87 1.16 - 2.01 1.29 - 3.34	0.87 0.92 1.04 1.21 1.45 <sup>*</sup> 1.82 <sup>***</sup>	0.67 - 1.12 0.71 - 1.20 0.80 - 1.35 0.93 - 1.58 1.08 - 1.95 1.24 - 2.68	3.72 <sup>***</sup> 3.20 5.81 <sup>***</sup> 12.06 <sup>***</sup> 22.07 <sup>***</sup> 41.14 <sup>****</sup>	1.84 - 7.51 1.56 - 6.53 2.87 - 11.77 6.01 - 24.20 10.57 - 46.06 17.97 - 94.16	1.75 <sup>*</sup> 3.65 <sup>****</sup> 4.79 9.52 <sup>****</sup> 14.47 <sup>****</sup> 14.56 <sup>****</sup>	1.10 - 2.79 2.34 - 5.68 3.08 - 7.46 6.10 - 14.85 9.03 - 23.20 8.26 - 25.65		
Wealth quintile <sup>6</sup> WQ4 WQ3 WQ2 WQ1 (low wealth)	0.96 1.09 1.32 <sup>*</sup> 1.34 <sup>*</sup>	0.79 - 1.18 0.89 - 1.35 1.07 - 1.63 1.07 - 1.68	1.51 <sup>*</sup> 1.43 <sup>*</sup> 2.08 <sup>***</sup> 2.13 <sup>****</sup>	1.09 - 2.09 1.03 - 1.97 1.52 - 2.84 1.56 - 2.91	0.98 1.70 2.71 <sup>**</sup> 4.36 <sup>***</sup>	0.47 - 2.05 0.84 - 3.43 1.37 - 5.34 2.22 - 8.59	0.87 0.61 <sup>**</sup> 0.56 <sup>**</sup> 0.29 <sup>***</sup>	0.62 - 1.22 0.43 - 0.86 0.39 - 0.79 0.20 - 0.41		
Education <sup>7</sup> A-level O-level None	1.38 <sup>*</sup> 1.32 <sup>*</sup> 2.01 <sup>****</sup>	1.04 - 1.84 1.01 - 1.73 1.54 - 2.62	0.75 0.58 <sup>**</sup> 0.72	0.51 - 1.08 0.41 - 0.82 0.52 - 1.00	1.33 0.72 0.80	0.59 - 3.01 0.33 - 1.56 0.38 - 1.66	0.84 0.55 <sup>**</sup> 0.37 <sup>***</sup>	0.54 - 1.30 0.36 - 0.84 0.25 - 0.56		
Dependency:										
<b>Comp 1: Physical<sup>®</sup></b> Low High	0.18 <sup>****</sup> 6.68 <sup>****</sup>	0.16 - 0.21 5.71 - 7.80	0.24 <sup>****</sup> 3.85 <sup>****</sup>	0.18 - 0.32 3.22 - 4.62	0.27 <sup>**</sup> 29.79 <sup>****</sup>	0.10 - 0.71 17.38 - 51.07	11.87 <sup>***</sup> 42.53 <sup>****</sup>	7.13 - 19.75 25.4 - 71.21		
<b>Comp 2: Cognitive<sup>8</sup></b> Low High	1.13 1.21 <sup>*</sup>	0.98 - 1.30 1.05 - 1.39	1.12 1.10	0.93 - 1.36 0.91 - 1.33	1.05 1.09	0.70 - 1.56 0.73 - 1.61	0.70 <sup>**</sup> 0.65 <sup>****</sup>	0.55 - 0.90 0.53 - 0.80		
<b>Comp 3: Mobility<sup>8</sup></b> Low High	1.50 <sup>***</sup> 0.81 <sup>**</sup>	1.31 - 1.73 0.70 - 0.94	1.18 0.94	0.99 - 1.40 0.77 - 1.15	1.01 1.88 <sup>**</sup>	0.70 - 1.45 1.27 - 2.79	0.77 <sup>*</sup> 0.70 <sup>**</sup>	0.61 - 0.97 0.55 - 0.89		
N N_g rho BIC Pseudo R2	12,488 5,994 0.45 13,705 0.13		15,846 7,087 0.40 8,497 0.15		15,846 7,087 0.63 3,342 0.30		15,846 7,087 0.49 5,820 0.15			

Table 49. Logistic regression: receipt of care from different sources for 3 PCA-derived dimensions of dependent	Table 49.	Logistic regre	ssion: receipt o	f care from	different sources	for 3 PCA-	derived dir	nensions of	dependenc
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Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001Reference categories: <sup>1</sup> male; <sup>2</sup> does not live with a partner; <sup>3</sup> has no children; <sup>4</sup> lives with partner and has children; <sup>5</sup> 60-64; <sup>6</sup> Wealth quintile 1 (high wealth); <sup>7</sup> Degree; <sup>8</sup> mid dependency Source: ELSA, waves 1-4

Initially comparing to the previous analysis using the Array of Need (AoN) measure (model 2, Table 39 to Table 42), all models using the PCA-derived dimensions of dependency measures show improvement in BIC over the models using the AoN measure, except for model 4 ('receives any formal care'). This suggests that the IoRN-based measure provides a better explanation for formal care receipt in response to dependency than the new measure. This makes sense, as the AoN measure is itself based on a tool that is designed to predict formal care service usage, focusing explicitly on the types of needs that are likely to be met directly by formal services. However, restricting the scope of dependency to needs that can be met by formal services provides only one part of the wider picture of wider care receipt in later life.

Beginning with discussion of independent variables, women have an increased chance of receiving all types of care except for formal care. Those living with a partner are more likely to receive care, but this increase is due to the increased likelihood of receiving care from a partner as living with a partner lowers the chances of receiving all other types of care. Older people with children have a lower chance of receiving formal care, and are less likely to receive care from a partner or child, compared to those living with a partner. However, there is no significant effect of having children on the receipt of unpaid care from outside the conjugal family, or on the receipt of private care. The very old are more likely to receive all types of care, although the effect is most marked in relation to formal care receipt. When dependency needs are controlled for independently of age, unpaid care only becomes more likely for those aged 80+.

Being in less advantaged social groups increases the likelihood that care will be received. Wealth is significant in all models and those in the lowest wealth quintile are more likely to receive unpaid care and formal care, but have a lower chance of receiving private care. This barrier to private care receipt is also reflected in educational qualifications, as those without education are less likely to receive care from privately paid sources. The effects of education are less consistent in relation to other types of care, as education has no significant effect when modelling care from formal sources (model 4). Between the socio-economic status measures, wealth is the more consistent measure in capturing the negative effects of lower social position on care receipt.

Turning to consider the effects of dependency using the 3 PCA-derived dimensions of dependency measures (developed in section 6.2), it is clear that physical dependency is the

single greatest factor in determining whether care is likely to be received. Experiencing high physical dependency dramatically increases the likelihood of receiving all types of care. OR for high physical dependency in all models is very high, particularly so with respect to receipt of formal care. The high OR in these models is likely a result of the prevalence of care amongst those with high physical dependency. For example, around 60% of people receiving care from any source and around 94% of those receiving formal care have high physical dependency (as shown in Figure 37). This issue may be due to component 1 (physical dependency) alone explaining around 30% of variance between the 23 items, while component 2 explains less than 10% and component 3 only around 5%. Due to the issue of high OR for the dimension of dependency described by component 1, a number of alternate approaches were considered to overcome this issue. These approaches included the following:

1. Splitting the component scores into 2 rather than 3 groups to create a dichotomous variable (classifying dependency as either 'low' or 'high'). When undertaking regression analysis, the OR for the physical dependency measure was lower. For example, when modelling formal care receipt using binary measures of dependency (not shown), the physical dependency measure produces an OR of 60.9. Further, by reducing the level of dependency an individual experiences to a binary measure necessarily restricts the degree to which the model reflects the impact of experiencing increasingly more severe levels of dependency on whether or not care is received. As such, this approach was not considered appropriate for the purposes of this chapter.

2. The second approach considered was to split the component scores into 10 deciles rather than 3 tertiles to provide a more graded approach to measuring the level of need and to enter the 10 deciles as a continuous measure. This could maintain the ordinal structure of the original component score but provide easier interpretation of the effects of greater dependency, avoiding extremely high OR ratios from high levels of dependency at one extreme of the scale compared to the other.

#### 6.3.2. Summary of section 6.3

This section explored the effects of a range of explanatory factors on the receipt of 4 types of care, controlling for relative dependency using PCA-derived domains of dependency either individually or simultaneously. Dependency in the Physical domain was shown to be the strongest factor affecting receipt of all types of care. Need in the Cognitive domain was shown to increase the likelihood of care from partners and children, but lowered the likelihood of receiving private care. However, the effect of dependency in this domain was not significant when considering receipt of formal care. Mobility domain needs were shown to increase the likelihood of receiving care, but the effects of this type of dependency were only significant in increasing the likelihood of receiving care from a partner or child.

## 6.4. Summary of chapter

This chapter used 2 different approaches to explore how dependency in different domains is associated with the receipt of particular types care. The chapter began with analysis using the IoRN-framework-based AoN measure – developed in chapter 5 – to explore how a pre-defined measure for assessing dependency could be used to examine the relationship between dependency and care. The analysis confirmed that classifying relative dependency following the IoRN-framework enabled different dimensions of need to be considered simultaneously. The analysis demonstrated that the AoN identified a greater likelihood of receiving all types of care for those with the greatest dependency needs. For people in groups other than AoN5 (the most dependent group) the specific type and level of dependency needs increased the likelihood of particular types of care. The findings suggested that the AoN was suited to identifying the types of dependency commonly met by formal services, but was unable to unpick the impact of less severe needs that are more commonly met by other types of care.

Section 6.2 continued by introducing PCA as a method to reduce the dimensionality of the full range of Mobility, ADL and IADL items in ELSA to summary measures of dependency across 3 alternative domains of need: Physical, Cognitive and Mobility. The regression analysis using

these 3 indicators was a better model fit than when using the AoN measure, showing the varying impact of different types of dependency needs on each type of care. In particular, this chapter demonstrated that all forms of care are more common for those who have difficulty performing household domestic tasks, while dependency resulting from mental health issues or difficulties with cognitively demanding tasks is most likely restricted to help from within the conjugal family. In this chapter, the analysis of care receipt treated informal, formal and private care as three entirely independent arrangements for care provision, and the next chapter builds on this by considering how care may be received from more than one source at the same time.

## **Chapter 7**

7. Exploring the relationship between informal and formal care The analysis presented in this thesis so far has focused on understanding how the complexity and type of needs affect receipt of different types of care, specifically differentiating between four types of care: unpaid care from partners and children, other unpaid care, formal care and private care. However, the range of care resources on which individuals may rely on to meet their particular needs do not exist in isolation from one another. Dependent on a person's needs and the availability of other care options, the receipt of informal, formal or private care alone may be sufficient in meeting their needs. Where informal, formal or private care alone is unable to meet a person's needs then other care may be required. Building on previous research exploring the relationship between informal and formal care, this chapter begins by exploring the inter-relationship between different types of care, focusing on how receipt of care from one source affects the odds of receiving care from another, before turning to consider how unpaid household and non-household care affects the receipt of formal care.

## 7.1. Exploring combinations of care from different sources

The previous chapters have considered the effects of dependency on receipt of care, focusing on the receipt of unpaid partner/child care, other informal care, and care from formal and private sources. This section examines how receipt of one type of care may directly affect the likelihood of receiving other types of care. The individual providers of care within the informal, other informal, formal and private care categories cover the majority care supplied to older people living at home. Care classified within the 'other (specified)' care category, which includes voluntary care and professional care from staff in a care home, has not been considered in the main analysis presented in this thesis due to the catch-all nature of this category (see sections 2.4.2 and 2.5.1.6). However, the 'other (specified)' category is considered in the preliminary analysis below to allow for care from these sources to be accounted for when considering the combinations of care on which older people rely.

Although the majority of older people may receive care from only one source, predominately from a partner or child, this is likely to change as needs become more complex, particularly amongst the dependent oldest old. To illustrate how patterns of care may change as needs become more complex, this section considers the number of care sources providing care to those with lesser or greater needs. Combinations of care from informal, formal, private and other sources were initially classified using the following categories:

- no care respondent gives a negative response to question hehpa\_new
- **single source only** *respondent confirms receiving help from only* 1 *of the following* 5 *sources: partner or child, other informal, formal, private, or other (specified)*
- more than 1 source respondent confirms receiving help from 2+ sources
- **unspecified** respondent confirms that they receive help with a difficulty (a positive response on variable hehpa\_new) but does not specify a source

The last group, 'unspecified', represents a form of missing data. These cases reflect individuals who have a difficulty, and are identified as receiving help, but no source of care is confirmed (including help from 'other person' – see discussion in section 2.5.1.6).

Table 50 shows a breakdown of the 'combinations of care' variable (including the unspecified care group). For the purposes of exploring the relationship between level of dependency and types of care received, the combinations of care measure is cross-tabulated with an indicator of the number of difficulties in a 6-item categorical version.

	# difficulties reported									
Combinations of care	0	1-3	4 – 8	9 – 13	14 – 18	19+	Total			
a. none b. single source c. more than one source d. unspecified	100.0	79.9 16.5 1.3 2.3	42.9 45.6 10.1 1.3	14.3 56.6 27.3 1.8	3.8 54.5 37.9 3.9	0.9 34.5 46.0 18.7	70.4 21.6 6.6 1.5			
Total	9,197	8,751	5,232	2,368	932	235	26,715			

Table 50. Combinations of care, by number of difficulties reported

Source: ELSA, waves 1-4

As expected, the proportion of respondents who do not receive care decreases as the number of difficulties reported increases, and the proportion receiving care from more than 1 source also

increases as the number of difficulties increases. Overall, a greater proportion who receive care receive it from only one source, with the exception of those who have 19-or-more difficulties where a majority receive care from multiple sources.

Of the 17,518 cases with a difficulty, 1.5% receives care but do not specify the source, representing 5% of all cases receiving help. As discussed in section 2.5.1.6, this group are predominately from ELSA wave 3, and from predominately proxy responses. There is no identifiable reason for this given in the data, but this group appear to be highly dependent, including 19% of the most dependent group (19-23 difficulties) receiving unspecified care.

Further investigation of the combinations of care received by people receiving care is shown in Table 51, breaking down the number of care sources by the specific types of care received concurrently by age.

Sources of received care	60-64	65-69	70-74	75-79	80-84	85-89	90+	Total
1 source only	81.85	82.99	77.30	77.70	68.82	61.43	55.46	75.04
Partner and Child only Other Informal only Formal only Private only	73.25 5.66 0.66 1.18	71.54 6.11 1.55 2.71	63.98 6.94 0.91 4.27	60.38 8.88 1.61 5.58	48.01 7.74 2.79 8.13	36.43 9.64 2.62 8.69	33.06 7.65 4.64 5.46	59.30 7.36 1.75 4.85
Other only	1.10	1.08	1.19	1.25	2.15	4.05	4.64	1.78
2 sources	12.12	11.29	15.21	15.55	21.13	25.71	27.32	16.71
Partner and Child + Other Informal Partner and Child + Formal Partner and Child + Private Other Informal + Formal Other Informal + Private Formal and Private	9.40 0.73 1.32 0.07 0.59 0.00	7.19 1.08 1.47 0.62 0.70 0.23	8.55 1.47 3.71 0.49 0.91 0.07	7.70 2.27 3.37 0.73 1.17 0.29	8.69 3.83 4.70 1.44 1.59 0.88	7.38 5.83 7.74 1.43 2.26 1.07	8.47 7.10 4.92 2.46 3.28 1.09	8.22 2.52 3.52 0.82 1.23 0.40
3 sources	0.88	1.31	2.24	2.71	4.70	5.95	8.47	3.01
Partner/child, Other informal + Formal Partner/child, Other informal + Private Partner/child, Formal + Private Other informal, Formal + Private	0.51 0.37 0.00 0.00	0.46 0.54 0.08 0.23	1.05 0.91 0.14 0.14	0.95 1.39 0.22 0.15	1.83 2.07 0.56 0.24	2.50 1.55 0.83 1.07	3.01 2.46 1.91 1.09	1.21 1.16 0.34 0.29
4 sources	0.07	0.23	0.21	0.22	0.40	0.48	1.09	0.29
Unspecified	5.07	4.18	5.05	3.82	4.94	6.43	7.65	4.95
Total	1,361	1,293	1,427	1,363	1,254	840	366	7,904

Table 51. Patterns of received care, by age group (% of ELSA respondents confirming help)

Source: ELSA, waves 1-4

Of those confirming receipt of any help, 75% receive care from only one source. The majority of respondents receive help from an informal source, with 59% receiving help from only a partner

or child, 7% receive care only from other informal sources, and 8% receiving care from a combination of these two informal sources. However, while around 88% of those in the youngest group receive only informal care, the proportion declines in older groups. For example, around 80% of those aged 70-74, less than 65% of those aged 80-84, while more than half of the oldest old receive care from multiple sources. Indeed, relatively few respondents receive combinations of care that do not include care from a partner or child. Excluding those who report unspecified care, only 18.5% of respondents who receive care do not receive help from a partner or child, and less than 10% do not receive any informal care whatsoever. By comparison, of those receiving care more than 80% do not receive either formal or private care.

The proportion of respondents receiving formal and neither informal nor private care increases from youngest to oldest, although the pattern is not one of consistent increase with age. This may be explained by the relatively small number of cases receiving formal care, particularly the number receiving formal care in isolation, which may result in greater fluctuations in patterns of care receipt. Unlike other forms of care that see a drop amongst the oldest age group when needs are most likely to be relatively complex, the trend of a greater proportion of the oldest old receiving formal care exclusively may reflect the targeting of social care services to those with high dependency unable to access other sources of help and support.

The proportion of respondents receiving private care and not receiving any informal or formal care in combination increases steadily, from around 1% in the youngest group to more than 8% of those aged 85-89, before declining in the oldest group. This confirms further the impact of increasingly complex needs in the oldest ages, when the types of help provided by private care may be insufficient in isolation to meet needs that are complex. This highlights that, while there is an increase in the proportion of people receiving help from multiple sources, particular combinations of care are noticeably uncommon.

The sample includes people who receive care from 'other' sources (n=413), although this group is only identified in Table 51 if they do not otherwise receive care from any other source, due to the complexity of showing every possible permutation of care received from 5 different sources.

As discussed in section 2.4.1 (see Table 4), this group is constituted by people receiving care from voluntary sources, from a member of staff at a care home, or from any other person not specified within any other group. Voluntary care is reported by less than 1% of those receiving any care (73 cases), and is not a large enough group to consider on its own but cannot meaningfully be combined with any other group. Similarly, around 3.2% of the sample receiving care (259 cases) specifies care from 'other person'. As this group cannot be usefully classified, it is included in the 'other' category of care. Finally, 89 cases report care from care home staff, although this group are only identified in wave 4 and as such cannot usefully be incorporated into the analysis as a specific type of care. As these different types of care do not reflect a cohesive type of care, they are grouped together within the 'other' group although for the purposes of analysis this group is not meaningful. Of cases receiving care from 'other' sources, 34% receive 'other' care exclusively, 42% from only one other source, and the remaining 24% from 2-or-more other sources. Of those who receive 'other' care in combination with care from any of the other 4 sources, 44% also receive care from a partner or child, 26% receive care from other informal sources, 15% receive formal sources and 12% receive care from private sources. This suggests that only a small number of the cases receiving care receive such care from one of these 'other' sources. The majority of these either receive no other care or receive 'other' care in combination with unpaid care. Alongside the 'other' group, it should also be noted that the care received by the 5% in the 'unspecified' group may make a significant difference to the balance between the different patterns of care presented in Table 51, but it is not possible to account for this in the current analysis.

Figure 41 summarises data from Table 51 by grouping the 2 types of informal care together as a single group 'informal' to identify combinations of informal, formal and private care.

From Figure 41, the proportion of cases receiving care but receiving unpaid care exclusively declines as age increases. This confirms that informal care becomes increasingly less able to meet all needs when dependency increases in later old age. There are few cases with patterns of care that include both formal and private care, suggesting when informal care becomes unable





Source: ELSA, waves 1-4 (following Table 51)

or insufficient to meet a person's needs, the majority of people who are receiving care continue to receive informal care in combination with either formal or private care.

Table 52 shows a breakdown of the proportion of respondents receiving help with difficulties from each source, and the number of sources providing care, by the AoN summary measure of relative dependency (developed in section 5.2.1), which will be used in logistic regression modelling in section 7.1.2.

	AoN1	AoN2	AoN3	AoN4	AoN5	Total
Confirms any care (%)						
from any source	21.55	80.71	71.85	81.31	90.85	29.58
from Partner or child	16.24	62.13	58.56	62.31	70.28	22.65
from Other informal	3.91	21.07	15.7	23.68	23.23	6.09
from Formal	0.71	14.13	6.72	10.59	18.17	2.26
from Private	2.44	11.73	9.34	9.35	12.03	3.57
Number of sources (%)						
none	78.45	19.29	28.15	18.69	9.15	70.42
single source only	17.04	50.49	50.64	46.42	48.26	21.55
more than 1 source	3.33	27.82	19.59	30.84	36.10	6.57
unspecified	1.19	2.40	1.63	4.05	6.50	1.46
Total	23,032	1,125	1,414	321	831	26,723

Table 52. Sources of received care and number of sources, by AoN relative dependency group

Source: ELSA, waves 1-4

As expected, those with AoN1 are consistently least likely to receive care although more than 3% receive care from more than 1 source. By comparison, more than 90% of those with AoN5

receive care and 36% receive care from multiple sources. Around 30% of those with AoN2 and AoN4 receive care from more than 1 source and the proportion is lower at around 20% for those with AoN3 receiving care from multiple sources.

Figure 42 shows a breakdown of the proportion of ELSA respondents classified by AoN and the different types of care (informal, formal and private) they receive in combination. The 2 remaining groups – 'other source' and 'unspecified' – are shown as a single group, since they are not considered in the analysis presented in this thesis and represent a catch-all group for all types of care not otherwise specified within the 4 main groups. Further, as discussed in section 2.5.1.6 the 'unspecified' group is predominately people in wave 3 and likely captures care received from a member of staff in a care home since this source was not specified in wave 3. As such, the majority of these cases are likely to be classified within the 'other' group but this assumption cannot be verified.





The majority of ELSA respondents who have difficulties with any Mobility, ADL or IADL items

either do receive any care or only receive unpaid care. Around 95% of those with AoN1 receives

Source: ELSA, waves 1-4 (following Table 52)

no care or only unpaid care, while for those with AoN2 around 77% receive either no care or unpaid care. Only 6.2% of those with AoN2 do not receive unpaid care, and less than 1% care including both formal and private sources together. For older people with more advanced needs, that is AoN2 or greater, around 60% receive care from a single source. A fractional proportion (0.2%) receives a combination of care including both formal and private sources and excluding unpaid care, although this group is greatest among those with AoN2 than for more dependent groups.

The substitution effect proposes a quantifiable relationship between informal and formal care, suggesting that an increase in care from one source produces a decrease in care from another source. However, only a small proportion (around 5%) of older people with any needs receive both unpaid and either or both formal and private care together, with the majority (almost 92%) receiving either only unpaid care or no care at all. If the substitution effect holds, this would suggest that there is an identifiable quantifiable 'point' at which informal care effectively replaces formal care entirely, representing a like-for-like replacement. However, knowing the hours of care received by those who receive *only* informal care, or indeed the hours of care received by those receiving *only* formal or *only* private care, reveals little of the substitution relationship between unpaid and other types of care without additionally knowing about the types of need and context in which care is received.

To further examine what care is received by those who receive care from a combination of different sources, Figure 43 shows a breakdown of the care received from informal, formal and private sources for those receiving care from 1, 2 or 3 of these sources.

The dominance of informal care is reflected by 92% of cases receiving care from only one source relying on informal care alone. Of those receiving care from multiple sources, only 3.7% do not receive any informal care. As such, it is evident that combinations of care involving multiple sources are likely to feature combinations of informal and either formal or private care.



Figure 43. Combinations of care received from 3 sources by number of sources

To understand how this is likely to change with increasing age and complexity of needs, Table 53 shows the proportion of cases with a difficulty, that is those in the ELSA sample who may report care, receiving combinations of informal, formal and private care, by age group (4-item categorical measure) and number of difficulties (5-item categorical version).

Table 53 shows that the majority of cases experiencing 1+ difficulty do not receive any informal, formal or private care and the majority of cases receiving care receive it from a single source. As shown in Figure 43, combinations of care are unlikely to include both formal and private care although care from all 3 sources is more likely in very old age and for those with complex needs (e.g. for those experiencing difficulty with 14+ items).

	Age				Number of difficulties					Total
# sources <sup>1</sup>	60-64	65-74	75-84	85+	1-3	4-8	9-13	14-18	19+	
0 No care 'other' only 'unspecified' 1 2 3	64.98 62.67 0.41 1.89 33.65 1.34 0.03	63.57 61.34 0.44 1.79 33.54 2.69 0.20	52.28 49.21 0.85 2.21 40.60 6.68 0.45	36.36 28.47 3.02 4.86 45.14 16.43 2.08	82.50 79.94 0.29 2.27 17.09 0.40 0.01	45.40 42.90 1.17 1.34 50.01 4.45 0.13	17.31 <i>14.31</i> <i>1.22</i> <i>1.77</i> 67.45 14.18 1.06	9.44 3.76 1.82 3.86 66.95 20.28 3.33	23.40 0.85 3.83 18.72 44.68 28.09 3.83	57.92 54.89 0.80 2.23 36.76 4.90 0.42
Total	3,646	7,036	5,153	1,686	8,752	5,233	2,369	932	235	17,521

Table 53. Number of sources providing care by age and number of difficulties

<sup>1</sup>Number of sources from the following: informal, formal, or private

Source: ELSA, waves 1-4

Source: ELSA, waves 1-4

The proportion reporting 'unspecified' care is dramatically greater for those with 19+ difficulties. As discussed, a large proportion of this group are resident in a care home reflecting the relatively high levels of need amongst this group. To unpick this further, Figure 44 shows the proportion of people in each age group reporting 'unspecified' care by number of difficulties.



Figure 44. Proportion of age and number of difficulties reporting unspecified care

From Figure 44, it is evident that more complex needs dramatically increase the likelihood that care is reported without identifying the source. For example, only 2 of 30 cases (6.7%) of the most dependent in the youngest group, and 18 out of 74 (24.3%) of the most dependent in oldest group, report care without specifying the source. Although when broken down by age, there are very few people with 19+ difficulties in each age group, it can be seen that those who receive care without specifying a source are among the most dependent older people in each age group, and particularly in the oldest ages.

Although it is not possible to identify the care received by this group, it could be assumed that some may receive care from within a care home, where such care may be designed to meet a broader range of needs than any individual source can conventionally meet. However, this does not allow an understanding of the combinations of care provided to older people living in a care home, except for a very small number of cases in wave 4. Therefore, this group is likely to reflect

Source: ELSA, waves 1-4

those whose level of dependency is far greater than older people who remain living at home. Further, it could be expected that those living in care homes will have the majority of their care needs met by professional staff, and representing a distinctly different type of care receipt. As such, it is necessary to exclude this group from the following logistic regression analysis.

This discussion, focusing on the receipt of combinations of care from different sources, demonstrates that the majority of older people who have needs and receive care are likely to receive care from a single source. However, it is necessary to consider how the receipt of care from different sources may be interwoven in order to unpick how the provision or lack of care from one source may impact on the likelihood that other types of care are received. For example, previous studies have shown informal care to effectively substitute for formal care whereby increasing amounts of informal care lowers the amount of formal care received (Bolin, Lindgren and Lundborg, 2008; Bonsang, 2009; Gannon and Davin, 2010; Van Houtven and Norton, 2004). Formal care in these studies relates to non-medical care such as home help and confirms that informal can effectively replace professional care that might otherwise be received from formal or private sources. However, the analysis presented in previous chapters suggests that the types of need most commonly met by informal, formal and private care are not necessarily the same, and direct substitution between different types of care is debatable. Further, the majority of older people with relatively low needs (i.e. those with 1-3 difficulties) receive no care and 80% of this group receiving no informal, formal or private care (excluding those classified with 'unspecified' care). In this context, it is unlikely that the absence of lowlevel informal care and support would otherwise be 'replaced' by equivalent formal care services.

The next section explores this in more detail by reframing the substitution between care from different sources by considering how the likelihood of receiving one type of care is affected by receipt of care from other sources.

#### 7.1.1. Descriptive analysis: Patterns of concurrent care

The exploration of factors affecting receipt of different types of care has shown that a given combination of needs – reflected by having a particular AoN – may make one type of care more likely than another. The analysis so far has not considered how receiving care from one source will affect the likelihood of additionally receiving care from other sources. In particular, the interrelationship between informal and formal care is a key area for analysis and it was shown in Table 50 that more than a quarter of ELSA respondents reporting 9+ difficulties receive care from more than 1 source concurrently. Extending the analysis presented in Table 52, Table 54 shows the proportion of ELSA respondents (excluding those without Mobility, ADL or IADL difficulties) receiving informal, formal or private care and the combinations of care from these 3 sources, by relative dependency across the ELSA-based AoN groups.

Pattern of care	AoN1	AoN2	AoN3	AoN4	AoN5	Total
Any Informal	30.6	70.7	64.1	72.9	78.0	38.9
Partner/Child only	24.1	49.6	48.3	49.4	54.8	29.6
Partner/Child and Other	2.9	12.5	10.1	13.7	15.5	4.9
Other Informal only	3.6	8.5	5.7	9.9	7.7	4.4
Any Formal	1.2	14.1	6.9	9.9	18.3	3.4
Any Private	4.1	11.7	9.3	9.6	12.1	5.5
Total	13,828	1,125	1,424	314	827	17,518
CONCURRENT CARE						
Partner/Child only	22.4	40.0	41.6	36.6	39.2	26.1
Other Informal only	2.9	4.2	3.4	6.4	3.7	3.1
Formal only	0.4	2.7	1.4	1.3	1.9	0.7
Private only	2.1	2.2	2.9	1.0	1.7	2.1
Partner/Child and Other	2.5	7.8	7.5	11.8	8.7	3.7
Informal and Formal	0.6	8.1	4.4	6.7	12.6	2.1
Informal and Private	1.7	6.7	5.3	6.7	7.0	2.7
Formal and Private	0.1	0.8	0.3	0.3	0.4	0.2
Inf/Formal/Private	0.1	2.0	0.7	1.3	2.9	0.4
Total	13,828	1,125	1,424	314	827	17,518

#### Table 54. Patterns of received care, by AoN group

Source: ELSA, waves 1-4

#### Receiving care from informal sources

From Table 54, 39% of ELSA respondents with a difficulty receive unpaid care with the majority receiving care from a partner or child. Of those receiving informal care, more than <sup>3</sup>/<sub>4</sub> receive only partner or child care. Almost 5% of older people with difficulties receive care from a partner or

child alongside care from other informal sources and slightly less receive only care from unpaid sources other than a partner or child. As such, care arrangements featuring more than one type of care are likely to include care from a partner or child in combination with other informal, formal or private care.

#### Receiving care from formal sources

The proportion of people receiving formal care is smaller than for the other 3 types of care with only 3.4% of older people with difficulties receiving this type of care. However, Table 54 shows around 77% of people receiving formal care also receive care from another source. The majority of these receive a combination of formal and informal care and less than 1% of those with difficulties receive formal care exclusively. This confirms that formal care is likely to be supplemented by other types of care with the majority of people receiving a combination of formal and informal.

#### Receiving care from private sources

A greater proportion of older people with needs receive care from private sources (5.4%) than formal sources (3.4%) with the majority either receiving private care exclusively (40% of those receiving private care) or in combination with informal care (56% of those receiving private care) but only a very small proportion of people receive both private and formal care. As evidenced in Figure 24, the majority of people receiving private care receive only private care and this help most commonly relates to help with shopping and work around the house. As such, Table 54 suggests that support provided by private care is likely to relate to routine household tasks and is likely to play a supplementary role alongside unpaid care.

#### 7.1.2. Modelling receipt of different types of care concurrently

This section explores how receipt of care from one source affects the likelihood of care from other sources being received. As per models in chapter 4 and chapter 6, receipt of care from the 4 main sources is modelled separately, with additional controls for concurrent care from other sources. Building on earlier analysis, the models in this section control for concurrent care from partners and children separately, since the effects of these are likely to be different in terms of

their effects on receiving additional care from other sources. As in earlier analysis, each model controls for demographic, socio-economic and conjugal family structure effects, alongside the AoN measure of relative dependency. Because the focus of the analysis presented here is to understand how care from different sources affect each other, the sample in this section is restricted to cases who receive any care, excluding cases where 'unspecified' care is reported.

The results of the 4 models are shown in Table 55. As concurrent care is likely to be correlated and subject to collinearity, the variance inflation factor (VIF) was calculated using ordinary least squares modelling for each of the 4 models. This was not found to be a problem, with VIF values for all independent variables being less than 4.9.

#### 7.1.2.1. Model diagnostics

The chi<sup>2</sup> test statistic is significant in all 4 models (p<0.001). Considering the benefits of additionally controlling for receipt of other types of care in the same model, the BIC value is lower in all models over models excluding concurrent care (available but not shown), and all BIC values are >10 in the full model, suggesting that there is a strong argument for including the additional controls. The pseudo  $r^2$  in these models suggests that including the additional measures in the model additionally explains a further 3-14% of the variation in the dependent variables over the model excluding these variables. The conditional intraclass correlation (rho) ranges from 0.34 in model 2 to 0.62 in model 3. This suggests that a relatively large proportion of the overall variation in the receipt of formal care and care from partners and children is explained by changes in individuals rather than the differences between individuals.

#### 7.1.2.2. Explanatory variables

Turning to consider the effects of explanatory variables, women are more likely to receive private care than men. However, there is no significant effect of gender on receipt of care from unpaid and formal sources when holding other factors constant. Older people living with a partner are less likely to receive unpaid care from other sources, but living with a partner has no significant effect in the context of formal or private care receipt, holding other factors

Care from:	1. Partı	1. Partner/child		2. Other informal		3. Formal		4. Private	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	
Female <sup>1</sup>	1.17	0.81 - 1.70	1.10	0.90 - 1.34	0.79	0.54 - 1.17	1.89 <sup>****</sup>	1.45 - 2.47	
Coniugal family					-		-		
Partner only <sup>2</sup>	0.28**	0.14 - 0.58							
Children only <sup>2</sup>	0.10***	0.07 - 0.16							
Lives with partner <sup>3</sup>			0.50***	0 38 - 0 65	0.64	0 38 - 1 08	1.06	0 75 - 1 50	
Has any children <sup>4</sup>			0.81*	0.67 - 0.99	0.51***	0.36 - 0.73	1.03	0.80 - 1.32	
Age group <sup>5</sup>					•				
65-69	0.76	0.43 - 1.33	0.77	0.56 - 1.04	3.45**	1.60 - 7.44	1.72 <sup>*</sup>	1.04 - 2.84	
70-74	0.88	0.50 - 1.55	0.85	0.63 - 1.15	3.70**	1.69 - 8.11	3.62***	2.24 - 5.84	
75-79	0.64	0.37 - 1.10	0.73 <sup>*</sup>	0.54 - 0.98	5.09***	2.36 - 11.00	3.79***	2.35 - 6.09	
80-84	0.77	0.43 - 1.35	0.72 <sup>*</sup>	0.53 - 0.98	10.78***	5.03 - 23.13	6.87***	4.26 - 11.06	
85-89	0.50 <sup>*</sup>	0.27 - 0.92	0.71 <sup>*</sup>	0.51 - 0.99	17.15	7.72 - 38.07	8.83***	5.35 - 14.57	
90+	0.90	0.38 - 2.09	0.77	0.51 - 1.18	23.27 <sup>****</sup>	9.60 - 56.41	8.64***	4.78 - 15.62	
Wealth quintile <sup>6</sup>									
WQ4	0.84	0.47 - 1.49	1.45 <sup>*</sup>	1.01 - 2.10	0.94	0.42 - 2.06	0.68 <sup>*</sup>	0.47 - 0.99	
WQ3	1.01	0.56 - 1.82	1.37	0.96 - 1.97	1.71	0.81 - 3.63	0.49 <sup>***</sup>	0.33 - 0.72	
WQ2	1.20	0.68 - 2.13	1.84	1.30 - 2.62	2.31	1.11 - 4.79	0.43	0.29 - 0.63	
WQ1 (low)	0.97	0.54 - 1.72	1.61	1.13 - 2.29	3.48**	1.68 - 7.22	0.19	0.13 - 0.28	
Education <sup>7</sup>									
A-level	0.96	0.47 - 1.98	0.76	0.49 - 1.16	1.63	0.68 - 3.91	0.87	0.54 - 1.42	
O-level	1.42	0.71 - 2.84	0.62 <sup>*</sup>	0.41 - 0.92	0.81	0.35 - 1.87	0.62	0.39 - 0.98	
None	2.17 <sup>*</sup>	1.11 - 4.24	0.72	0.49 - 1.06	0.85	0.38 - 1.88	0.43***	0.28 - 0.67	
AoN group <sup>8</sup>									
AoN2	4.19 <sup>***</sup>	2.49 - 7.04	1.79 <sup>***</sup>	1.39 - 2.29	11.94 ***	7.67 - 18.57	1.90***	1.39 - 2.60	
AoN3	2.76	1.72 - 4.43	1.71	1.34 - 2.17	7.47	4.70 - 11.87	2.01	1.48 - 2.74	
AoN4	2.87	1.26 - 6.52	1.75	1.16 - 2.65	7.59	3.76 - 15.31	1.81	1.02 - 3.23	
AoN5	7.32	3.68 - 14.55	2.43	1.82 - 3.24	27.97	16.78 - 46.61	2.94	2.04 - 4.23	
Concurrent Care <sup>9</sup>									
Partner			0.08 <sup>***</sup>	0.06 - 0.10	0.10 <sup>***</sup>	0.06 - 0.18	0.03	0.02 - 0.05	
Child	***		0.41***	0.34 - 0.50	0.47***	0.33 - 0.67	0.16	0.13 - 0.21	
Other Informal	0.08	0.06 - 0.12	***		0.86	0.62 - 1.20	0.36	0.28 - 0.47	
Formal	0.18	0.10 - 0.31	0.41	0.33 - 0.53	**		0.49	0.35 - 0.70	
Private	0.04	0.02 - 0.06	0.74	0.56 - 0.98	0.53	0.35 - 0.79			
Ν	5,213		6,961		6,961		6,961		
N_g	3,104		3,879		3,879		3,879		
rho	0.55		0.34		0.62		0.39		
BIC	2,832	(-506)	6,112	(-343)	2,968	(-50)	4,211	(-441)	
Pseudo R <sup>2</sup>	0.32 (	(+14%)	0.18	(+7%)	0.24	(+3%)	0.24	(+11%)	

Significance values: \* p<0.05; \*\* p<0.01; \*\*\* p<0.001 Reference categories: <sup>1</sup> male; <sup>2</sup> lives with a partner and has children; <sup>3</sup> does not live with a partner; <sup>4</sup> has no children; <sup>5</sup> 60-64; <sup>6</sup> Wealth quintile 1; <sup>7</sup> Degree; <sup>8</sup> AoN1; <sup>9</sup> no care from this source Source: ELSA, waves 1-4

constant. It might be expected that controlling for having children and receiving care from a child separately could potentially identify younger carers as more capable at accessing formal services (Rolls et al, 2011). However, older people with children are less likely to receive care from other informal and formal sources, and children have no significant effect on receipt of care from private sources, holding the effects of other variables constant. Older people with
children who live with a partner are more likely to receive care from other unpaid sources. The effect of older age on receipt of either type of unpaid care is not clear, although those aged in the range 75-89 are slightly less likely to receive care from other formal sources. The effects of ageing are clear in relation to private and formal care, with those 80+ being more than 10 times as likely to receive formal care as someone aged 60-64, while private care receipt appears to peak slightly earlier.

Poorer old people are more likely to receive other informal care and formal care, and less likely to receive private care, while the odds of those without qualifications are around 0.43 to 1 compared to those with a university degree. Both wealth and education are significant in model 4, suggesting that financial resources are not the only factor affecting paying for private care, with poorer less educated older people being the least likely to rely on private care.

As in the analysis presented in section 6.1, care is most common amongst those who have high levels of dependency (AoN5). However, amongst those with less pronounced needs, those with AoN2 (i.e. those with low ADL needs and medium personal care needs) are more likely to receive partner and child care and formal services than those with greater ADL dependency (AoN3 and AoN4). This suggests that personal care is the key driver of formal care provision, and support from the family. Those with dependency classified in AoN groups 2 and 3 are more likely to receive care from other formal sources than the reference group (AoN1), but there is little difference in the effects of having increased ADL needs (the difference between AoN2 and AoN3). There is a greater chance of care from other informal sources for those with additional mental health conditions (AoN4), while this group are less likely to receive private care than those with the same needs but who do not have additional mental health difficulties (AoN3). The next sections consider the effects of receiving one type of care on the likelihood of additionally receiving care from other sources.

#### 7.1.2.3. Concurrent care from a Partner or Child

Holding the effects of dependency and other factors constant, receiving care from any other source dramatically lowers the likelihood of care being received from a partner or child. In particular, the odds of someone who receives any care receiving care from a partner or child are around 25 to 1 (1/0.04) compared to those who do not receive private care, 12.5 to 1 (1/0.08) for those not receiving private care, and 5.5 to 1 (1/0.18) for those not receiving formal care. Combinations of partner/child and formal care are more likely than combinations of partner/child care and private or other informal care together. In this context, the effects of partner and children are likely to be different so conflation of these 2 types of care here is not the optimal approach.

#### 7.1.2.4. Concurrent care from Other Informal sources

All types of care lower the chance that other informal care will be received. The odds of someone that receives care receiving other informal care is 1.35 times (1/0.74) greater if they don't receive private care, 2.4 times (1/0.41) greater if they don't receive care from a child or if they don't receive formal care, and 25 times (1/0.04) greater if they don't receive care from a partner. Considered in this way, care from a partner is the least likely and private care the most likely to be received in combination with other informal care.

#### 7.1.2.5. Concurrent care from Formal sources

There is no statistically significant change in the likelihood of formal care receipt between those who either do or do not already receive other informal care, and unlike other types of care, formal and other informal care are clearly able to operate together, suggesting a complementary relationship. Older people who already receive any other type of informal or private care are less likely to receive formal care. Older people receiving care are around 1.9 times (1/0.53) as likely to receive formal care if they are not already receiving private care, and over twice (1/0.47) as likely if they do not already receive care from a child. This suggests that formal care is most often received by those without the support of a partner, children or from private sources, particularly for those with high dependency needs.

#### 7.1.2.6. Concurrent care from Private sources

Finally, turning to the effects of receiving different types of care on the receipt of care from private sources, as with all other types of care, those already receiving care from a partner are very unlikely to receive private care. Older people who receive care are more than 33 times (1/0.03) as likely to receive private care if they are not already receiving care from a partner. There is a greater chance of private care amongst those already receiving care from a child and other informal care, and older people have double (1/0.49) the chance of receiving private care if they are not already receiving private care if they are not already receiving care from a child and other informal care, and older people have double (1/0.49) the chance of receiving private care if they are not already receiving formal care. Private care can therefore be seen to be most likely to be received by those already receiving formal care, and least likely amongst those receiving care from a partner or child. This supports other studies suggesting that private care is often used to replace care that would otherwise need to be supplied by children.

Further, although there only 105 cases (less than 0.1% of the sample with a difficult, from Table 54), who receive a combination of formal and private care, the odds ratio in Table 55 suggests formal care may be more commonly received in combination with private care than other types of unpaid care. Finally, of the different types of informal care, other informal care is the most likely to be received in combination with private care, and there are clearly circumstances in which a combination of both informal and private care are relied upon. This suggests that there may be a complementary rather than substitutionary relationship between these 2 types of care.

#### 7.1.3. Summary of section 7.1

This section has expanded the previous analysis that used the AoN measure (developed in section 6.1) to explore the relationship between dependency and care receipt, by exploring how receiving care can determine the likelihood of receiving care from other sources. Analysis of concurrent care was additionally conducted using the PCA-derived measures of dependency, but the effects of care-on-care were almost the same so this analysis is not presented. The findings suggests that receipt of partner/child care remains the dominate source of support which may offer a direct substitute for the majority of care from other sources. In the absence of care from

within the family, other types of care may be seen to be complementary. Understanding the substitution between different types of care therefore requires accounting for differences in the types of support most often provided by informal, formal and private sources. Adopting this approach to considering concurrent care identifies the dynamics of care receipt in later life.

The analysis suggests that those receiving partner/child care are the least likely to receive other types of care, while receivers of formal care are the most likely to receive support from another source. As such, the degree to which different types of care directly substitute for one another is debatable as there is more likely to be a more complex relationship involving not just substitution from one care type to another, but also a supplementary/complementary relationship when different types of care occur together. In terms of formal care, it can be assumed that care from other sources could be considered supplementary, while non-family unpaid care and private care may be more directly interchangeable and thus may substitute for one another but remain complementary to other types of care. The dynamics of different types of care must be understood as more than a binary between 'substitution' or 'complement'.

# 7.2. Extending the exploration of substitution between informal and formal care

Litwin and Attias-Donfut (2009) considered aspects of substitution and explored the way care from people living in the same house affects the receipt of other care. Using data drawn from the SHARE study in France and Israel, they differentiate unpaid care provided by someone within the same household (most commonly a partner or child) from all care received from outside the household, including unpaid and professional care. As in other research using SHARE data, the classification of professional care conflates state-funded and privately paid care to a single type. As demonstrated throughout this thesis, formal care and private care vary in the types of help they provide and the common characteristics of the people who use them. By conflating formal and private care to a single professional care category, the differences that exist in the relationship between unpaid care and other types of care will remain obscured. Although their analysis is restricted because of this, their study provides a valid approach to considering other

aspects of substitution using ELSA, due to the comparability of the measures of dependency and care receipt collected in ELSA and studies within the SHARE group. This section of the thesis therefore replicates the original Litwin and Attias-Donfut (2009) study, but builds on their study by addressing a number of issues.

Firstly, the original study focused only on those aged 75+, excluding consideration of differences in care receipt between the relatively young and older. To broaden the scope of analysis, the replication study includes respondents aged 60+ with difficulties. Secondly, a central aspect of the original study is the differentiation between unpaid household and non-household care. This provides a way to directly assess the interchange between unpaid and formal care, by focusing on 2 different realms of unpaid care. The replication study undertaken also differentiates between household and non-household care, but additionally disentangles formal and private care, which were collectively classified as professional care in the original study. As has been shown throughout this thesis (and in section 7.1 in particular), the contexts in which formal and private care are received are different and are likely to respond differently to aspects of dependency. By classifying both care types within a single 'professional care' category, the original Litwin and Attias-Donfut (2009) study is flawed in that it cannot identify differences in the effect of household care on the receipt of two very different types of care. In light of this, a key distinction in the present study is the ability to differentiate formal and private care. Reframing the focus of the original Litwin and Attias-Donfut (2009) study, this section explores the effect of unpaid care received from household on care from non-household members and the receipt of formal rather than professional care, whereby private care is excluded from the analysis.

Finally, the explanatory variables used in the original study measure wealth, represented in quintiles, as an indicator of socioeconomic status. However, the wealth quintiles are computed only from the wealth of their subsample (aged 75+). As such, the quintiles do not reflect relative social status within the wider population, but rather relative wealth within a narrow subsample of older people aged 75+. As such, it seems to be unclear how their wealth quintiles represent

the structure of socio-economic status within the population. In order to address this concern, the replication study presented uses wealth quintiles based on relative wealth within the whole ELSA sample, and as such is more able to distinguish between those amongst the lowest and highest status groups, according to wealth.

The next section details the derivation of the new variables, and specifies the research questions that will be addressed.

#### 7.2.1. Identifying Household and Non-Household care

Following Litwin and Attias-Donfut (2009), indicators of unpaid household and non-household care are used to explore the relationship between informal and formal care in this analysis. Receipt of household care is derived from 2 aspects of ELSA. Firstly, co-residents are identified in ELSA using information on the composition of the household (i.e. who lives with each respondent and their relationship to others within the same household). Secondly, information on co-residents in conjunction with information on care from family and friends (as discussed in section 2.4.2) was used to derive indicators of whether care is received from a co-resident partner, from a co-resident child, and from any other person living in the same household. For example, someone living with a partner and receiving care from a partner is identified as receiving household partner care.

Similarly, someone living with a child and receiving help from a child is identified as receiving household child care. It is possible that those who have children both inside and outside the household could potentially be misclassified as receiving household child care, for example if they do in fact only receive care from a child not living with them. However, this approach assumes that where child care is identified that this is provided by a child living in the household if one is present. Finally, unpaid care from outside the household is confirmed if someone identifies a source of unpaid care not already identified as a household member. As in the rest of this thesis, formal care is classified as any formally provided health or social care, including care supplied by a local authority, health visitor or nurse (from Table 4).

As in prior analysis, the ELSA sample is restricted to respondents reporting at least one difficulty (Mobility, ADL or IADL), since respondents cannot receive care unless they have at least one of these difficulties. In order to present direct analysis across all relevant variables, cases with missing data for any of the relevant variables were excluded.

#### 7.2.2. Research questions

In the original study, three hypotheses were tested to examine whether substitution occurs between professional and informal care, whether there is an increased prevalence of professional care amongst those with increased ADL/IADL needs, and whether professional care is more likely to be received by children and other relatives who provide help than by spouse carers (Litwin and Attias-Donfut, 2009:76). As discussed, the conflation of formal and private care to a single category of professional care makes the interpretation of the relationship between unpaid and both formal and private care problematic. As such, the questions considered in the Litwin and Attias-Donfut study are refined in this replication study to better explore the relationship between household, non-household, and *formal* care. The questions considered are as follow:

- 1. Does formal care substitute for unpaid care?
- Is mixed formal and informal care more prevalent among persons with high levels of need?
- Are children and other family carers more likely to receive formal support than spouse carers?

In the original study, substitution is confirmed where the most common pattern of care is *either* formal *or* informal and rejected if the most common pattern of care is a combination of formal *and* informal care (Litwin and Attias-Donfut, 2009). As shown in Table 19, 76% of responses from those confirming care receive care from a partner or child, while only 7.6% receives formal care. Adopting their approach to identifying substitution is unsatisfactory due to the overwhelming majority of cases receiving only informal care. In order to answer the first question, this analysis therefore adopts a more appropriate test, focusing only on those receiving formal care, where

substitution is confirmed if a greater proportion of cases receive *only* formal care, rather than combinations of formal and unpaid care.

The second question will be addressed by examining whether combinations of formal and informal care are more prevalent among those with high ADL and IADL difficulties. Finally, the last question will be addressed by identifying whether those receiving care from a partner are more likely to receive formal care than those receiving other types of unpaid care. By differentiating between care from partners and children, this analysis expands the analysis of concurrent care presented in sections 7.1.

Replicating the structure of Litwin and Attias-Donfut (2009) to explore these questions, the analysis covers 3 stages. The first stage describes characteristics of the ELSA sample used in the analysis, presenting data from ELSA waves 1-4 individually to confirm the consistency of these measures across waves. The second stage uses bivariate cross-tabulation of patterns of care received from household members and unpaid non-household and formal sources. The last stage presents multinomial logistic regression analysis, which is undertaken to explore patterns of non-household care receipt. The dependent variable in this stage identifies receipt of care from non-household members, with the variables considered in sections 1 and 2 as explanatory variables.

#### 7.2.3. Sample characteristics

Table 56 shows the profile of the ELSA sample used in this analysis, presenting results for each wave separately to check consistency in the distribution of the variables of interest across waves.

From Table 56, the group aged 65-74 is the largest at 40% with around 10% in the oldest group and 20% in the youngest group. Around 60% of the sample is female, and slightly more than half of those in the sample are married or live with a partner. Around a quarter of respondents in each wave are in the poorest wealth quintile, compared to around 16% in the wealthiest

	ELSA – 2002		ELSA – 2004		ELSA – 2006		ELSA – 2008	
	n	%	n	%	n	%	n	%
AGE (group)								
Baseline $(60 - 64)$	906	19.3	798	19.4	752	20.3	1.006	23.2
Early (65 – 74)	1.983	42.2	1.667	40.5	1.405	37.9	1.767	40.8
Mid (75 – 84)	1,430	30.4	1,276	31.0	1,133	30.6	1,139	26.3
Late (85+)	379	8.1	380	9.2	417	11.2	419	9.7
GENDER			•				_	
Men	1 898	40.4	1 604	38.9	1 448	39.1	1 683	38.9
Women	2,800	59.6	2.517	61.1	2,259	60.9	2.648	61.1
	2,000	55.0	2,517	01.1	2,235	00.5	2,010	01.1
	2.440	45.4		47.0	4.046			40.0
NO	2,118	45.1	1,944	47.2	1,816	49.0	2,080	48.0
Yes (married/conabiting)	2,580	54.9	2,177	52.8	1,891	51.0	2,251	52.0
WEALTH							•	
1 – Low	1,191	25.4	985	23.9	874	23.6	1,009	23.3
2 –	1,004	21.4	884	21.5	773	20.9	905	20.9
3 –	957	20.4	813	19.7	783	21.1	879	20.3
4 -	808	17.2	776	18.8	702	18.9	842	19.4
5 – High	738	15.7	663	16.1	575	15.5	696	16.1
ADL								
None	2,924	62.2	2,601	63.1	2,375	64.1	2,823	65.2
One	894	19.0	784	19.0	685	18.5	803	18.5
Two or more	880	18.7	736	17.9	647	17.5	705	16.3
IADL								
None	3,049	64.9	2,611	63.4	2,414	65.1	2,847	65.7
One	823	17.5	742	18.0	609	16.4	760	17.5
Two or more	826	17.6	768	18.6	684	18.5	724	16.7
CARE (INE – HH member)								
No	3.602	76.7	2,922	70.9	2,966	80.0	3,231	74.6
Yes	1.096	23.3	1.199	29.1	741	20.0	1.100	25.4
	,		,	-			,	-
CARE (INF – OUTSIDE HH)	2 750	70.0	2.20	70.2	2 05 0	02 F	2 5 5 0	02.0
NO	3,750	79.9	3,208	79.3 20.7	5,058	82.5 17 5	3,550	82.0 19.0
163	542	20.1	633	20.7	049	17.5	701	18.0
CARE (FORMAL)								
No	4,525	96.3	3,987	96.7	3,590	96.8	4,180	96.5
Yes	173	3.7	134	3.3	117	3.2	151	3.5
N (sample size)	4,698	100.0	4,121	100.0	3,707	100.0	4,331	100.0

Table 56. Socio-demographic characteristics, functional health status, and care need, people aged 60+

Source: ELSA, waves 1-4

quintile. The larger group with low wealth in this subsample is likely due to the sample being restricted to those aged 60+, where excluded respondents aged 50-59 are likely to be on average wealthier than older respondents.

The majority of around 65% of respondents report no ADL or IADL difficulties. A small proportion of respondents receive formal care, and around 18% receive unpaid care from someone outside the household. The most common source of care is unpaid care provided by someone within the same household, and around a quarter of respondents receives this type of care.

#### 7.2.4. Bivariate associations: Care from outside the household and key variables

This section does not differentiate between ELSA waves, and presents tabulations based on the combined sample from waves 1 to 4 to explore differences in the care received from outside the household. To begin with, Table 57 shows the pattern of formal and informal care combinations from outside the home, by care from different household members. The source of care from within the household has been divided into 4 groups: those not receiving care from someone in the household, those receiving care from a partner, those receiving care from a child but not a partner, and those receiving care from any other person in the same household without also receiving care from a partner or child. The Litwin and Attias-Donfut (2009) study combined the 2 latter categories – those receiving care from a household member other than a partner – although this is likely necessitated by smaller sample sizes. The larger sample size of ELSA allows for differentiation between household care from partners, children, and other household members. Although there are only 39 cases where household care does not include care from a partner or child this provides some clarity to household care provision beyond that presented in the original study.

	Care received from a household member									
	None		Partner		Child <sup>1</sup>		Other <sup>2</sup>		Total	
Care received from outside household	n	%	n	%	n	%	n	%	n	%
None	10,018	78.8	3,022	82.5	340	78.3	26	66.7	13,406	79.5
Informal only	2,252	17.7	556	15.2	57	13.1	11	28.2	2,876	17.1
Formal only	156	1.2	44	1.2	26	6.0	0	0.0	226	1.3
Informal & Formal	295	2.3	41	1.1	11	2.5	2	5.1	349	2.1
Total	12,721	100.0	3,663	100.0	434	100.0	39	100.0	16,857	100.0

Table 57. Care received from within and without the household, persons aged 60 or more years

Significance of the four-by-four comparison:  $x^2$ =117.7 (9 degrees of freedom (df)) p<0.001

<sup>1</sup> not also receiving care from partner; <sup>2</sup> not receiving care from either partner or child Source: ELSA, waves 1-4 (2002 to 2008 – respondents with no missing data and reporting 1+ Mobility, ADL or IADL

difficulty)

#### 7.2.5. Household and non-household care

From Table 57, 21% of responses from people with a difficulty involve care from outside the home, with the majority receiving care from unpaid sources alone. Of the 3.5% who receive

formal care, the majority receive a combination of formal and unpaid non-household care. In terms of household care, 75% do not receive unpaid household care and 22% receive care from a partner. Of those receiving unpaid household care (4,136 cases), only 1% do not receive care from a partner or child.

A greater proportion of those receiving care from a partner do not receive any care from outside the household, while around  $1/3^{rd}$  of those receiving household care that does not include care from a partner or child also receive non-household care, although this group is very small.

There is a significant association between care received from a household member and the pattern of care received from outside the household.

Of the 4,136 responses identifying care from a household member, 3,388 (82%) receive neither formal nor informal care from outside the household, 624 (15%) additionally receive only informal care, 70 (1.7%) additionally receive formal care but do not receive non-household informal care, and the remaining 54 (1.3%) receive both formal and informal non-household care in addition to household care.

Summarising the patterns of household and non-household care received by respondents who receive *any* care:

- 44% receive care from a co-resident partner without additional non-household formal or informal care
- 33% receive only non-household informal care
- 8% receive non-household informal care in addition to care from a partner but no formal care
- 5% receive co-resident child care without additional household or non-household care
- 4% receive no household care but receive both formal and informal non-household care
- 2% receive formal care alone, without other household or non-household care
- 3.2% receive other combinations of care

#### 7.2.6. Key variables and patterns of non-household care

Table 58 presents the bivariate associations between the control variables and the pattern of care received from outside the household.

	Pattern of care received from outside of household								
	None		Informal only		Formal only		Both		X
	n	%	n	%	n	%	n	%	
AGE (group)									
Baseline (60 – 64)	3,040	87.8	395	11.4	13	0.4	14	0.4	
Early (65 – 74)	5,847	85.7	857	12.6	51	0.7	67	1.0	1,300***
Mid (75 – 84)	3,697	74.3	1,055	21.2	98	2.0	128	2.6	(9df)
Late (85+)	822	51.5	569	35.7	64	4.0	140	8.8	
GENDER									
Men	5,681	85.6	782	11.8	74	1.1	96	1.4	254***
Women	7,725	75.6	2,094	20.5	152	1.5	253	2.5	(3df)
PARTNER									
No	5,318	66.8	2,145	27.0	178	2.2	317	4.0	1,500***
Yes	8,088	90.9	731	8.2	48	0.5	32	0.4	(3df)
WEALTH									
1 – Low	2,671	65.8	1,095	27.0	112	2.8	181	4.5	
2 –	2,664	74.7	765	21.5	54	1.5	83	2.3	971***
3 –	2,885	84.1	469	13.7	33	1.0	45	1.3	(12df)
4 –	2,744	87.7	343	11.0	11	0.4	30	1.0	
5 – High	2,442	91.4	204	7.6	16	0.6	10	0.4	
ADL									
None	9,376	87.4	1,267	11.8	39	0.4	41	0.4	1,900***
One	2,387	75.4	659	20.8	52	1.6	68	2.1	(6df)
Two or more	1,643	55.4	950	32.0	135	4.5	240	8.1	
IADL									
None	10,113	92.6	775	7.1	21	0.2	12	0.1	4,200***
One	1,923	65.5	929	31.7	51	1.7	31	1.1	(6df)
Two or more	1,370	45.6	1,172	39.0	154	5.1	306	10.2	
N (sample size)	13,406	79.5	2,876	17.1	226	1.3	349	2.1	<u> </u>
6 FL 6 A									

Table 58. Patterns of non-household care, by background characteristics and functional health status

Source: ELSA, waves 1-4

All variables have significant associations with non-household care. To summarize the patterns from Table 58, older respondents are more likely to receive non-household care, as are women, those without a co-resident partner, those with lower wealth, and those with more ADL and IADL difficulties. These patterns of association are consistent for all patterns of care from outside the household.

#### 7.2.7. Modelling patterns of non-household care

Table 59 presents results from multinomial regression modelling the different patterns of nonhousehold care, to allow for the effects of household care, co-residence with a partner and other explanatory variables on the receipt of different patterns of non-household care. The reference category for the multinomial model is 'does not receive care from outside the household'. The individual reference categories (RF) for explanatory variables are shown alongside the relative

	Pattern of care received from outside of household								
	Informal only			Formal only			Formal and Informal		
	RRR 95% CI		RRR	95% CI		RRR	RR 95% CI		
Care from HH member RC - No Yes	0.49***	0.43	0.56	0.60**	0.42	0.84	0.24***	0.17	0.34
AGE (group) RC: (60 – 64) Early (65 – 74) Mid (75 – 84) Late (85+)	1.01 1.37 <sup>***</sup> 2.16 <sup>***</sup>	0.88 1.19 1.82	1.17 1.58 2.58	1.97 <sup>*</sup> 4.07 <sup>***</sup> 7.21 <sup>****</sup>	1.06 2.24 3.86	3.66 7.38 13.48	2.23 <sup>**</sup> 4.16 <sup>***</sup> 10.03 <sup>***</sup>	1.23 2.34 5.58	4.07 7.42 18.06
GENDER RC: Men Women	1.75***	1.58	1.94	1.33	0.99	1.80	1.45**	1.11	1.89
<b>PARTNER</b> RC: No Yes	0.47***	0.42	0.53	0.46***	0.31	0.67	0.31***	0.20	0.47
<b>WEALTH</b> RC: High 2 – 3 – 4 – 5 – Low	1.24 <sup>*</sup> 1.36 <sup>***</sup> 2.21 <sup>***</sup> 2.39 <sup>****</sup>	1.02 1.12 1.85 2.00	1.51 1.64 2.66 2.85	0.46 1.07 1.71 2.44 <sup>**</sup>	0.21 0.58 0.96 1.41	1.00 1.98 3.05 4.23	1.81 2.10 <sup>*</sup> 3.68 <sup>***</sup> 4.95 <sup>****</sup>	0.85 1.02 1.84 2.52	3.85 4.33 7.36 9.72
<b>ADL</b> RC: None One Two or more	1.12 1.47 <sup>***</sup>	0.99 1.29	1.27 1.68	2.17 <sup>**</sup> 4.37 <sup>***</sup>	1.40 2.90	3.37 6.58	2.08 <sup>**</sup> 5.15 <sup>***</sup>	1.37 3.53	3.16 7.50
<b>IADL</b> RC: None One Two or more	5.99 <sup>***</sup> 9.35 <sup>***</sup>	5.32 8.13	6.75 10.75	8.21 <sup>***</sup> 21.21 <sup>***</sup>	4.84 12.66	13.93 35.56	8.90 <sup>***</sup> 74.71 <sup>***</sup>	4.50 40.35	17.59 138.33

Notes: RC: reference category.

1. The reference category for the pattern of care received from outside the household is 'none'.

2. Pseudo R<sup>2</sup>= 0.27

3. Sample N: 16,857

Source: ELSA, waves 1-4

risk ratio and 95% confidence intervals (CI) for each explanatory variable. Relative risk ratio (RRR)

can be interpreted in the same way as odds ratios (UCLA, 2015), with the models compared to

the reference group, being the group who do not receive any unpaid household care. The effect

of explanatory variables represents the ratio increase/decrease in the likelihood of non-

household care from each source relative to the receipt of no non-household care, given other

explanatory variables in the model are held constant (UCLA, 2015).

#### 7.2.7.1. Discussion of multinomial regression on independent variables

There is a significant negative association between receiving household care and receipt of nonhousehold care, particularly combinations of formal and unpaid non-household care. Compared to those aged 60-64, the oldest old have a greater likelihood of receiving formal care, with or without additionally receiving unpaid non-household care, than receiving unpaid non-household care on its own. Women have a higher relative risk of unpaid non-household care although the risk of formal care alone is not statistically significant. Living with a partner makes all nonhousehold care less likely, with a slightly lower chance of both formal and unpaid non-household care. Compared to the wealthiest group, the poorest quintile have increased chances of nonhousehold care, with this group being around 5 times as likely to receive both formal and unpaid non-household care for those with ADL difficulties, although there is no statistically significant difference in the risk of non-household care that excludes formal care for those with a single ADL difficulty. Those with 2+ ADL difficulties have more than four times the chance of care including formal support. IADL difficulties dramatically increase the risk of non-household care, in particular the likelihood of receiving a combination of formal and unpaid non-household care.

#### 7.2.8. Discussion of findings

The analysis presented in this section looked at the relationship between care received from a someone living within the same household and care from any source outside the household. Using the Litwin and Attias-Donfut (2009) study as a framework to explore the relationship between household and non-household care, the analysis was conducted to explore 4 questions, which are addressed in turn.

#### 1. Does unpaid care substitute for formal care?

In order to identify substitution between formal and informal care, there would need to be a greater proportion of people receiving only formal care than a combination of formal and unpaid care. To determine whether formal care substitutes for unpaid care, this section considers the

different types of unpaid care received by those receiving formal care. Table 60 presents the

relevant information (previously shown within Table 58).

	Care received from a household member									
	None	Partner	Child <sup>1</sup>	Other <sup>2</sup>	Total					
Non-household care										
Informal & Formal	295	41	11	2	349					
Formal only	156	44	26	0	226					
Total	451	85	37	2	575					

#### Table 60. Formal care and unpaid non-household care, by household care receipt

Pearson x<sup>2</sup>=25.9 (3df) p<0.001

<sup>1</sup> not also receiving care from partner; <sup>2</sup> not receiving care from either partner or child

Source: ELSA, waves 1-4 (2002 to 2008 – respondents with no missing data and reporting 1+ Mobility, ADL or IADL difficulty)

Of those receiving formal care (575 cases), only 156 (27%) do not additionally receive some form of unpaid care. This confirms that, when disregarding the source of care, unpaid care represents a complement to, rather than a substitute for, formal care. Looking at the difference between household and non-household care more closely, of those receiving formal care without receiving unpaid household care (451 cases), more than half additionally receive unpaid nonhousehold care, suggesting formal care is complementary to purely non-household unpaid care. Of those receiving formal care without also receiving unpaid non-household care (226 cases), only 70 cases (31%) receive both formal and unpaid household care, suggesting formal care may actually substitute for purely household-based care. There are further differences depending on whether a combination of household and non-household care is received. For example, of those receiving child household care and formal care together (37 cases), the majority (70%) do not additionally receive non-household care. Of those receiving both partner care and formal care (85 cases), slightly more than half (52%) do not receive additional unpaid help from outside the household. This illustrates the importance of understanding the different contexts in which care occurs before the relationship between formal and unpaid care can be fully determined.

2. Is mixed formal and informal care more prevalent among persons with high levels of need?

This question was addressed by examining whether the proportion receiving a combination of both informal and formal care is greater for those with high rather than low ADL/IADL needs. This is clearly confirmed by the bivariate and multivariate analyses presented in Table 58 and Table 59, where those with 2+ difficulties have a markedly higher likelihood of receiving care from a combination of sources. This supports the previous analysis suggesting a complementary relationship between unpaid and formal care for those most likely to receive formal care

# 3. Are children and other family carers more likely to receive formal support than spouse carers?

Turning to the last question, looking at the differences in formal support between partners and other family care members, identified by greater formal support to children and other family members and partners having a lower likelihood of formal care receipt than other family members. Firstly, the bivariate analysis presented in Table 57 shows that 2.3% of those receiving care from a partner additionally receive care from formal services. By comparison, 8.5% of those receiving care from a child in the household also receive formal care, while around 5% of those receiving care from someone else within the household also receive care from formal services. This confirms care from partners is fundamental in providing help that might otherwise require formal services of some sort, demonstrating differences in patterns of formal care according to who the unpaid carer is. In particular, this demonstrates those receiving household care from a child are more likely to receive formal care exclusively, and care from a co-resident other than a partner or child is likely to be supplemented by non-household care.

#### 7.2.9. Summary of section 7.2

This section explored the relationship between the provision of care by household members and receipt of informal and formal support from outside the household, replicating a previous study conducted by Litwin and Attias-Donfut (2009). The analysis used a range of methods, including univariate and bivariate descriptive analysis, and multinomial logistic regression, finding that unpaid care tends to be complementary to formal care, while unpaid household care is more likely to substitute for other unpaid care, particularly from children. This analysis expands on previous analysis exploring the inter-relationship between patterns of formal and informal care provision. This analysis specifically addresses limitations within the original Litwin and Attias-Donfut (2009) study, making distinction between children and other household members, explicitly identifying formal care rather than using an aggregate professional care category, and focusing directly on the relationship between informal and formal care.

#### 7.3. Summary of chapter

Debates on the current and future provision of formal care services often portray formal services under increasing pressure as a direct result an ageing and increasingly dependent population. It is therefore of primary interest to understand the interaction between informal and formal care receipt. This section presented two approaches exploring how different types of care operate together. The analysis presented in section 7.1 explored the impact of receiving care from one source on receipt of care from other sources, finding direct substitution between care received from a partner or child, and all other types of care. The relationship between other types of care can be considered complementary, and sometimes supplementary, depending on the type of support provided. Section 7.2 expanded on the role of unpaid care at home, examining the impact of household and non-household care on formal care receipt. The analysis helpfully unpicks the different roles of partners and children in the provision of unpaid care, which have been considered together in the analysis presented in the previous chapters.

## Chapter 8 8. <u>Conclusions and Review</u>

#### 8.1. Reviewing progress against research aims

This thesis has provided a detailed analysis of the nature of dependency, considering a range of different methodological approaches to consider how dependency and need affect the types of care people receive in old age. The analysis has applied a combination of different analytical techniques including descriptive analysis and regression methods to ELSA data in order to meet the research aims set out in section 2.1. To summarise, the research aims were as follows:

- To illustrate the diversity of needs in later life as a result of functional mobility, ADL and IADL difficulties.
- 2. To provide a more nuanced understanding of the nature and characteristics of need using measures that capture the multi-dimensional nature of dependency.
- 3. To explore the relationship between multi-dimensional needs and the receipt of different types of care in later life.
- 4. To investigate the inter-relationship between different types of care, focusing on the substitution between informal and formal care

A key criticism when reviewing the literature surrounding the relationship between older people's needs and the care they receive was a reliance on binary indicators of ADL dependency, which might be considered more appropriate to differentiate those living in residential care settings (e.g. Pickard, 2008), a population expected to be more dependent. Studies applying these measures to older people living in the community without differentiating between the characteristics of different types of need, for example by conflating the effects of ADL and IADL needs to a single measure, are unlikely to capture how need is an outcome of the combinations of different difficulties older people experience, occurring across different domains of dependency. Without acknowledging this, the study of how different types of care respond to the needs of older people will be restricted by a lack of understanding of how less critical needs are met, and how changes in dependency may lead to a reliance on other types of care. To examine this further, the research presents a detailed yet more holistic multivariate approach to examining dependency as it occurs in later life, resulting from combinations of characteristically different needs.

#### 8.2. Contribution to field of research

The analysis presented in section 3.2 expands on previous studies, utilising the detailed information collected in ELSA, which provides a depth of information that is commonly unavailable in other research. Few recent quantitative studies have presented as detailed a picture of dependency, and the thesis adds to the work of Katz et al (1963) and Lawton and Brodie (1969), exploring the hierarchical structure of ADL and IADL needs. Jagger et al (2009) considered 13 different items that were used to explore the hierarchical structure of dependency. This thesis builds on their research, providing an in-depth descriptive analysis of ADL, IADL and mobility difficulties, which establishes a more detailed picture of the process by which particular needs accumulate in later life.

The thesis considers a number of approaches to examine the dimensionality of dependency. Chapter 4 considers the impact of adopting either more or less detailed measures of dependency. The analysis suggests when aggregating needs, as in the majority of studies within this field (e.g. Bolin, Lindgren and Lundborg, 2008; Bonsang, 2009), the benefits of parsimony in simpler models may obscure the more dynamic relationship between dependency and care. This work is therefore unique in this respect, but fits alongside the work of Vlachantoni et al (2015) and Breeze and Stafford (2010) in its exploration of the characteristics of those receiving different types of care in old age. A key contribution in this area is the consistent focus on different care outcomes, specifically the identification of the very task-specific nature of particular types of care, building on the work of Litwak (1985) and Vlachantoni et al (2011) in this respect.

Using the longitudinal structure of ELSA to consider the initiation of care receipt in response to changes a range of specific difficulties is an approach that has never been presented using ELSA. Studies with a similar structure, such as the analysis of transition into limitation incident (Zaninotto, Nazroo and Banks, 2010) and informal care-giving (Hirst, 2005; Rafnsson, Shankar

and Steptoe, 2015) represent complementary studies, although they focus on quite different aspects of dependency and care in later life.

Additionally, the thesis introduces a novel approach to measuring dependency, utilising a purpose built social care assessment tool – the Indicator of Relative Need – to develop an approximate measure in ELSA. This may be of interest to policy makers, since it was shown to be highly accurate in predicting formal care receipt, but the tool appears less suited to the application to more general needs of older people in the home. As such, the PCA-derived measures of dependency, developed in chapter 6.2, provide a more valid approach to measuring the needs of older people living at home. The use of PCA methods to reduce the dimensionality of a large number of binary variables is unconventional, particularly in this context, although a similar approach has been used by Nazroo, Zaninotto and Gjonça (2008). The analysis in this thesis expands the scope for the application of PCA-derived summary measures of dependency, particularly in the application to exploring care receipt in older people.

Finally, chapter 7 examines the relationship between different types of care using 2 approaches. Firstly, considering how receipt of care from one source may influence the receipt of care from other sources. Secondly, looking specifically at the way care from a co-resident affects the receipt of formal care and other types of unpaid care. There is a large body of literature looking at substitution between unpaid and formal care, and this thesis contributes to the wider field of research on substitution within European studies (Bolin, Lindgren and Lundborg, 2008; Bonsang, 2009; Gannon and Davin, 2010; Van Houtven and Norton, 2004). In particular, the analysis represents one of few studies looking at these issues from a UK perspective, for example Mentzakis, McNamee and Ryan (2009) and Pickard (2012), although these other studies adopt widely different approaches to consider this topic. Further, the replication of a previous study (Litwin and Attias-Donfut, 2009) could potentially be used as a means to undertake direct comparative analysis of informal and formal care receipt in different European contexts, and represents a valid use of the ELSA data for future research.

#### 8.3. Limitations of research

One of the central limitations of the research is the aggregation of unpaid care from partners and children to a single category of care. This was necessitated by space restrictions, whereby separating informal care into 3 separate groups (e.g. care from partners, children, and all other informal sources) would result in an unmanageable number of possible permutations of informal, private and formal care given the length of this thesis. As such, it was necessary to limit the scale of analysis using less detailed measures, although care from partners and children was considered separately in the analysis of chapter 7. It would be of interest to undertake further investigation, looking specifically to analyse care from partners and children separately, to further unpick how informal care responds to different dimensions of dependency, for example by using the AoN measure developed in this thesis.

Modelling the effect of changes in states of dependency on initial receipt of unpaid care provides a methodological approach to considering the causal path of dependency on care in later life. However, there were limitations in this analysis, the most notable being the exclusion of formal care due to very small numbers of cases receiving no care at baseline and receiving formal care at follow-up. This approach could potentially be expanded to explore transitions from informal to formal care, focusing on formal care use at follow-up by those already receiving unpaid care at baseline. However, this is likely to be problematic in the context of the simultaneity of care transitions.

The interdependent nature of different types of care is a key issue in attempting to unpick how older people make use of the care resources that are available to them. As such, a central limitation of this study remains the lack of engagement with the issues surrounding endogeneity bias informing the caring decisions of children. A common approach to dealing with this issue is to adopt a 2-part utilisation model, by specifying instrumental variables to capture the child's decision to care as a choice that maximises the overall utility to be gained (Pezzin, Kemper and Reschovsky, 1996; Van Houtven and Norton, 2004; Moudouni et al, 2012). There is potential to adopt a similar approach using ELSA, although information on children in ELSA is limited and

provides little information conventionally used in other studies, including information on the proximity between parent and child, and the demographic and economic characteristics of children.

However, Pezzin, Kemper and Reschovsky (1996) propose a two-stage model to estimate the family optimization problem, whereby the decision whether to care for a parent is determined by the optimal combination of the amount of unpaid care to provide given three alternative living arrangements: independent living, co-residence, and institutional care. In terms of the direct and indirect effects of formal care provision, their model estimates the change in informal hours (direct effects) and living arrangements (indirect effects), given a change in formal hours. They model an unobserved latent variable reflecting the value to an unpaid carer of choosing to provide an amount of care given a choice between living arrangements, where the value of each arrangement is hierarchically structured following its potential for providing additional assistance. They use two-step estimation ordered probit modelling to estimate the effect on informal care hours, conditional on living arrangement choices, where the amount of care is measured dependent on whether the parent lives independently or with the child. Further, they model this for children with married and unmarried dependents separately, since the presence of a partner significantly determines the need to seek other types of unpaid care.

It is possible to derive similar information in ELSA, including co-residence and household/nonhousehold care, following the design of the replication study presented in section 7.2. As such, there is scope to use a similar 2-stage instrumental variables approach using lagged variables to consider the interrelationship between unpaid and formal care more robustly. Further, using lagged measures would represent a more optimal use of the longitudinal design of ELSA, since the replication study was limited to cross-sectional analysis due to the panel structure of ELSA being inappropriate for the multinomial logit modelling approach adopted in the original study. Additionally, replicating the Litwin and Attias-Donfut (2009) study involved discounting the innovative approaches developed throughout the thesis, including the AoN measure and the PCA-derived domains of dependency, in favour of simple counts of ADL and IADL difficulties.

While this was to enable a direct comparison to be made with the original study, it would be interesting to extend the replication analysis to include the new measures developed here. Further, the replication analysis could also be extended in the future to allow consideration of the connections between household and private care, which was not possible here due to space limitations.

A final and important limitation of the thesis is the problem of the representative of the analysis, since the weights supplied within ELSA are not appropriate for the type of longitudinal analysis conducted in this study. Although preliminary exploratory analysis suggested that the unweighted analysis would remain representative of the wider English population, it would be helpful to investigate other methods to address this issue.

#### 8.4. Conclusions

The role of informal care in supporting the needs of older people is of central importance to the ongoing supply of formal care, and future increases in the elderly population are expected to place greater demands on unpaid carers in the very near future (Pickard et al, 2000). As such, there is a need for a more fluid picture of the relationship between dependency and need, which can accommodate the types of need that, although currently met by help from family and friends, may in the near future become an area of concern as unpaid care becomes increasingly necessary as the population ages. The thesis suggests that, when considering the dependency needs experienced by older people living in the community, it is important to be aware that this group includes people with a range of needs, both complex and less severe. In order to fully understand the dynamic relationship between dependency and the receipt of informal and formal care in the future, it will become necessary to use more appropriate measurements of dependency that are better suited to capturing how needs develop and affect older people living at home.

#### 8.5. Future Research directions

This thesis focuses explicitly on dependency and receipt of care for older people living in England, and is not representative of the UK as a whole. As such, there is potential for future

research to consider these questions in the broader UK context, including applying the IoRNframework to the other ELSA sister studies, including TILDA and NICOLA as they become available. Additionally, preliminary work for this thesis had originally considered using other studies, including the CFAS study, when developing an IoRN-based measure of dependency. This remains a potential avenue for further investigation, and it would be of interest to conduct comparative research using other studies, including working with CFAS, BHPS and GHS data, to widen the scope of the current study to explore the nature of dependency in old age across the UK.

As discussed when addressing the limitations of the thesis, the replication analysis presented in section 7.2 may provide scope for developing future research. For example, by adopting a twostep instrumental variable approach, following the studies of Van Houtven and Norton (2004) and Moudouni et al (2012), accounting for endogeneity bias in the exploration of the substitution between informal and formal care. As noted in section 8.3, the lack of detail on children's characteristics in ELSA makes the study by Pezzin, Kemper and Reschovsky (1996) a more appropriate basis for future analysis.

The analysis looking at the initiation of unpaid care could potentially be expanded to consider first receipt of formal care, although the challenge here would be the small numbers of cases receiving formal care. This is likely to make unpicking the way less common forms of care operate dynamically with other types of care particularly problematic. Further investigation would be necessary to identify if these challenges could be overcome using ELSA, or if other available data may provide means to explore these questions further.

Finally, this research extends previous research by going beyond simplified indicators of need, using a multivariate data reduction approach to account for the dimensionality of dependency. It is acknowledged by the author that an alternative, potentially interesting, methodological approach would be to take a latent variable or structural equation modelling approach to capturing an underlying concept of dependency. However, these methods are beyond the

existing research capability of the author, and depending on funding, could be a future avenue of research.

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