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UNIVERSITY OF SOUTHAMPTON

FACULTY OF BUSINESS, LAW AND ART

Southampton Business School

**The Use of Telecare to Support People with Dementia
to Remain Living in their own Homes**

by

Katherine Elizabeth Elliott Penny

Thesis for the degree of Doctor of Philosophy

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ABSTRACT

FACULTY OF BUSINESS, LAW AND ART

Southampton Business School

THE USE OF TELECARE TO SUPPORT PEOPLE WITH DEMENTIA TO REMAIN LIVING WITHIN THEIR OWN HOMES

Katherine Elizabeth Elliott Penny

There are currently 820,000 people in the United Kingdom living with dementia and around 670,000 partners, family members, and friends providing them with support. The behavioural disturbances and memory loss that typify dementia can make the role of caregiver extremely challenging. The consequent burden that many carers experience is closely associated with the care receiver's admission into institutional care. Due to the UK's ageing population, the number of people with dementia is set to rise to over one million by 2021. Consequently, the UK government is keen to explore different options to support carers, and to meet the increasing demand on care services. One such option is telecare, which uses information and communication technology to help manage the risks of community living for people with dementia, and to support care delivery.

This thesis presents a hybrid simulation model, TeleDem, which explores the influence of telecare on the number of people with dementia able to remain living in their own homes. Discrete Event Simulation (DES) is a widely used Operational Research (OR) tool for modelling complex stochastic systems, and its successful use in healthcare applications and care pathways has been well documented. The hybrid approach used in this thesis enhances the capability of DES by combining it with elements of Agent Based Simulation (ABS) in order to capture the complexity of this human centric system. Statecharts, a key component of ABS, are used to convert the passive entities associated with traditional DES into autonomous beings (or agents) whose behaviour is determined by their environment and their interactions with other elements of the system. In the TeleDem model these transformed entities are better equipped to reflect the human beings they represent; capturing each person's disease progression, level of dependency, and their informal carer's level of carer burden. These factors then govern the person's movement through the social care system. The TeleDem Simulation models the potential experiences of thousands of hypothetical telecare service users. This enables the exploration of a range of scenarios to inform planning decisions for the provision of telecare services for people with dementia.

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DECLARATION OF AUTHORSHIP

I, ***Katherine Elizabeth Elliott Penny***

declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

The Use of Telecare to Support People with Dementia to Remain Living in their own Homes.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission:

Signed:

Date:

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Dedicated to the memory of my wonderful parents

Elizabeth Ann Penny

2nd December 1938 – 7th September 2015

and

Michael James Benjafield Penny

27th April 1938 – 20th August 1998

Definitions and Abbreviations

A&E	Accident and Emergency
ABS	Agent Based Simulation
AD	Alzheimer's Disease
ISPOR	International Society for Pharmacoeconomics and Outcomes Research
ADL	Activity of Daily Living
AKTIVE	Advancing Knowledge of Telecare for Independence and Vitality in later life Project
ADCS – ADL	Alzheimer's Disease Cooperative Study Activities of Daily Living Inventory
APOE-E4	Apolipoprotein E
AT	Assistive Technology
ATT	Assistive Technology and Telecare
ATTILA	Assistive Technology and Telecare to maintain Independent Living At Home for People with Dementia
BHPS	British Household Survey
CIRCLE	Centre for International Research on Care, Labour and Equalities
CJD	Creutzfeldt-Jakob disease
CLC	Care Life Cycle Project
COPD	Chronic Obstructive Pulmonary Disorder
DES	Discrete Event Simulation
DS	Dependency Scale
ELA	Everyday Life Analysis
ELSA	English Longitudinal Study of Ageing
EPSRC	Engineering and Physical Sciences Research Centre
FAST	The Functional Assessment Staging
GDP	Gross Domestic Product
GHS	General Household Survey
GP	General Practitioner
GPCOG	General Practitioner Assessment of Cognition
GPS	Global Positioning System
HCC	Hampshire County Council
IADL	Instrumental Activity of Daily Living
ICD-10	10th revision of the International Statistical Classification of Diseases and Related Health Problems
ISPOR	International Society for Pharmacoeconomics and Outcomes Research
JIT	Joint Investment Team

MCI	Mild Cognitive Impairment
MCS	Monte Carlo Simulation
MMSE	Mini Mental State Exam
MRC CFAS	Medical Research Council Cognitive Function and Ageing Study
NAO	National Audit Office
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NMDA	N-Methyl-D-aspartat
NPI	Neuropsychiatric Inventory
ODOP	Opening Doors for Older People Initiative
ONS	Office of National Statistics
OR	Operational Research
PSSRU	Personal Social Services Research Unit
QALYs	Quality Adjusted Life Years
RCT	Randomised Control Trial
SCIE	Social Care Institute for Excellence
SD	Systems Dynamics
SIMUL8	DES modelling software
TECS	Technology Enabled Care Services Programme
UK	United Kingdom
UTOPIA	Using Telecare for Older People In Adult social care
WSD	Whole Systems Demonstrator
ZBI	Zarit Burden Inventory, also referred to as Zarit Burden Interview
6CIT	6-Item Cognitive Impairment Test

Chapter 1: Introduction

1.1 Aim of the Research

The aim of this research was to explore the impact of telecare services for people with dementia living at home through the application of Operational Research (OR) modelling techniques.

This work originally formed part of the Care Life Cycle (CLC) Project; a five-year multidisciplinary research programme funded by the Engineering and Physical Sciences Research Council (EPSRC) (2010-15, grant number EP/H021698/1).

This chapter sets out the context of the research, outlines the main areas of interest, sets out the research objectives and the research questions, and then considers the paradigmatic framework of the research. The chapter concludes with the ethical approval required for the work and an overview of the document structure.

1.2 Context of the Research

1.2.1 The Ageing Population

“Vastly improved life expectancy, one of the great triumphs of the last century, looks set to be one of great challenges of this one.” (Parliament UK, 2015)

Due to medical advances, improved housing and standards of living, better nutrition, and changes in the population's smoking habits, life expectancy in Britain has reached its highest level on record for both males and females (ONS, 2015a). However, improved mortality rates in old age, combined with sustained low fertility following the post war baby boom has resulted in an ageing population.

The 2011 census showed us that 9.2 million people (16% of the population) living in the United Kingdom (UK) were aged over 65 (ONS, 2013a). By 2035 it is projected that this figure will rise to 17 million accounting for 23 per cent of the total population (ONS, 2012). The fastest growth within the older population is expected among the 'oldest old' (those aged 85 and over) (ONS, 2012). Between 1985 and 2010 the number aged 85 and over more than doubled, rising from nearly 0.7 million to over 1.4 million by 2010 (ONS, 2012). The number of people aged 100 and over living in the UK rose by 72% over a decade to 14,450 in 2014 (ONS, 2015a). National Population Projections indicate that by mid-2039, more than 1 in 12 of the population will be aged 80 or over (ONS, 2015b).

These statistics represent a significant demographic shift in the UK's population; a shift that will result in an increased demand on health and social care services (Bardsley *et al.*, 2011). In particular these 'extra' years lived in old age are often experienced in a state of frailty, disability, and ill health (Victor, 2009). It is in this context that the EPSRC funded the 'Care Life Cycle (CLC): responding to the health and social care needs of an ageing society' programme of research.

The purpose of the CLC programme was to develop a suite of innovative modelling tools using quantitative survey data, qualitative case study data, and expert opinion. Topics of study have included linking health and social care for people with age-related sight loss by building a hybrid simulation model (Viana *et al.*, 2012), determining transitions into residential care in later life (Robards *et al.*, 2014; Vlachantoni *et al.*, 2016a), and exploring trajectories of informal care and health (Vlachantoni *et al.*, 2016b). The CLC worked with non-academic partners and policy stakeholders, with the aim of using these modelling tools and the results to better inform interventions and policy design within the field of health and social care. The research presented in this thesis contributes to the CLC project by examining the provision of telecare for meeting the social care needs of people with dementia.

A strength of this research, and the work of the CLC, is its interdisciplinary nature. This work brought together the disciplines of Gerontology and OR, and was therefore supervised by an interdisciplinary team. The supervisory team was comprised of: Professor Sally Brailsford, a Professor of Management Science at the Southampton Business School; Professor Maria Evandrou, the Director of the Centre for Research on Ageing; and Dr. Steffen Bayer, whose past research combines both qualitative research and OR modelling approaches, and includes an interest in home-based technology supported health delivery.

1.2.2 Dementia: Prevalence and Projections

People living for longer goes hand in hand with a rise in the prevalence of age related chronic diseases such as arthritis, diabetes, chronic heart failure, and dementia (Jagger *et al.*, 2007). Dementia is one of the major causes of disability and dependence amongst older people (Singh *et al.*, 2014). The term 'dementia' describes a group of progressive symptoms that occur when the brain becomes damaged by certain diseases or conditions including Alzheimer's disease, vascular dementia, dementia with Lewy Bodies, Picks disease, and Parkinson's disease dementia.

Alzheimer's disease is by far the most common cause of dementia, accounting for 62% of all cases (Prince *et al.*, 2014). Symptoms include memory loss, mood changes, problems with communication, confusion, and disorientation, leading to an increased dependency on other people and social care services. Figure 1.1 outlines a few key statistics relating to dementia in the UK.



Figure 1.1: Summary of UK Dementia Statistics (Murray *et al.*, 1999; Lakey, 2009; Charlesworth, 2010; Prince *et al.*, 2014)

Research indicates that 5% of people over the age of 65 years have some form of dementia, with the prevalence rising to around 20% for those over 80 years of age and one in three by 90 years (Liffe and Drennan, 2001). According to figures released in 2014 by the Alzheimer's Society there are 815,827 people with dementia living in the UK (Prince *et al.*, 2014). The number of people in the UK with dementia is forecast to increase to over one million by 2025 and over 2 million by 2051. This represents an increase of 40% over the next 12 years, and of 156% over the next 38 years (Prince *et al.*, 2014).

Luengo-Fernandez *et al.* reported in 2010 that the UK economy spends just over £23 billion every year providing dementia care, which is far more than is spent on any other single disorder, with cancer care only equating to £12 billion by comparison. Half of the

cost of dementia care, £12.4 billion per year¹, is met by informal carers (Luengo-Fernandez *et al.*, 2010). This figure is based on the estimated 1.5 billion hours of unpaid care provided by informal carers to people with dementia living in the community (Luengo-Fernandez *et al.*, 2010).

Informal care, which is defined by the Alzheimer's Society as: 'unpaid care provided by family members and friends', is the mainstay of dementia care in the UK (Knapp *et al.*, 2007). The Alzheimer's Society estimate that at least 670,000 people are acting as a primary carer for someone with dementia (Prince *et al.*, 2014). Looking after someone with dementia can be incredibly challenging; in the later stages of the disease it can literally be a 24 hour-a-day activity. As a result, informal carers often experience high levels of emotional and physical burden. It is therefore essential to find ways to offer support to enable carers to continue caring (Medical directorate and Nursing directorate, 2014).

Consequently, over the last two decades policy makers and care professionals throughout the UK have been looking for new ways to provide care, offering greater choice over care pathways, while containing costs. One such option that was proposed in the Department of Health's (2009a) Dementia Strategy was telecare.

1.2.3 Defining Telecare

The Scottish Government (2008) defines telecare as the:

“continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology to trigger human responses, or shut down equipment to prevent hazards.” (The Scottish Government, 2008, p. 1)

The term 'telecare' is often used interchangeably with 'assistive technology', 'telehealth', 'telemonitoring' and 'telemedicine', which can cause confusion for both researchers and service providers (Gibson *et al.*, 2016). It is therefore important for the purposes of this research to make clear distinctions regarding terminology; for instance, Assistive Technology (AT) is an umbrella term, which encompasses a broad array of equipment. AT can be defined as:

¹ *“Informal care costs are equivalent to the opportunity cost of unpaid care. This opportunity cost can be considered a measure of the amount of money that carers forgo to provide unpaid care for their spouses, friends or relatives suffering from dementia.”* (Luengo-Fernandez *et al.*, 2010, p. 13). *The hours of care are then valued based on the UK gender-specific average wage for employed carers, and the minimum wage for unemployed or retired carers.*

“Any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed.” (Royal Commission on Long Term Care, 1999, p. 1)

AT can range from simple items such as walking sticks or grab rails, to complex systems such as telecare or telehealth (Siotia and Simpson, 2008). Telecare is a subtype of AT and can be described as remote social care or monitoring (Bower *et al.*, 2011; Gibson *et al.*, 2016). On the other hand, telehealth, telemonitoring, and telemedicine are all concerned with the provision of remote health care; including the monitoring of acute or chronic conditions (Henderson *et al.*, 2013a), such as Chronic Obstructive Pulmonary Disease or Diabetes. Although reference is made to the broader term ‘assistive technology’ throughout this body of work, telecare forms the primary focus. Technologies concerning the delivery of health care are not explored in any further detail. The Royal College of Nursing describes telecare as follows:

“Telecare uses a combination of alarms, sensors and other equipment, usually in the home environment, to help people live more independently by monitoring for changes and warning the people themselves or raising an alert at a control centre. Examples of telecare devices include personal alarms, fall detectors, temperature extremes sensors, carbon monoxide detectors, flood detectors and gas detectors.” (Royal College of Nursing, 2017)

If tailored appropriately to the person’s needs, telecare can support the delivery of care at home for people with dementia. An automated medication dispenser that alerts a carer if tablets are missed; GPS technology that locates someone who may have become disorientated while away from their home; or a carbon monoxide detector that links to a gas shut off valve, reducing the risks associated with cooking, are all examples of telecare that can be used to support someone with dementia. This enables the person to remain within their familiar surroundings for as long as possible, helping them to enjoy a better quality of life for longer, while also providing invaluable support to their carers (Tunstall, 2014). It is also proposed that telecare can reduce care spending by delaying the need for residential care, preventing hospital re-admissions, and by helping care workers to efficiently manage their case load (O’Sullivan, 2011).

Consequently, telecare is a key feature of the UK’s policy discussion (Roulstone *et al.*, 2013b). Since the later 1990s, reference has been made to the technology in numerous strategic documents (Barlow *et al.*, 2005a), and a great number of pilot studies have been launched across the country in order to provide evidence for the large-scale roll-out of the technology. These small scale projects give us important insight into the potential of

telecare, yet they are limited in terms of what they can tell us about the impact of mainstream delivery (Bayer *et al.*, 2007).

In 2008, the Department of Health attempted to address this lack of evidence by launching the world's largest Randomised Control Trial (RCT) of telehealth and telecare. Entitled the Whole Systems Demonstrator (WSD) Programme, this large-scale RCT set out to examine the clinical and cost-effectiveness of telecare (Newman *et al.*, 2014). However, the results from the trial were inconclusive, with the Executive Summary of Findings highlighting issues with the trial design and also discussing the challenges of organisational barriers such as budgeting priorities, staff motivation, and inter-organisational care pathways, as significant limitations (Newman *et al.*, 2014).

Yet despite this continued gap in robust evidence, interest and investment from industry, government and research bodies remains high (Greenhalgh *et al.*, 2012); with UK health and social care policy continuing to focus on mainstreaming the technology.

1.2.4 Role of Modelling

Simulation modelling provides an opportunity for policy makers to explore the impact of the mainstream implementation of telecare for people with dementia. A model offers a simplified representation of a complex system in order to aid understanding and decision making. It allows us to test out different scenarios and experiment on the system under a range of conditions. Simulation in Operational Research (OR) encompasses a range of techniques including Discrete Event Simulation (DES), System Dynamics (SD), and Agent Based Simulation (ABS). DES and SD can make efficient use of small samples of observational data, providing insight into a complicated care system. Using a DES in combination with elements of ABS, such as statecharts, offers the potential for greater realism. It is within this context that this research chose to use hybrid simulation modelling to provide understanding of how telecare might impact care delivery for people with dementia.

1.3 Research Objective and Research Questions

1.3.1 Specific Objective

The specific objective of this research is to:

Design and build a hybrid simulation model combining Discrete Event Simulation with statecharts to examine the impact of telecare on a) the numbers of people with dementia able to remain living within their own homes rather than entering institutional care, and b) the ability of these patients' carers to cope.

1.3.2 Research Questions

1. *How can the use of statecharts enhance the capability of Discrete Event Simulation to effectively take into account the variability associated with the progression of dementia, and also the variation in the ability of carers to cope?*
2. *What are the advantages and disadvantages of using statecharts in addition to 'standard' DES for modelling patient care pathways?*
3. *What can simulation modelling show us regarding the impact of telecare on institutional care admissions for people with dementia?*
4. *Can OR modelling approaches help local authorities improve the way they plan services for people with dementia? And if so, how?*

1.4 Achieving the Research Objective

1.4.1 The Research Paradigm

A research paradigm, in its simplest terms, is a set of common beliefs that guide how a problem should be understood and investigated (Guba and Lincoln, 1994). In 1979 Burrell and Morgan published 'Sociological Paradigms and Organisational Analysis', in which they defined four paradigms as the basis for social research, 'Radical Humanist', 'Radical Structuralist', 'Interpretive', and 'Functionalist'.

Simulation modelling is a quantitative OR technique: it assumes that reality is objective and observable, with the focus on understanding society through modelling the relationships between different elements of the real world. In other words, simulation

modelling takes a positivist approach, and can therefore be identified as sitting within Burrell and Morgan's 'functionalist' paradigm. The functionalist paradigm is of highly pragmatic orientation, focussing on the understanding of society in a 'way which generates knowledge which can be put to good use' (Burrell and Morgan, 1979).

However, 'hard' quantitative OR techniques, such as simulation, are increasingly being combined with qualitative methods from the 'soft' (interpretivist) paradigm; for example: Sachdeva *et al.* (2007); Holm *et al.* (2013); and Tako and Kotiadis (2015). In its simplest terms, interpretivism is 'concerned with understanding social phenomena from the perspectives of those involved' (Edwards and Holland, 2013, p. 16); knowledge is generated through human interaction and negotiation. Interpretivism deploys a naturalistic approach to data collection, using techniques such as semi-structured or unstructured interviews, and observations.

Involving stakeholders in model development provides a range of benefits. It offers a more in-depth understanding of the area of study, and ensures that the design and structure of the model incorporate the relevant elements. It enables the modeller to identify domain experts who can then assist with model parameterisation in the absence of empirical data, and it also facilitates model validation (Blackett, 1950; Ackoff, 1979; Nutt, 1986; Harper and Pitt, 2004; Sachdeva *et al.*, 2007; Franco and Montibeller, 2010; Holm *et al.*, 2013; Kotiadis *et al.*, 2014; Tako and Kotiadis, 2015; Crowe *et al.*, 2017).

Furthermore, it has been argued that combining quantitative and qualitative OR methodologies for modelling care systems improves stakeholder acceptance and encourages implementation of results (Sachdeva *et al.*, 2007; Crowe *et al.*, 2017). Therefore, this thesis adopts a mixed-method approach, using qualitative stakeholder engagement activities to inform quantitative model building, as outlined in the following section.

1.4.2 Methodology

Chilcott *et al.* (2010) describes the model development process as six activities: understanding the decision problem, conceptual modelling, identification of information to inform the model, model implementation, model checking, and reporting. To achieve the research objective, this thesis addresses the six activities by following a mixed-method approach as outlined below.

1.4.2.1 Understanding the decision problem

The purpose of this stage of the process is to become immersed in the relevant research evidence in order to determine the broad scope of the model and to establish its purpose (Squires and Tappenden, 2011). To achieve this, the following steps were taken:

- Background research was carried out to ensure a clear understanding of dementia, its progression, and the impact the condition has on both the individual and their carers (see Chapter 2).
- A review was carried out exploring a broad range of sources, both within the academic and grey literature to understand the role of telecare for supporting people with dementia (as shown in Chapter 3).
- The OR literature was reviewed to explore previous applications of simulation in Health and Social Care (see Chapter 4). This assisted in the identification of hybrid-modelling as an appropriate simulation modelling approach.
- An 18-month scoping exercise was undertaken to engage with key stakeholders from within the dementia/telecare care pathway (see Chapter 5).

In parallel to the background research and literature review, the first 18 months of research for this thesis were also used as a scoping exercise to engage with key stakeholders, as defined in Section 5.1. Adopting a qualitative approach to understanding the structure of the system, by interviewing, observing, and consulting with key stakeholders, facilitated the modelling process. The initial phase of the stakeholder engagement process provided the opportunity to define, discuss, and explore the area of interest. This exercise built on previous work, examining the use of telecare with dementia for Hampshire County Council, carried out in 2009 for a Masters research project (Penny, 2009).

1.4.2.2 Conceptual modelling

A conceptual model is a simplified representation of a real system that is independent of the software in which the model will be implemented (Robinson, 2008). Building the conceptual model is an iterative process of review and refinement, as the key elements of the system are identified and conceptualised into a visual framework.

The stakeholder engagement enabled conceptual model building through the identification of domain experts who could inform the development and design of the model. They assisted with defining the scope of the model, its main objective, and the key elements to include. The details of this process are set out in Chapter 5.

1.4.2.3 Implementation of the model

Implementation of the model involves building the model in a computer program (Chilcott *et al.*, 2010). Once the conceptual model was finalised (see Section 6.4.2) it was used to inform the structure for the hybrid simulation model, which is referred to hereafter as the TeleDem Simulation (see Chapter 6). The TeleDem Simulation was implemented in the software, SIMUL8.

1.4.2.4 Identification of information to inform the modelling

Chilcott *et al.* (2010) suggest that this activity in model development is not a single step, but rather an ongoing process, as evidence can be used to understand, shape, and interpret all aspects of the model. The literature was explored and key papers were identified to populate the model. These papers are discussed in more detail in Chapter 7. Domain experts (see Figure 5.3) identified through the stakeholder engagement were consulted to help parameterise the model in the absence of empirical data.

1.4.2.5 Model Checking

This activity is concerned with whether the model is implemented correctly within the package of software (verification), and whether it accurately represents the real-world system (validation) (Anderson *et al.*, 2003). Once parameterised, the TeleDem Simulation was carefully verified (Chapter 6, Section 6.7) and validated to ensure it reflected the real-world system that it was designed to represent (Chapter 7, Section 7.16). Domain experts involved through the stakeholder engagement were also involved in the model structure and input validation.

1.4.2.6 Reporting

This final activity, described by Chilcott *et al.* (2010), relates to reporting the model results to decision makers. Once the TeleDem Simulation was built and validated, the model was used to run experiments and collect results (see Chapter 8). These results are explored and discussed in the concluding chapter of this thesis (Chapter 9), where they are used, alongside the background research and stakeholder engagement, to address the core objective of this research and answer the research questions.

1.4.3 The Modelling Framework

In order to create a visual framework to outline the process of building the TeleDem Simulation, Chilcott *et al.*'s (2010) six activities were broken down into nine steps,

describing the research tasks of this thesis (see Figure 1.2). For simplicity the nine steps are depicted sequentially, however the model building process is inherently more complex in practice, with feedback, review, and refinement forming key concepts, as highlighted in the previous sections. Nonetheless, the modelling framework provides a simplified guide, that is repeated throughout the thesis at the start of each chapter, to highlight the journey through the process.

Figure 1.3 illustrates how the steps within the modelling framework correspond to Chilcott *et al.*'s (2010) activities. It summarises the key research activities of this thesis, and highlights how this all links together as a research project to address the research questions.

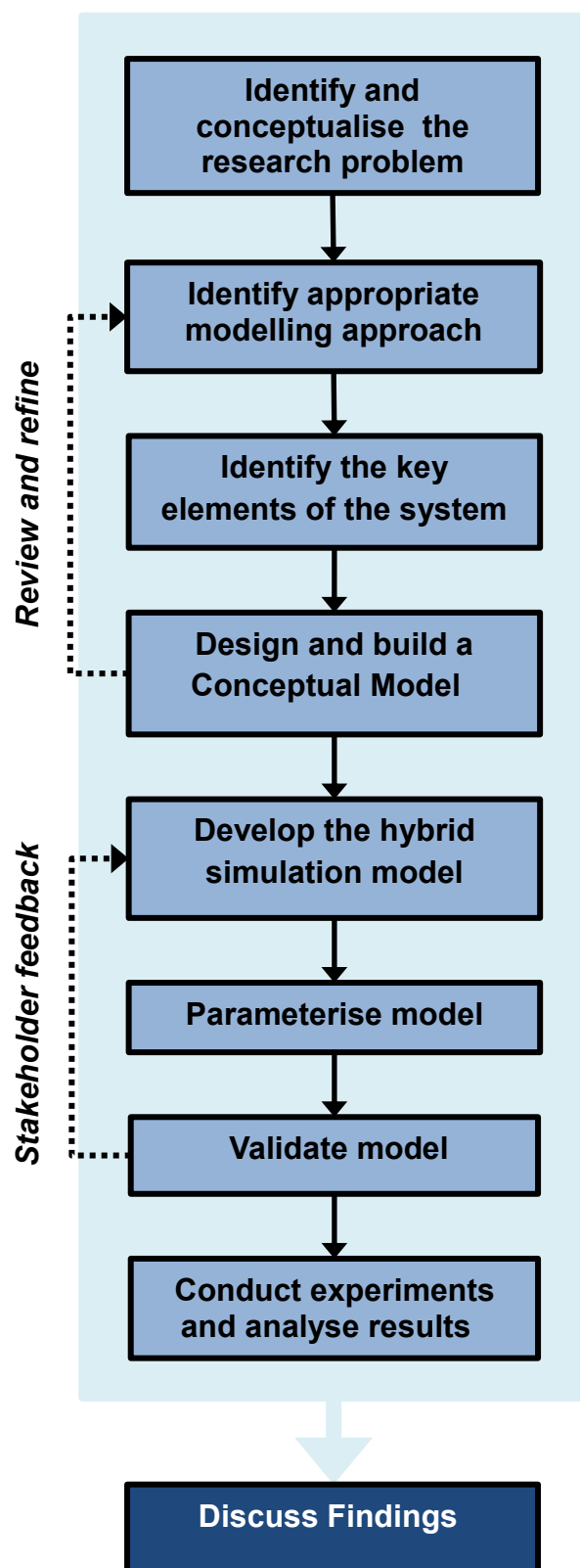


Figure 1.2: The Modelling Framework

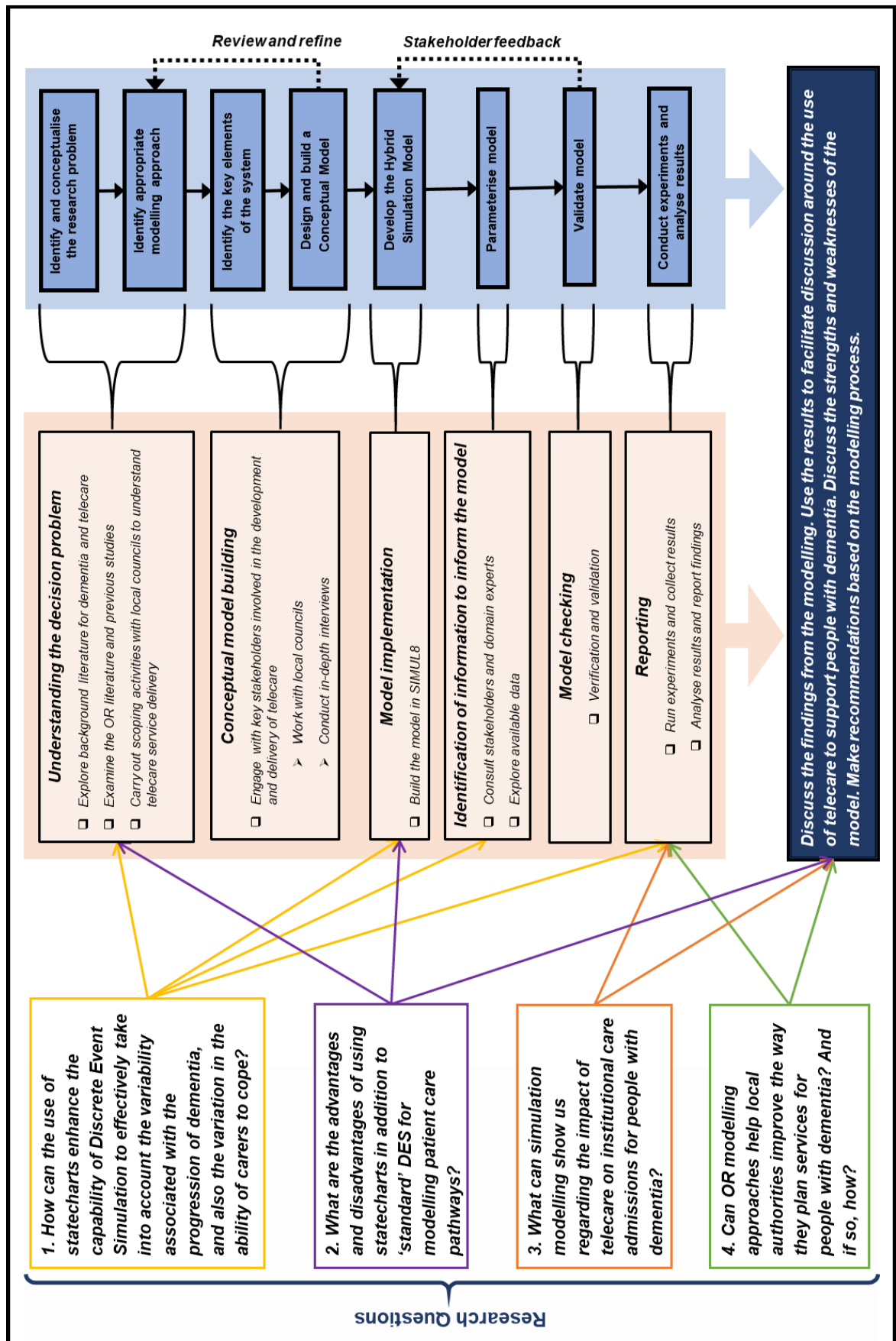


Figure 1.3: How the Research Questions will be Addressed

1.4.4 Ethical Approval

Ethical approval was required for the stakeholder engagement activities. This was obtained through the Ethics and Research Governance Online (ERGO) system at the University of Southampton (see Appendix 1 for the forms submitted and Appendix 2 for University Ethics Committee sign off). Approval was required because engaging with stakeholders included speaking to people with the early stages of dementia and their carers, as well as discussing telecare with various professionals involved in the development and delivery of the equipment.

Further ethical approval was obtained from Dorset County Council as the researcher attended 18 months of confidential meetings in which social care clients and their circumstances were discussed. Ethical approval was also sought in order to conduct an evaluation of a telecare pilot study as a means of data collection. Although the pilot was eventually redefined taking it beyond the scope of this research, the ethics approval did allow for access to a range of information that assisted in the development of the DES model. The necessary 'External Research Intention' forms were completed and submitted to Ann Harris, Senior Research Officer, Research & Service Planning Team, Commissioning & Contracts, County Hall, Dorchester, Dorset DT1 1XJ.

1.5 Thesis Structure

The following table (Table 1.1) provides an outline for how this thesis is structured. The table is followed by Figure 1.4, which maps the thesis structure to the modelling framework, showing which chapter addresses which step in the model building process.

Table 1.1: Outline of the Thesis Structure

Chapter Heading	Purpose of the Chapter
Chapter 1: Introduction	Introduces the work.
Chapter 2: Dementia	Provides contextual information regarding dementia, in terms of the forms it can take, the symptoms, prevalence, progression, and the economic and social costs. It also considers the role of informal carers and the impact of carer burden.
Chapter 3: The Role of Telecare in Meeting the Social Care Needs of People with Dementia	Offers an overview of telecare and how the equipment can support people with dementia. It then explores a brief history of telecare, along with the benefits and barriers to telecare identified through the various pilot studies conducted in this field. The chapter concludes by considering how the evidence gap for telecare may be addressed.
Chapter 4: Literature Review - OR Modelling in Health and Social Care	The main literature review of the thesis, examining previous examples of modelling applications in the fields of health and social care. The chapter also examines hybrid modelling and its potential. The chapter concludes by highlighting the scientific gap in the previous research that this thesis hopes to address, alongside a justification of the modelling approach selected.
Chapter 5: Stakeholder Engagement and Conceptual Model Building	Describes the activities undertaken to engage with stakeholders involved in the development and delivery of telecare. It describes the role of the stakeholder engagement in the development of the conceptual model.
Chapter 6: The TeleDem Simulation	Outlines the hybrid modelling methodology of the research. It describes how the TeleDem Simulation was developed from the conceptual model. It provides a detailed account of the model's key features and its architecture within the modelling software. The concluding section of the chapter explores model verification.
Chapter 7: Model Input Data	Provides an overview of how the TeleDem Simulation was parameterised. The sources that were used; the main assumptions that were made and, finally, how the model was validated.
Chapter 8: Results	Sets out the output from the TeleDem Simulation. The chapter explores a series of scenarios that the model was used to test and provides analysis of the results.
Chapter 9: Discussion and Conclusion	This chapter brings together the background research, evidence from the stakeholder engagement, and the results from the TeleDem Simulation to address the core objective of this research and answer the research questions. The chapter also makes recommendations based on the modelling process, discusses the limitations of this work, and makes recommendations for future work.

Source: Author's Work

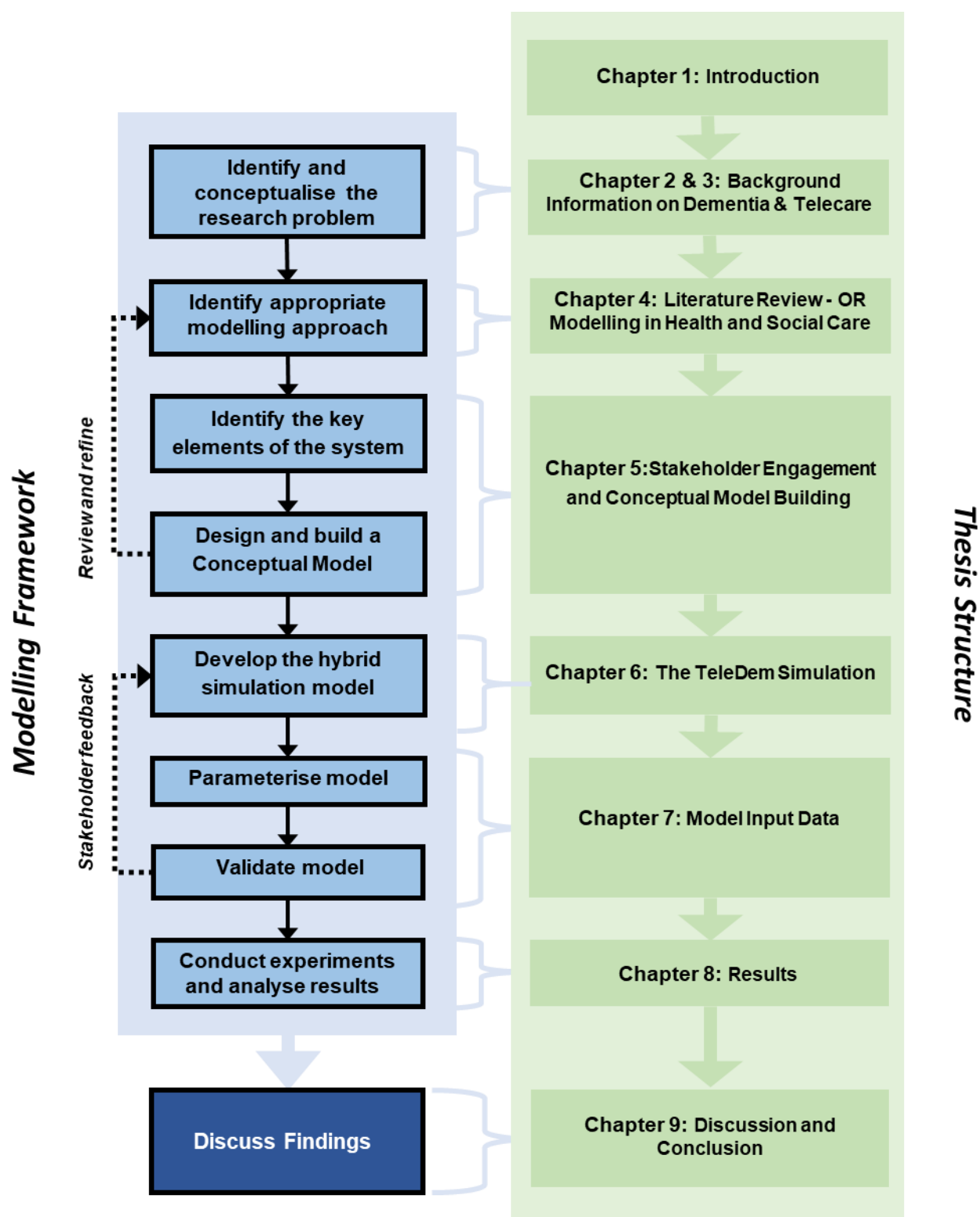


Figure 1.4: Linking the Thesis Chapters to the Modelling Framework

Chapter 2: Dementia

2.1 Chapter Overview

This chapter, alongside Chapter 3, addresses the first step in the modelling framework (Figure 2.1). Section 1.4.2.1, 'Understanding the decision problem', in Chapter 1, highlighted the importance of initiating the model building process by becoming immersed in the relevant research evidence. It was therefore necessary for the purposes of this research to develop an understanding of dementia in terms of the impact that it has on the individual and their carer.

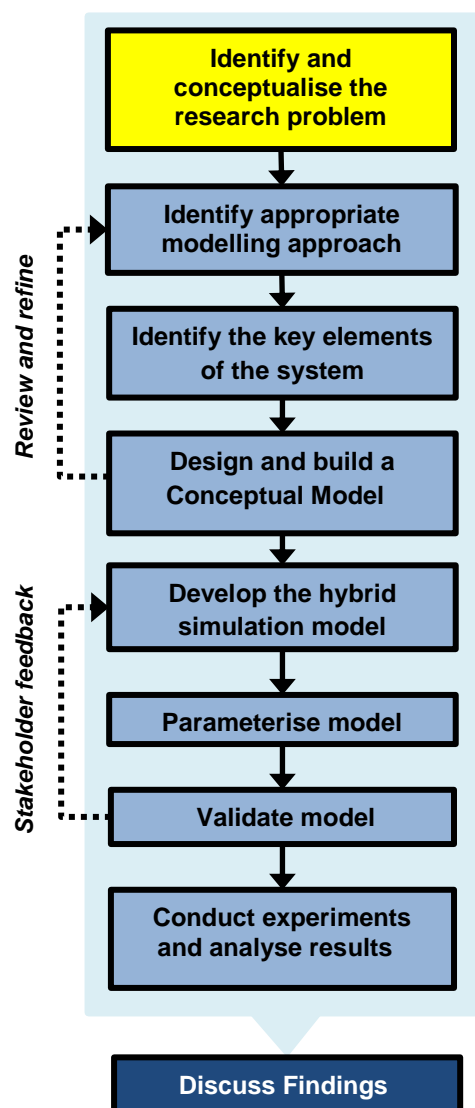


Figure 2.1: Addressing Part One of the Modelling Framework – Dementia Background

A broad range of literature was explored, including journal articles, book chapters, policy documents, and charity publications. Web of Science (a widely used citation indexing

service for peer reviewed journal content) and Google Scholar were the primary databases used to identify journal articles and book chapters. The search engine 'Google' was used to explore grey literature. The specific search terms used, and the key inclusion and exclusion criteria, are covered in each of the respective chapters.

This chapter focuses on the experience, treatment, and management of dementia. Search terms for finding the dementia related literature included 'dementia' or 'Alzheimer's disease', paired with one of the key areas of interest, for instance: 'symptoms', 'risk factors', 'diagnosis', 'physical health', 'treatment', 'progression', 'informal care', 'meeting care needs', 'cost', 'independence', and 'experience of'.

The chapter begins with a brief introduction to dementia, considering life expectancy and prevalence. It then examines the various conditions that cause dementia, the symptoms of the disease, risk factors, diagnosis, treatment, progression, how that progression is measured, and how the associated care needs are met. The chapter also explores the perspective of the informal carers who form the mainstay of British dementia care. The concept of carer burden is examined, along with its impact on admissions into institutional care. The next section considers the economic costs of dementia care in the UK, and the final two sections look at dementia from the person's perspective.

2.2 An Introduction to Dementia

'Dementia' is not a disease in itself, it is an umbrella term referring to a number of different diseases that cause a person to experience a similar set of symptoms (Moore, 2009). The International Classification of Diseases (ICD-10) describes dementia as follows (Figure 2.2).

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

Figure 2.2: The ICD-10 Definition of Dementia (World Health Organisation, 2016)

There are over 200 different diseases and conditions that can cause dementia, however many are very rare. Each subtype is characterised by variations in progression and subtle

differences in patterns of expression and neuropathology (Charlesworth, 2010). Figure 2.3 shows a pie chart of some of the most common subtypes of dementia.

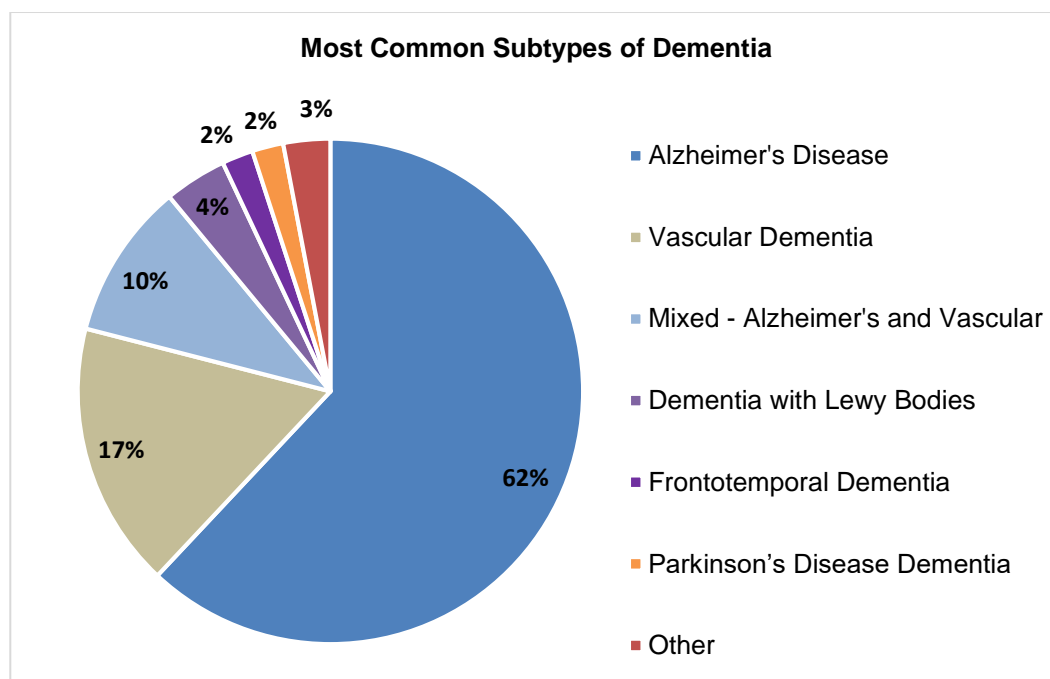


Figure 2.3: The Most Common Subtypes of Dementia (Prince *et al.*, 2014)

The pie chart shows that 89% of people with dementia have Alzheimer's disease (AD), vascular dementia or a combination of the two; with Alzheimer's alone accounting for more than half of all dementias. While the prevalence of Alzheimer's, vascular, and Lewys Bodies increase exponentially with age, frontotemporal dementia is commonly associated with young-onset dementia and is most often diagnosed between the ages of 45 and 65 (Prince *et al.*, 2014). Further information on some of the different types of dementia, the primary symptoms, and causes are further discussed in Appendix 3.

Life expectancy from the onset of dementia can vary by disease type; people with Alzheimer's disease, for example, typically live for eight to ten years after symptoms begin (Alzheimer's Society, 2017a). However, life expectancy will vary considerably depending on the person's age at onset. For instance, someone diagnosed at 70 may live up to ten years, whereas someone who is 90 at disease onset, will live, on average, for three years (Alzheimer's Society, 2017a). According to Knapp *et al.* (2007) dementia is responsible for around 60,000 deaths each year in the United Kingdom (UK). Data from the Office for National Statistics (ONS) shows that it is the UK's leading cause of death in women.

The Alzheimer's Society report 'Dementia UK: second edition' provided up-to-date prevalence and projection statistics for dementia in the UK (Prince *et al.*, 2014). The report showed that in 2013 there were 815,827 people in the UK living with dementia; a figure that is likely to double in the coming decades (Lakey *et al.*, 2012). Dementia is not an inevitable part of getting older; however the risk of developing dementia increases with age and differs by gender (see Table 2.1).

Table 2.1: Number of People with Dementia in the UK, by Age and Sex in 2013

Age in Years	Male	Female	Total
30-34	191	207	398
35-39	124	185	310
40-44	180	446	626
45-49	735	649	1,383
50-54	1,348	1,209	2,557
55-59	3,330	1,854	5,184
60-64	15,611	16,256	31,867
65-69	25,467	32,286	57,753
70-74	37,250	40,126	77,376
75-79	50,580	75,093	125,674
80-84	67,040	105,187	172,226
85-89	51,818	118,932	170,750
90-94	28,236	96,517	124,754
95+	6,681	38,288	44,969
Total	288,591	527,236	815,827

Source: Prince *et al.*, 2014

2.3 Symptoms

Dementia is chronic and progressive, resulting in deterioration in cognition, behaviour, and daily functioning. Symptoms can therefore be grouped by cognitive, behavioural, and motor functions; Table 2.2 demonstrates this categorisation.

Table 2.2 The Main Symptoms of Dementia

Cognitive	Behavioural	Motor
Decline in: <ul style="list-style-type: none"> ▪ General intellectual ability ▪ Memory ▪ Orientation ▪ Attention ▪ Language ▪ Apraxia ▪ Agnosia ▪ Construction ▪ Visio-spatial function 	<ul style="list-style-type: none"> ▪ Change of personality ▪ Depression ▪ Anxiety ▪ Apathy ▪ Restlessness/wandering ▪ Problems adjusting to day and night ▪ Hallucinations ▪ Delusions ▪ Aggression – physical and verbal ▪ Shouting/screaming/wailing ▪ Self-neglect leading to malnutrition ▪ Repetitive questioning ▪ Following someone around 	<ul style="list-style-type: none"> ▪ Muscle control deficit ▪ Rigidity, slowness ▪ Greater risk of falls ▪ Incontinence

Source: Bjørneby *et al.* (1999)

Some individuals may only experience a few of the symptoms; some symptoms, such as aggression, may be temporary, while others, such as memory loss, will deteriorate over time (Alzheimer's Society, 2016a).

2.4 Risk Factors for Dementia

The strongest known risk factor for dementia is age (Charlesworth, 2010; Hamblin *et al.*, 2013; Alzheimer's Society, 2017b); 45% of those over the age of 95 are living with dementia (Brayne *et al.*, 2006). Women are at a higher risk of developing Alzheimer's disease than men, especially at very old ages (Fratiglioni *et al.*, 1997). The condition is more prevalent among women, even when taking into account the higher longevity of women versus men. The reasons for this remain unclear (Alzheimer's Society, 2017b). In addition to age and gender, there are a range of other risk factors that have been subject to extensive scientific exploration, at times with conflicting results. These include genetic, psychological, and lifestyle elements (Charlesworth, 2010). Appendix 4 examines the risk factors in further detail.

2.5 Diagnosis

The UK's performance on diagnosis compares poorly with other countries. In the 2007 National Audit Office (NAO) publication, 'Improving services and support for people with dementia', it was also suggested that only around one-third of people with dementia in the

UK received a formal diagnosis over the course of their illness (National Audit Office, 2007). For those that do get diagnosed, it can be a long process. Findings from the 2004 'Facing Dementia Survey' showed that it typically took 32 months from first noticing symptoms for a person to receive a diagnosis of Alzheimer's disease; this was longer than France (24 months), Spain (18 months), Italy (14 months) or Germany (10 months) (National Audit Office, 2007).

Alzheimer's disease and dementia often remain undiagnosed until symptoms become moderate or severe (Bond *et al.*, 2005). This delay can be attributed to several factors; firstly it can be challenging, even for healthcare professionals, to distinguish the symptoms of early dementia from 'normal ageing' and 'mild cognitive impairment' (MCI). MCI refers to a situation where a person experiences minor problems with cognitive functions such as impaired memory or thinking, but not to an extent that impacts their daily life (Alzheimer's Society, 2016b). Only a third of people diagnosed with MCI will develop dementia, and some recover to a 'normal' state (Hamblin *et al.*, 2013).

Secondly, dementia in any form provokes a great deal of anxiety; consequently fear and denial of the disease might cause a delay in seeking a diagnosis (Bond *et al.*, 2005). Finally, a lack of information regarding possible treatments or supportive care options may postpone people seeking advice (Bond *et al.*, 2005).

Early diagnosis of dementia was a core aim of the 2009 National Dementia Strategy, published under the title, 'Living Well with Dementia' (Department of Health, 2009a). The paper highlighted that if a diagnosis is made too late, the person may no longer be in a position to make choices. Furthermore, the paper added that:

“Diagnoses are often made at a time of crisis²; a crisis that could potentially have been avoided if diagnosis had been made earlier.” (Department of Health, 2009a, p. 33)

Early and accurate diagnosis can be helpful, as it allows the person and their family to understand what is happening to them and to better prepare for the future (Graham and Warner, 2009). It means that they can have more control over their care by making decisions early on and putting plans in place. It also enables them to get access to appropriate support services and financial assistance. Furthermore, some people respond

² A crisis was described by Caplan (2011) as 'an obstacle that is insurmountable through customary methods of problems solving'. In the context of dementia care, that can relate to a range of factors, such as the person being unable to live alone; experiencing more falls; or a change in behaviour that puts them at risk, such as wandering away from home and becoming lost. It can also relate to informal care collapse, where the carer is no longer able to provide care due to increased carer burden; in other words, they have reached crisis point.

to treatments that can alleviate symptoms of dementia; early diagnosis means earlier access to these medications.

2.6 Dementia and Physical Health

Older people with dementia frequently have a number of co-morbidities (Bunn *et al.*, 2014). The ageing process naturally makes people more prone to physical conditions, however cognitive deterioration and loss of daily functioning can make the healthcare needs of people with dementia far more complex. Consequently, the progression of dementia puts people at increasing risk of emergency hospital admission (Toot *et al.*, 2013). People with dementia over the age of 65 currently occupy one in four acute hospital beds in the UK at any one time (Lakey, 2009).

In addition to the risks associated with co-existing diseases, reduced cognitive ability limits the capacity of a person with dementia to care for themselves, and therefore they are more prone to infections, malnutrition, dehydration, and falls (Rubenstein *et al.*, 1996; Burger *et al.*, 2000; Van Doorn *et al.*, 2003; Carter and Porell, 2005; Milisen *et al.*, 2007; Williams and Weatherhead, 2013; Marshall *et al.*, 2016). Four out of the five most common comorbidities that result in a hospital admission for someone with dementia are preventable: a fall, broken/fractured hip or hip replacement, urine infection, and chest infection (Scrutton and Brancati, 2016). Consequently, simple measures such as: closer monitoring and regular medication reviews, alongside increased support with nutrition and hydration, could reduce the frequency of potentially avoidable hospital admissions (Van Doorn *et al.*, 2003). Scrutton and Brancati (2016) stressed the importance of improving how comorbidities are prevented, diagnosed, treated, and managed for people with dementia in the UK. Comorbid conditions frequently go undiagnosed, yet they can cause a faster decline in daily functioning, reduced quality of life, and premature death (Scrutton and Brancati, 2016).

2.7 Treatment of Dementia

There is no cure for Alzheimer's disease or any other common type of dementia (Alzheimer's Society, 2016c). However, in the last 15 years, treatments have been developed to help manage the symptoms (Graham and Warner, 2009). There are two main types of medication used for Alzheimer's disease: acetylcholinesterase inhibitors, which are also known simply as 'cholinesterase inhibitors'; and NMDA receptor antagonists (such as Memantine) (Alzheimer's Society, 2016c). Cholinesterase inhibitors

(donepezil, rivastigmine and galantamine), currently represent the best available treatment for managing the symptoms of Alzheimer's disease (Getsios *et al.*, 2010). Unfortunately, some people experience no benefit from taking memantine or cholinesterase inhibitors, and it is not possible to predict who will and who will not benefit from them (Graham and Warner, 2009).

In some instances, if a person with dementia is experiencing challenging and disruptive behaviour, such as aggression or agitation, they may be prescribed antipsychotic drugs (Graham and Warner, 2009). There are gaps and contradictions within the evidence as to how frequently, and with what level of risk, these drugs are used (Banerjee, 2009). Some people do benefit from these medications, however for others, they can cause significant harm (Banerjee, 2009). The National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE) guidelines on dementia advises against the use of any antipsychotics 'unless the person is severely distressed or there is an immediate risk of harm to them or others' (NICE, 2015).

2.8 Progression and Increasing Dependency

A common simplification when describing the disease progression is to classify it into three worsening stages of: mild, moderate, and severe. In the later stages, as the structure and chemistry of the brain deteriorates, the symptoms for all types of dementia become progressively similar. Table 2.3 outlines the typical stages of dementia for Alzheimer's disease.

No two people are affected by their dementia in exactly the same way, the nature and rate of progression varies greatly between individuals (Musicco *et al.*, 2009; Thalhauser and Komarova, 2012; Alzheimer's Society, 2017a; Barocco *et al.*, 2017). Average disease progression is generally considered to be slower for Alzheimer's disease compared to other dementias, however durations have been reported to range from a few years to two decades (Mann *et al.*, 1992). Numerous papers have sought to identify correlations between rate of decline and a broad range of factors including: age at onset, gender, educational level, co-morbidities, and genetic factors. However, the findings are often inconclusive, and at times, contradictory; for instance diabetes mellitus has been found to both increase and decrease the speed of progression in Alzheimer's disease (Barocco *et al.*, 2017).

Table 2.3: The Stages of Alzheimer's Disease

Stage	Characteristic Symptoms
Early Stage: Mild	<p>The onset of Alzheimer's is often gradual, so frequently goes undetected as initial symptoms may be mistakenly attributed to stress, bereavement, or dismissed as a normal process of ageing. Someone with Alzheimer's may:</p> <ul style="list-style-type: none"> ▪ mislay items around the house ▪ forget recent conversations or events ▪ struggle to find the right words or lose the thread of what is being said ▪ become slower at grasping new ideas ▪ become unwilling to try out new things ▪ become confused or lose track of the day or date; leading to missing appointments or not paying bills ▪ show poor judgement, or find it harder to plan or make decisions ▪ have problems judging distance or seeing objects in three dimensions ▪ become more withdrawn, losing interest in other people or activities ▪ become increasingly reliant on others for keeping appointments, managing finances, or medications.
Middle Stage: Moderate	<p>As the dementia progresses it will become increasingly clear that the person needs help with managing day-to-day tasks which will impact on their ability to live independently. This can give rise to changes in behaviour often through frustration, the person may become easily angry, aggressive, or upset and they may begin to lose their confidence. Someone with moderate Alzheimer's may:</p> <ul style="list-style-type: none"> • struggle with household tasks such as preparing meals and cleaning • need frequent reminders or assistance to eat, wash, dress and use the toilet • become increasingly forgetful, forgetting recent events, names of family members and close friends, which can often result in repetitive questioning • become easily disorientated and confused about where they are • leave the house with a sense of purpose, and then become lost, often referred to as 'wandering' or 'purposeful walking'. This behaviour often leads to an increased risk of personal injury. • become confused by the concept of 'night' and 'day', which then impacts sleep • behave in ways that may seem unusual, such as going outside in their nightclothes, becoming very agitated or unknowingly behaving in socially inappropriate ways • experience difficulty with perception and, in some cases, having delusions or, less often, hallucinations • increased risk from falls • reduced capacity to care for themselves, which means that they are more prone to infections, malnutrition and dehydration
Late Stage: Severe	<p>In this stage the person will become completely dependent on others for their physical care. Loss of memory may become very pronounced, with the person unable to recognise familiar objects, surroundings or even those closest to them, although there may be sudden flashes of recognition. The person may also become increasingly weak. They may start to shuffle or walk unsteadily, eventually spending more time in bed or a wheelchair. Other symptoms may include:</p> <ul style="list-style-type: none"> • difficulty eating and, sometimes, swallowing • considerable weight loss, although some people eat too much and put on weight • incontinence - losing control of their bladder and sometimes their bowels • great difficulty with communication, though the person may repeat a few words or cry out from time to time.
Final Stage	<p>At this stage the person will be unable to speak or move properly; they lose the ability to respond to their environment or communicate. Speech may be limited to single words or phrases that may not make sense. They require assistance with eating and drinking and they may struggle to swallow.</p>

Source: Adapted from Alzheimer's Society (2017a), Spackman et al., (2013), and Graham and Warner (2009)

2.8.1 Measuring Progression

There are a range of clinical scales available to measure the progression of dementia, examples of which are shown in Table 2.4 .

Table 2.4: Clinical Scales for Measuring Disease Progression in Dementia

Measure	Description	Examples of Clinical Scales
Neuropsychological Decline	Neuropsychological measures look at cognitive decline. The Mini Mental State Examination is the most widely used measure of cognitive function (Burns <i>et al.</i> , 2004). The test has a maximum score of 30 points, with questions relating to memory, orientation to time and place, attention, and language (Burns <i>et al.</i> , 2004). An MMSE score of 25-21 is associated with mild dementia, 20-11 for moderate and 10-0 for severe (Pernecky <i>et al.</i> , 2006).	Blessed Dementia Scale (Blessed <i>et al.</i> , 1968) Abbreviated Mental Test (AMT) (Hodkinson, 1972) Mini Mental State Examination (MMSE) (Folstein <i>et al.</i> , 1975).
Functional Decline	Measures of functional decline look at the person's ability to complete activities of daily living (ADL), which can range from instrumental (IADL) to basic (BADL). IADLs include: <ul style="list-style-type: none"> • Housework • Preparing meals • Taking medications as prescribed • Managing money • Shopping for clothes or food • Communication (telephone) • Transportation within the community Whereas BADLs focus on the more fundamental daily tasks, such as: <ul style="list-style-type: none"> • Eating • Bathing • Dressing • Toileting • Transferring (walking) • Continence 	Katz Index of ADL (Katz <i>et al.</i> , 1963) Functional Assessment Staging (FAST) (Reisberg, 1988) Cleveland Scale for Activities of Daily Living (Patterson <i>et al.</i> , 1992) Alzheimer's Disease Cooperative Study Activities of Daily Living Inventory (ADCS-ADL) (Galasko <i>et al.</i> , 1997).
Neuropsychiatric Features	Scales for neuropsychiatric features are widely used to measure the impact of drug interventions. They assess behavioural disturbances; for instance the Neuropsychiatric Inventory assesses for delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability, apathy, and abnormal motor behaviour (Burns <i>et al.</i> , 2004).	Behavioural symptoms in Alzheimer's disease: phenomenology and treatment (BEHAVE-AD) (Reisberg <i>et al.</i> , 1987). Neuropsychiatric Inventory (NPI) (Cummings <i>et al.</i> , 1994).

Global Assessments	<p>Global Assessments describe severity of dementia in broad terms; they can be useful for looking at a population and measuring change (Burns <i>et al.</i>, 2004).</p> <p>The Clinical Dementia Rating (CDR) has previously been described as the gold standard of global ratings of dementia in trials of patients with Alzheimer's disease (Burns <i>et al.</i>, 2004). It uses six domains, assessing: memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care. However, dependence as a measure of progression has been gaining increased attention across the academic literature.</p> <p>The Dependence Scale (DS) (Stern <i>et al.</i>, 1994) is a 13-item questionnaire, which is completed by the primary caregiver. It ranges from relatively subtle needs, such as requiring reminders or advice, to more fundamental forms, such as needing to be fed. In some cases, the need is only for supervision, without any specific tasks linked to the need. The total DS score is the sum of the scores on all 13 items and can range from zero, meaning not dependent at all, to 15, which would indicate a patient is fully dependent (Zhu <i>et al.</i>, 2008). Lenderking <i>et al.</i> (2013) found the DS to be a 'reliable, valid, and interpretable measure of dependence associated with AD' (Lenderking <i>et al.</i>, 2013, p. 738).</p>	<p>Dementia Rating Scale (Lawson <i>et al.</i>, 1977).</p> <p>Global Deterioration Scale (Reisberg <i>et al.</i>, 1982).</p> <p>Clinical Dementia Rating (CDR) (Hughes <i>et al.</i>, 1982).</p> <p>Dependence Scale (DS) (Stern <i>et al.</i>, 1994).</p>
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Sources: Various (see text for specific references)

2.8.2 Dependency as a Measure of Progression

Decline in Alzheimer's disease can be gradual, and therefore 'it can be difficult to identify clinical milestones that signal disease advancement' (Kahle-Wroblewski *et al.*, 2015, p. 115). Many studies focus on a single aspect, such as cognition, when considering disease progression (Jones *et al.*, 2015). However, by only focussing on a single factor, important aspects may be insufficiently addressed. Global Assessments attempt to tackle this by taking a more holistic approach. The Dependence Scale (DS) (Stern *et al.*, 1994), for instance, is a global assessment that measures the progression of dementia by the person's need for assistance.

Research has shown that increasing levels of dependence correlate with a decline in cognition (Sarazin *et al.*, 2005; Spackman *et al.*, 2013; Jones *et al.*, 2015; Kahle-Wroblewski *et al.*, 2015); an increase in behavioural disturbance (Tun *et al.*, 2007; Spackman *et al.*, 2013; Jones *et al.*, 2015; Kahle-Wroblewski *et al.*, 2015); a decline in

physical functioning (Brickman *et al.*, 2002; Spackman *et al.*, 2013; Jones *et al.*, 2015); a decline in patient quality of life (Samus *et al.*, 2006; Jones *et al.*, 2015); an increase in resource use (McLaughlin *et al.*, 2009; Jones *et al.*, 2015; Kahle-Wroblewski *et al.*, 2015); and an increase in caregiver burden (Zhu *et al.*, 2008; Lenderking *et al.*, 2013; Jones *et al.*, 2015; Kahle-Wroblewski *et al.*, 2015). It has therefore been suggested that the construct of 'dependence' 'might be a more simple measure to explain the multifaceted disease progression of AD and convey the increasing need for care' (Spackman *et al.*, 2013, p. 1).

Kahle-Wroblewski *et al.* (2015) explored the concept of dependence by mapping the Alzheimer's Disease Cooperative Study Activities of Daily Living Inventory (ADCS-ADL) items onto the DS levels of dependence. They began their study by categorising the ADCS-ADL questionnaire (see Appendix 5) into 4 subgroups as shown in Figure 2.4.

Basic Activities of Daily Living (BADL)	Instrumental Activities of Daily Living (IADL)	
Q1 (Eating)	Q7 (Telephone)	
Q2 (Walking)	Q8 (Television)	
Q3 (Toilet)	Q9 (Conversation)	
Q4 (Bathing)	Q10 (Dishes)	
Q5 (Grooming)	Q11 (Belongings)	
Q6A (Clothing)	Q12 (Drink)	
Q6B (Dressing)	Q13 (Cooking)	
	Q14 (Litter)	
	Q15 (Travel)	
	Q16A (Shop)	
	Q16B (Pay)	
	Q17 (Appointments)	
	Q18 (Alone)	
	Q19 (Current)	
	Q20 (Read)	
	Q21 (Write)	
	Q22 (Hobbies)	
	Q23 (Appliances)	

KEY: Sub-Groups

- Household Activities
- Basic Activities Sub-Domain
- Outdoor Activities Sub-Domain
- Communications Sub-Domain

Figure 2.4: ADCS-ADL Questionnaire Categorised into Four Sub-groups (Kahle-Wroblewski *et al.*, 2015, p. 117)

The categorisation of the ADCS-ADL questionnaire was then used to assist in defining unique levels of dependency, see Table 2.5. Kahle-Wroblewski *et al.* used data from the Geras³ Study (referred to hereafter as GERAS), an 18-month observational cohort study looking at the routine care of 1,497 community living people with Alzheimer's disease and their caregivers in France, Germany, and the UK. Further details on study design and methods for GERAS can be found in Wimo *et al.* (2013).

³ The name Geras is not an acronym, it is taken from the Greek god of old age: Geras (the origin or the terms geriatric and gerontology) and has been capitalised inadvertently within the academic literature. It is therefore commonly referred to as the GERAS study or simply as GERAS (Catherine Reed, 2017, personal communication, 6th December 2017).

Table 2.5: Types of Impairment, Relevant ADCS-ADL Questions and Corresponding Care Need Assigned to Level of Dependence

Level of Dependence	Types of Impairments	ADCS-ADL Questions	Care Needs
0	No IADL/BADL impairment	No impairments in ADCS-ADL	None
1	Some supervision needed on isolated IADLs.	You would expect to see one item requiring supervision from the following clusters: Household activities, Communication and engagement, or Outdoor activities.	Independent living with check-ins
2	Supervision on multiple IADLs	You would expect to see at least two items requiring supervision or assistance from the following clusters: Household Activities, Communication and Engagement, or Outdoor Activities, OR complete loss of one Household Activity.	Limited/informal home care services
3	Supervision on all types of IADLs or home-bound	You would expect to see all items requiring supervision for: Household activities, Communication and engagement, or Outdoor activities. Possibly some supervision required for: <ul style="list-style-type: none"> • Q4 – Bathing • Q1 – Eating 	Extensive home care services with supervision or Assisted living
4	Supervision on some BADLs	In addition to the previous requirements, you would expect to see supervision or assistance required for: <ul style="list-style-type: none"> • Q6B – Dressing • Q5 – Grooming • Q4 – Bathing • Q3 – Toileting • Q1 – Eating 	Assisted living and nursing support
5	Impaired transfer OR complete incontinence	In addition to requiring support with all other ADLs, support also required for Walking (Q2) and Toileting (Q3)	Nursing home

Source: Kahle-Wroblewski et al. (2015, p. 116–117)

Kahle-Wroblewski *et al.*'s aim was to provide a useful way of staging disease progression, identifying six discrete levels of dependency associated with dementia advancement. They also assessed cognitive function, behavioural symptoms, caregiver burden, and cost. Summary statistics for Kahle-Wroblewski *et al.*'s (2015) work are included in Appendix 6. Their findings were consistent with those of previous studies (Zhu *et al.*, 2008; Lenderking *et al.*, 2013; Jones *et al.*, 2015) and demonstrated that levels of dependence are an informative way of defining milestones.

A key element to note from Kahle-Wroblewski *et al.*'s (2015) work outlined in Table 2.5, is the increasing emphasis on supervision over the course of disease progression.

Supporting someone with dementia goes beyond assisting with practical household tasks and personal care; as the disease progresses, a significant amount of carer time is dedicated to supervision in order to manage the risks of day to day life. Wimo *et al.* (2002) found that 14% of informal carer's time was spent assisting with ADLs, 35% was spent assisting with IADLs, and 51% was dedicated to supervision/surveillance.

Caro *et al.* (2002) described patients as fully dependent on their carer when they required more than 12 hours of supervision per day. Caro *et al.* (2002), studied data for 1,287 individuals with Alzheimer's disease and their carers. Like the work of Kahle-Wroblewski *et al.* (2015), people were assigned to one of six levels of dependency, with level zero representing independence, and level five the highest level of dependence. They found that 46% of their cohort were assigned to dependency levels 3 or higher. For this group, 80% required 12 hours or more of supervision.

2.9 Meeting Care Needs

The previous section of this chapter highlighted that people with dementia require increasing levels of support and supervision as their condition deteriorates. At disease onset, people with dementia are often cared for at home, supported in performing activities of daily living by family and friends (Wübker *et al.*, 2015). However, as dementia advances into the severe stages, care at home may no longer be possible as the person's care needs become too great, and the burden experienced by the person's carer becomes overwhelming. At this point many people with dementia require care in a long-term institutional setting (Yaffe *et al.*, 2002). The following sections explore the role of informal carers, community care services, and institutional care settings in meeting the care needs of people with dementia.

2.9.1 Informal Care in the UK

For the purposes of this thesis an 'informal carer' is defined as any person, such as a spouse, other family member, friend, or neighbour, who provides ongoing assistance to the person with dementia in a non-professional capacity. This definition excludes instances where only financial support is provided to the recipient (Beesley, 2006). Other publications have used the terms 'caregiver', 'carer', or 'unpaid carer' in the same context.

Informal care provided by family members and friends is the backbone of dementia care in the UK (Knapp *et al.*, 2007). According to Prince *et al.* (2014), there are 670,000 people in the UK providing unpaid care for people with dementia, outstripping social care services and private care providers combined. Luengo-Fernandez *et al.* (2010) estimate that informal carers in the UK provided 1.5 billion hours of unpaid care for people with dementia in 2008. They also indicated that approximately 34% of the hours were supplied by economically active individuals. The pressure placed upon informal carers has increased as society has become more focused on community-based support over providing care in an institutional setting.

“This shift towards a greater reliance on home-based care is due in part to the recognition by governments that most patients who require care with ADLs and IADLs wish to remain at home for as long as possible, but also because many governments have relied on informal caregiving as a relatively inexpensive means of relieving spending pressures in their health care systems.” (Moise *et al.*, 2004, p. 34)

Research has consistently shown that women are more likely to be carers than men (Arber and Ginn, 1995; Glaser *et al.*, 2003; Vlachantoni, 2010); this was corroborated by findings from the 2011 Census, which revealed that 58% of informal carers in the UK in 2011 were female, and 42% were male (ONS, 2013b). In 2000 it was estimated that 16% of people over the age of 65 were providing some form of care; this age group also made up 28% of carers providing 20 hours or more care each week (Beesley, 2006). Many informal carers supporting people with dementia are older themselves, physically frail, and have health conditions of their own (Farina *et al.*, 2017). The responsibility of most day-to-day care tends to be associated with one family member: a spouse, daughter, daughter-in-law, son, other relative, or nonrelative, in that order of likelihood (Aneshensel *et al.*, 1995; O’Rourke and Tuokko, 2000).

According to Vlachantoni (2010), who used the English Longitudinal Study of Ageing (ELSA) to examine different characteristics and caring patterns of carers aged over 50 in England, one fifth of carers provide around the clock care. Vlachantoni, (2010) found that:

“Men and women were equally likely to care round-the-clock, and the majority of these carers looked after their spouse/partner. However, women were more likely to be round-the-clock carers at a younger age and to be looking after parents/parents-in-law or children/grandchildren, while men were more likely to be round-the-clock carers at older ages and to be looking after their spouse/partner.” (Vlachantoni, 2010, p. 21)

The ELSA dataset, which includes over 10,000 respondents, showed that more than three quarters of carers were married, and two fifths of all carers lived with the person they cared for. Vlachantoni (2010), found that marital status was an important determinant for women, who were likely to care for longer hours across all the older ages. Whereas men were more likely to care in older ages for their spouse or partner (Vlachantoni, 2010).

Fifty percent of people with dementia living in the community receive over 35 hours of informal care a week (Murray *et al.*, 1999). Informal carers are a vital resource, and without them the formal care system in the UK would collapse. It is therefore a national policy priority to provide informal carers with adequate support (Farina *et al.*, 2017).

In 2014, the Office of Health Economics produced a report entitled, 'The Trajectory of Dementia in the UK' on behalf of Alzheimer's Research UK. The report estimated that for the ratio of carers to dementia care recipients to remain stable over the coming years, the number of informal carers would have to more than double to 1.7 million by 2050 (Lewis *et al.*, 2014). However, this ratio is unlikely to remain stable; the ageing population, smaller family sizes, fragmentation of traditional family networks, increased geographic mobility, and changes in labour force participation (Moise *et al.*, 2004; Comas-Herrera *et al.*, 2007), have all contributed to an emerging 'informal care gap' (Pickard, 2015). Consequently, any projections made in relation to the future costs of long-term care are sensitive to assumptions made regarding the future supply of informal care (Knapp *et al.*, 2007).

2.9.1.1 The Social Cost of Caring: Carer Burden

Caring for someone with dementia extends beyond day to day hands-on support; it includes 'anticipating future support needs, monitoring and supervising, preserving the individual's sense of self, and helping the individual to develop new and valued roles' (Farina *et al.*, 2017, p. 2). Caring for someone with dementia can be exceedingly challenging. Agitation, aggression, and a lack of awareness of their own condition, can make someone with dementia resistant to accepting support (Murray *et al.*, 1999).

Although many carers gain satisfaction from their role, there are also many negative aspects of care giving (Knapp *et al.*, 2007). Caring for an individual with dementia can often be a prolonged and difficult job, which can eventually impact the carer's wellbeing (Lliffe and Drennan, 2001; Hamblin *et al.*, 2013). There have been numerous studies that have looked at the impact of caring on carers. Carers can experience feelings of anger, worry and guilt; physical exhaustion; depression; emotional burnout; marital stress; financial hardship and social isolation', as a consequence of their role (Zarit *et al.*, 1985;

Black and Almeida, 2004; Gaugler *et al.*, 2004; Gort *et al.*, 2007; Razani *et al.*, 2009; Charlesworth, 2010).

As dementia progresses, the role of an informal carer can become particularly difficult, as symptoms worsen and challenging behaviours develop. Carers must learn to adjust to increasingly challenging symptoms, such as sleep disturbance, faecal incontinence, aggression, wandering, and personality change. Hamblin *et al.* (2013) point out that although for some individuals, 'physical capabilities may remain intact, cognitive decline means eventually sufferers may be unable to recognise their carer' (p. 22); this can be particularly distressing for the person's loved ones. Moise *et al.* (2004) suggest that carers of people with dementia experience greater levels of burden when compared to carers of people with physical disabilities, as caring for someone with dementia requires continual vigilance.

“There will come a point where the patient will need constant surveillance due to problems such as wandering and behavioural problems that are extremely taxing for carers, such that care can no longer be provided at home.” (Moise *et al.*, 2004, p. 62)

Razani *et al.* (2007) examined 34 individuals with mild dementia and their carers; they identified significant correlations between informant-based ADL measures and Caregiver Burden Inventory (CBI) scores. In other words, they found deterioration in day to day functional abilities increased carer burden. They therefore concluded that ADL abilities of individuals with dementia can predict carer burden and psychological distress. Kahle-Wroblewski *et al.* (2015) made a similar link when comparing Zarit Burden Inventory (ZBI)⁴ scores relative to level of dependency. Their analysis showed that burden associated with providing care for a person with Alzheimer's disease at dependency level 3 was 38.5% greater than the level of burden experienced by carers of people at level 2. Equally, carer time spent on supervision and assisting with ADLs was 2.39 times greater in level 3 than level 2 (Kahle-Wroblewski *et al.*, 2015).

Ory *et al.* (1999) examined data from the 1996 National Caregiver Survey, which looked at more than 1,500 carers. They reported that informal carers for people with dementia spend significantly more hours per week providing care than non-dementia carers. They

⁴ The Zarit Burden Inventory, is the most widely used assessment for burden experienced by carers of people with dementia (Hébert *et al.*, 2000). It originated as a 29-item questionnaire and was developed by Zarit *et al.* in 1980. The revised version contains 22 items and consists of a self-reported questionnaire that includes questions on carer stress, time available for self, and impact of duties on carer's social life. Responses are recorded as a frequency of occurrence on a 5-point scale ranging from 0 (never) to 4 (nearly always). The ZBI total score has a range of 0-88, with higher scores indicating greater burden (Burns *et al.*, 2004).

also found that dementia caregivers experience greater impacts on their ability to remain employed, greater levels of strain, mental and physical health problems, a decrease in time spent with other family members and enjoying leisure activities, and increased family conflict (Ory *et al.*, 1999). A qualitative study of carers by Vellone *et al.* (2012) found that carer's felt that their quality of life would improve if they could have more time for themselves, away from the person they provide care for.

Evidence suggests that informal carers are more likely to experience poor health as a consequence of their caring role (Morris *et al.*, 1988; Moise *et al.*, 2004; Yeandle *et al.*, 2006). Kiecolt-Glaser *et al.*, (1991) indicated that spousal carers of people with progressive dementia, particularly Alzheimer's disease, suffer from overwhelming burden, isolation, depression, and physical illness. These findings were echoed in Schneider *et al.* (1999). Morris *et al.* (1988) indicated that the way relationships are altered due to cognitive decline has a particularly significant impact on incidence of depression amongst carers of people with dementia. Grief over the immediate care giving responsibilities and the anticipated loss of a loved one can further contribute to experiences of depression (Dempsey and Baago, 1998).

Murray *et al.* (1999) interviewed 20 co-resident spouses of people with probable Alzheimer's disease. Their results showed that the most commonly expressed difficulties experienced by the spousal carers, included: loss of companionship due to the decline in quality of communication, loss of reciprocity due to growing dependency, and deterioration in their partner's social behaviour (Murray *et al.*, 1999). The paper also reported carer satisfaction, stemming from: companionship, mutual affection, continued reciprocity, feelings of job satisfaction, and fulfilment of a sense of duty.

A systematic review carried out in 2017 of the factors associated with the quality of life (QOL) of family carers of people with dementia, identified 909 relevant abstracts (Farina *et al.*, 2017). From this extensive body of literature, 41 papers met the inclusion criteria of the review and were selected for further analysis. They found there was no strong evidence to suggest that the demographic characteristics of either the carer or the person with dementia, such as age, gender, marital status, or level of education, impacted on carer QOL. However, seven papers reported a correlation between increasing functional impairment and decreasing carer QOL (Clark and Bond, 2000; Serrano-Aguilar *et al.*, 2006; Novelli *et al.*, 2010; Bruvik *et al.*, 2012; Conde-Sala *et al.*, 2013; Schifczyk *et al.*, 2013; Nogueira *et al.*, 2015). Furthermore, the review found that all studies which compared subjective carer burden (typically measured by the ZBI) to carer QOL, reported a negative association.

It is therefore unsurprising that carer burden has consistently been shown to be one of the main predictors of institutional care admission for people with dementia (Colerick and George, 1986; Zarit *et al.*, 1986; Lieberman and Kramer, 1991; Nygaard, 1991; Aneshensel *et al.*, 1993; Cohen *et al.*, 1993; Gold *et al.*, 1995; Hébert *et al.*, 2001; Gort *et al.*, 2007; Charlesworth, 2010). Hébert *et al.*, (2000) found that the severity of dementia, level of carer burden, the need for constant supervision, cohabiting, and the use of two or more home care services were all correlated with desire to institutionalise. They concluded their paper by highlighting the importance of measuring carer burden and depressive mood, as both factors are 'amenable to modification through targeted interventions' (p. 698).

Studies of interventions that have targeted informal carers have shown positive outcomes for both the person with dementia and their carer in terms of reduced carer burden and delayed admissions to institutional care (Mittelman *et al.*, 2006; Andrén and Elmståhl, 2008; Tremont *et al.*, 2008; Dowd *et al.*, 2018). It is therefore of paramount importance to identify and explore possible ways of supporting informal carers (Dowd *et al.*, 2018). 'Systems and services should work to maximise carer health and support their independence while still caring' (Farina *et al.*, 2007. p. 7).

2.9.1.2 The Financial Cost to Informal Carers

In addition to the impact that caring can have on a person's mental and physical wellbeing, the economic impacts must be considered. Glendinning (1992) explored the costs of care within the household by studying 30 carers and the people they cared for. Glendinning (1992) indicated that caring costs invariably exceed the income and resources of the individual. House and furniture adaptations, specialist equipment, substitute care if they were working, and regular household upkeep can require additional financial contributions. Informal carers have been found to use their own savings, borrow money, or cut back on their own spending to cover the cost of care (Glendinning, 1992). Based on a survey of nearly 4,000 carers, Carer's UK (2013a) found that one in ten carers had used up all of their savings to pay basic bills, 44% of carers were in debt, 19% were unable to afford their rent or mortgage repayments, and 45% were cutting back on essentials like food or heating.

Furthermore, carers have reduced opportunities to work and earn an income. Berecki-Gisolf *et al.* (2008) stated that 'caring for a frail, ill or disabled person was followed by a decrease in labour force participation' (P.127). Berecki-Gisolf *et al.* (2008) also refer to the interplay between the impact of caring on carer health, and how poor health status can

then reduce labour force participation, which is particularly notable for older people and women (Cai and Kalb, 2006).

Ory *et al.* (1999) found that a higher percentage of carers for people with dementia reported problems relating to employment complications when compared to non-dementia caregivers. They found that dementia carers reported 'having to take less demanding jobs, having to take early retirement, turning down promotion, losing job benefits, and having to give up work entirely' (Ory *et al.*, 1999, p. 181). Evandrou (1995) distinguished between 'sole', 'joint', and 'peripheral' carers, suggesting that while all groups had lower incomes than non-carers, sole carers incur the greatest losses. Evandrou (1995) found that people who provide 20 or more hours per week of informal care earn 25% less than employed non-carers. More recently, King and Pickard (2013) suggested that employment can be negatively affected, even when carers are providing lower intensity hours. They studied the impact of caring on employment in midlife by carrying out a longitudinal analysis of the first four waves of the English Longitudinal Study of Ageing (ELSA). The study showed that both men and women, aged between 50 and state pension age who start providing care for 10 or more hours a week are significantly less likely to remain in employment one wave later, than those who do not provide care (King and Pickard, 2013).

Evandrou and Glaser (2003) used work and caring history information from the British Family and Working Lives Survey (1994/5) to examine the impact of caring on employment and pension provision. They found that among women aged between 45 and 59, one fifth stopped work entirely and another fifth reduced their working hours in order to take on caring responsibilities. They found that, on average, carers retired eight years earlier than their counterparts, which not only diminished their income, but also limited their pension contributions (Evandrou and Glaser, 2003). It is estimated that lost income through informal care equates to £690 million, which in turn means a loss of £123 million in taxes paid to the Exchequer (Knapp *et al.*, 2007).

Over the last two decades the needs of carers have been increasingly recognised by policy makers, with Carers Strategies developed across the UK to improve recognition and support for carers. 'Helping carers to combine caring responsibilities with paid work is becoming a key policy objective' (Colombo *et al.*, 2011, p. 85).

2.9.2 Community Care Services

Formal community care services and institutional care begin to take a more prominent role in care provision as the person's dementia progresses (Moise *et al.*, 2004).

“Patients in the intermediate to late stages of dementia require full support with ADLs, requiring more professional care giving and, almost inevitably, admission to a long-term care institution.” (Moise *et al.*, 2004, p. 39)

Community care can be provided with or without the involvement of informal carers (Moise *et al.*, 2004). There are many different services available to help bridge the gap between informal care and institutional care. The Alzheimer’s Society’s 2011 publication, ‘Support. Stay. Save’ (Quince, 2011), reported a broad range of services accessed by people with dementia and their informal carers. These included: respite services⁵; support groups; home adaptations; support with household tasks, such as cleaning, shopping, and gardening; and physiotherapy, in addition to support provided by care workers to assist with personal care, such as cooking, bathing, toileting, or getting dressed (Quince, 2011).

Scherer *et al.* (2008) examined the relationship between level of dependence in Alzheimer’s disease and the acquisition of support to assist with dressing, toileting, bathing, cooking, and companionship. Their study was based on 300 observations from 75 participants based across three sites in America. Unsurprisingly, they found the uptake of formal support increased substantially when the total dependence score was in the moderate to severe range (Scherer *et al.*, 2008).

Social care in the UK, unlike the NHS, is not free at the point of delivery, instead it is means tested, so anyone with wealth or assets equating to more than £23,250, will be asked to contribute or pay in full for services they receive (NHS Choices, 2015). Furthermore, the demand for care outstrips the available funding, therefore people with higher levels of need take priority. However, from April 2020, the £23,350 threshold will increase alongside the introduction of the cap on care costs, so more people will be eligible for support (NHS Choices, 2015).

2.9.3 Institutional Care

Agüero-Torres *et al.* (2001) reported that dementia is the main cause of admission into institutional care amongst people aged over 65 years. According to Smith *et al.* (2000) around 90 % of people with dementia enter a form of institutional care before death. The late stages of dementia require ‘continuous care, rendering it almost impossible to provide adequate care at home’ (Moise *et al.*, 2004, p. 42). People with dementia who live alone

⁵ Respite care is defined by Moise *et al.* (2004, p. 36) as the provision of ‘appropriate and temporary care or supervision of functionally impaired persons to enable the care giver to maintain his/her provision of assistance to the person’.

are likely to move into institutional care earlier, as it is challenging to provide overnight supervision in the community (Draper, 2013). However, in the late stage of dementia, the person's level of care need is likely to be too great to be met by informal care, regardless of whether they cohabit (Moise *et al.*, 2004).

According to the Alzheimer's Society, in 2014 38.7% (311,730) of people with late-onset dementia were living in an institutional care setting, either residential care or nursing home; while 61.3% (493,639) were living in the community (Prince *et al.*, 2014). They estimated that only 5% of people with dementia living in the community had severe dementia (Prince *et al.*, 2014).

2.9.4 Delaying Institutional Care

There are both social and economic advantages to supporting people with dementia in the community for as long as possible (Dowd *et al.*, 2018). Jing *et al.* (2016) found that people with dementia who were supported at home experienced a higher quality of life than those in institutional settings. Furthermore, numerous studies have associated institutional placement with both accelerated cognitive decline in people with AD (Wilson *et al.*, 2007), and reduced life expectancy (Van Dijk *et al.*, 1991; Aneshensel *et al.*, 1993, 2000; McClendon *et al.*, 2006). Aneshensel *et al.* (2000) suggested that people with dementia living in institutional settings experience higher mortality than patients at the same stage of dementia who remain in the community. McClendon *et al.* (2006) reported that delaying admission to long term care reduced the risk of death in AD; they found that 'the later the placement, the smaller the impact of placement on survival time' (p. 220).

Older people **“prefer to remain in their homes because they are able to maintain the integrity of their social network, preserve environmental landmarks and enjoy a higher quality of life. Furthermore, admission to nursing homes is expensive both in terms of public and private finances.”** (Luppa *et al.*, 2010, p. 31)

Wübker *et al.* (2015) studied the cost difference between home based care and long term institutional care in eight European countries. They found that average institutional care costs for the UK were 1.4-fold higher than home care costs per month. However, they also noted that this relationship was dependent on the person's level of care need. Costs for people at the highest levels of dependency increased dramatically in homecare settings, and they suggested that this may translate to higher costs for supporting someone at home in the most severe stages of dementia compared to in an institutional setting.

Tucker *et al.* (2008) promote adoption of a 'balance of care' approach, whereby service providers seek to determine the optimal mix of services to meet people's needs, in order to provide people with more options to be supported in the community. The findings from their paper suggest that a number of people within their institutionalised study cohort could have been 'more appropriately supported in their own homes at a cost no greater than local agencies currently incur' (Tucker *et al.*, 2008, p. 81).

The belief that the majority of people with dementia would prefer to be cared for in their own homes underpins community care policy across Europe (Tucker *et al.*, 2008; Wübker *et al.*, 2015). Consequently, there is a common desire expressed throughout the literature to avoid inappropriate and premature care home placement. However, the research also highlights that interventions with this objective need to consider the person with dementia and their informal carer as a unit (Yaffe *et al.*, 2002), to ensure that the continuation of home support is in the best interests of both the person with dementia and their carer (Verbeek *et al.*, 2012).

2.10 Economic Impact of Dementia

The total estimated worldwide cost of dementia in 2010, taking into account informal care and the direct costs associated with health and social care, was \$604 billion dollars; with Western Europe and Northern America accounting for 70% of this cost (Wimo and Prince, 2010). To put that into perspective, see Figure 2.5.

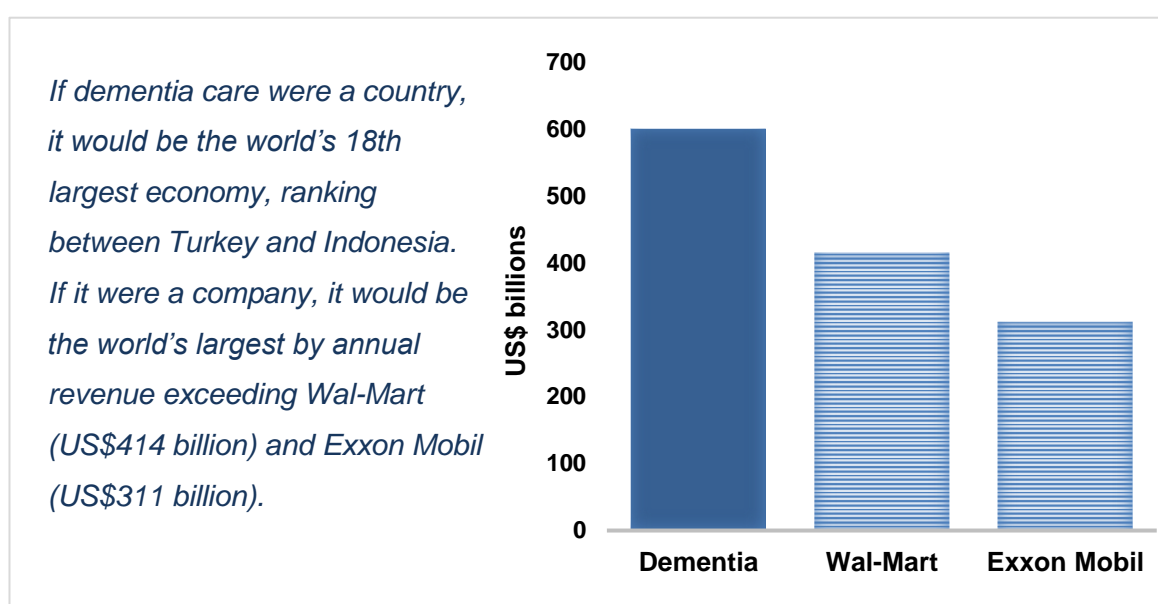


Figure 2.5: Cost of Dementia Compared to Company Revenue (Wimo and Prince, 2010, p. 5)

It has been suggested that in the coming years residential care capacity will need to expand by around 115%, and the hours of home care will need to increase by 103% in order to meet the growing demands of the ageing population (Hamblin *et al.*, 2013).

MacDonald and Cooper (2006) referred to an impending crisis of availability; they noted that between 1996 and 2006 the number of long term care places fell by one sixth. Using available projections of population ageing and the prevalence of dementia, MacDonald and Cooper (2006) estimated that by 2043 the UK will need more than double the number of care home places 'to maintain the present ratio of institutional to community services for dementia' (p. 16). Wittenberg *et al.* (2006) produced projections of demand using the Personal Social Services Research Unit's (PSSRU) long-term care projections model. The results showed that:

“Long-term care expenditure would need to rise by around 325 per cent in real terms between 2002 and 2041 to meet demographic pressures and allow for real rises in care costs of 2 per cent per year for health and social care.” (Wittenberg *et al.*, 2006, p. 25)

Furthermore, the study examined the future cost of dementia care, showing that between 2002 and 2031, public spending on long-term care services for older people with cognitive impairment in England is likely to increase from £5.4 billion to £16.7 billion (from 0.60% to 0.96% of GDP).

In 2008 the Health Economics Research Centre at the University of Oxford calculated that dementia cost the UK economy £23 billion annually (Luengo-Fernandez *et al.*, 2010). This is more than the cost for cancer and heart disease combined, see Figure 2.6.

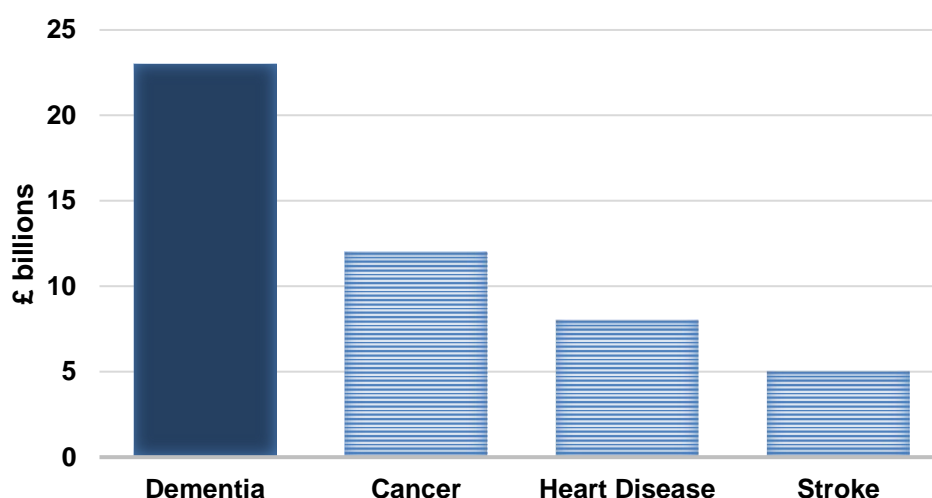


Figure 2.6: Costs to the UK Economy for Dementia, Cancer, Heart Disease and Stroke (Luengo-Fernandez *et al.*, 2010)

The costs of dementia are mostly associated with meeting social care needs, with social care provision and informal care costs making up the majority of the £23 billion figure. Luengo- Fernandez *et al.* (2010) valued informal care at £12 billion per year, based on 1.5 billion hours of care provided by unpaid carers. Councils spend £9.1 billion pounds a year on social care support (Luengo-Fernandez *et al.*, 2010); with Forder and Fernandez (2011) suggesting that 57% of net council spending in England relates to residential placements within care homes and nursing homes.

According to a UK market report published by LaingBuisson, entitled 'Care of Older People', residential care home placements, during the 2016 -17 financial year, cost on average £600 a week, while nursing home fees cost £841 a week on average (Laing, 2017). This equated to an average cost of £31,200 and £43,732 a year respectively. Around 70% of care home places are government funded, and 30% funded privately (National Audit Office, 2007).

A study conducted by Forder and Fernandez (2011) on behalf of Bupa looked at average length of stay for 11,565 residents in Bupa Care Homes for the period November 2008 to May 2010. The paper, which primarily focused on frail elderly and dementia residents, found that the mean length of stay was 801 days, but with a considerable tail of long-stayers.

"Half of residents had died by 462 days. Around 27% of people lived for more than three years, with the longest stayer living for over 20 years. People had a 55% chance of living for the first year after admission, which increased to nearly 70% for the second year before falling back over subsequent years." (Forder and Fernandez, 2011, p. 3)

If the mean length of stay in residential care equates to just over two years, that effectively translates to an average cost of over £60,000 per person. For someone remaining in residential care home for 20 years, that would be £624,000.

Currently tax income is used to support care provision, however if the dependency ratio of the older population relying on the support of the younger generations continues to rise, it is likely that this support alone will become insufficient to maintain the care service for older people. In a report released in 2012 by Carers UK, it was suggested that by 2060 the dependency ratio of people working to those not working will be two to one, compared to four to one in 2012. This will mean that a shrinking workforce will need to work longer in order to meet the growing care and pension costs. Consequently, action is already being taken to extend retirement age (Carers UK, 2012).

Furthermore, Luengo-Fernandez *et al.* (2010) attributed productivity losses equating to a further £29 million, and health care costs of an additional £1.2 billion, as contributing to the £23 billion annual cost of dementia. The paper associates productivity loss with premature death or absence from work due to dementia. However, due to the fact that the majority of dementia cases affect people over the age of 65 years, only a comparatively small amount of money is currently lost through patients having to stop work or dying before reaching retirement age (The Health Foundation, 2011).

Figure 2.7 shows the split between health and social care costs for dementia, cancer, coronary heart disease (CHD), and stroke. The health care contribution is relatively small when compared to other conditions because, as previously stated in Section 2.7, there is no long-term treatment for dementia, so dementia is predominantly seen as a social care issue.

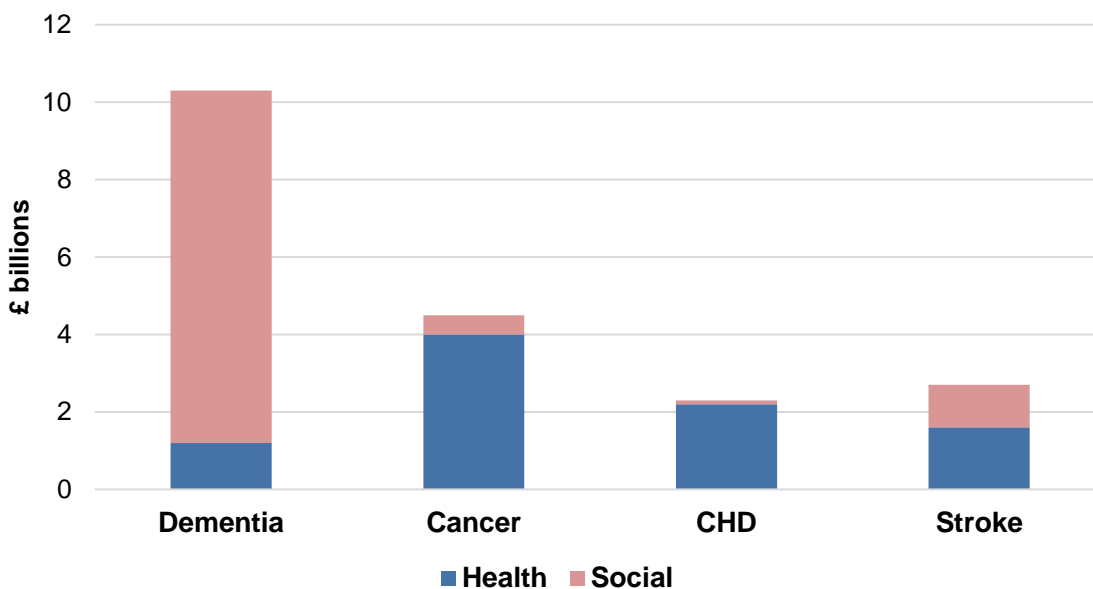


Figure 2.7: Health and Social Care Costs

In 2014, the Alzheimer's Society released the Dementia UK: Update (Prince *et al.*, 2014), which followed on from an earlier 2007 Dementia UK publication by Knapp *et al.* (2007). This document provided estimates for the costs of healthcare, social care, and unpaid care for people with dementia using the best currently available information. The more up-to-date figures provided by the Dementia UK: Update are not too dissimilar to those released by Luengo-Fenandez *et al.*, they simply reflect costs increasing over time. The subsequent report estimated the overall economic impact of dementia in the UK to be £26.3 billion by 2015 (Prince *et al.*, 2014). This works out as an average annual cost of £32,250 per person. It also suggested a higher level of healthcare spending at

approximately £4.3 billion, of which around £85 million is spent on diagnosis. Moreover, the report stated that:

- £10.3 billion is spent on social care for people with dementia in the UK.
- Social care is either publicly funded (£4.5 billion; 17.2% of the overall total cost of dementia) or privately funded (£5.8 billion; 22.9% of the total).
- The cost of unpaid care for people with dementia in the UK is £11.6 billion, working out as 44% of the total cost of dementia.
- The total number of unpaid hours of care provided to people with dementia in the UK is worth £1.34 billion.
- Police costs of missing person enquiries attributable to dementia probably range between £22.1 and £40.3 million per year.
- Unpaid care accounts for three-quarters (74.9%) of the total cost for all people with dementia who are living in the community

2.11 Considering the Person

2.11.1 The Experience of Living with Dementia

The experience of dementia from the individual's perspective is relatively under researched (Aggarwal *et al.*, 2003). In the past the assumption has been that people with dementia cannot reliably report their subjective experiences (Phinney, 2010). Therefore, perspectives on dementia or dementia services are usually solicited from family members or carers rather than from the person with dementia (Aggarwal *et al.*, 2003). Nonetheless, the literature that is available paints a picture of people dealing with the emotional impact of the condition; attempting to overcome profound challenges, while also trying to find meaning and quality of life (Phinney, 2010).

A person's experience of dementia can vary depending on their awareness and understanding of what is happening to them; this is also referred to as a person's 'insight'. Some people are fully aware that something is wrong, while others have no awareness at all. Some people are aware of their cognitive decline and actively try to deny it. Rosenberg and Nygard (2012) point out that people with the early stages of dementia will often initiate various strategies in order to compensate for or hide problems they are experiencing as a consequence of their condition. However, these strategies are not always successful and often require constant adjustments (Harman and Clare, 2006).

Absence of insight in people with dementia is probably the most common cause of lack of cooperation within care; ultimately varying degrees of insight can become a crucial factor in determining a person's right to remain independent (Fairburn, 1997). A person with dementia may be completely unaware that their behaviour has changed or that their actions may pose a risk to themselves or others, and therefore decisions have to be made on their behalf within their best interests. Lack of insight on the part of the individual can further contribute to carer stress (Fairburn, 1997).

As dementia advances, the person may become more and more frustrated, panicked, and aggressive as they become increasingly confused and disorientated (Aggarwal *et al.*, 2003; Hamblin *et al.*, 2013). Anxiety is commonly linked to dementia and is associated with a reduction in quality of life (Seignourel *et al.*, 2008). Starkstein *et al.* (2007) reported that 'excessive anxiety and worry were significantly associated with restlessness, irritability, muscle tension, fears, and respiratory symptoms of anxiety' (p42). They also stated that anxiety in Alzheimer's disease is a frequent comorbid condition of major depression (Starkstein *et al.*, 2007).

Communication difficulties, and the fear of embarrassment can result in people with dementia finding themselves increasingly isolated and detached from those around them. Duane *et al.* (2013) emphasise the importance for people with dementia to feel connected in order to avoid feelings of loneliness; Stanley *et al.* (2010) link a reduction in contact to feeling not needed or part of society. Losing track of conversations and struggling to express themselves means that a person can feel excluded and lonely even when surrounded by friends and family. This can be exacerbated for people whose first language is not English, particularly if advancing dementia means that they revert to speaking their mother tongue and therefore 'speak a language that their younger family members may not understand' (Age UK, 2010).

Feelings of uncertainty can become so frequent and profound that the person may feel they can no longer trust their own judgement; this can lead to a lack of self-confidence and feelings of insecurity (Phinney, 2010). If the person is unable to fulfil their previous roles they may begin to feel unproductive, unimportant, and as if they are a burden to others (Harris and Keady, 2004).

Fear and sadness are common emotions experienced by people with dementia (Aggarwal *et al.*, 2003); they worry about what the future will bring and may feel sadness as they consider the hopelessness of their situation (Phinney, 2010). In 2003, Phinney and Chesla conducted a series of interviews with nine people experiencing mild to moderate dementia. From their analysis they discussed the concepts of 'being slow', as the human

body slows down and every day activities become increasingly challenging (Phinney and Chesla, 2003). One husband commented:

“My wife is having a lot of difficulty. She feels that everything takes a longer time and is harder. ... Daily life is a burden. She says it and she means it and I agree with her. ... [It is] hard work.” (Phinney and Chesla, 2003, p. 288)

They also discussed ‘being lost’, as people struggle to find their way in an unfamiliar world. This not only refers to losing sense of direction, but also losing understanding of the steps required to carry out a task or losing comprehension of the objects around you. Phinney and Chesla (2003) also describe the concern around what others might think; the person may worry that they will no longer be perceived as competent. The concept of feeling embarrassed when problems are witnessed by others and the fear of being seen as incompetent are echoed in findings from other papers (Gillies, 2000; Aggarwal *et al.*, 2003; Offord *et al.*, 2006). Finally, the Phinney and Chesla (2003) explored the concept of ‘being blank’, where meaningful practices and habits fall by the wayside. In short, this refers to the collapse of involvement; the person loses track of what they were saying and therefore they struggle to engage with other people; instead the person may sit still and gaze into space. One of their interviewees explained:

“It’s scary. Yeah it’s scary. Uhm [pause] I suppose in a way it’s like being in a fog, and you can’t find your way out of it. [long pause] I mean, not knowing is frightening.” (Phinney and Chesla, 2003).

Despite the broad array of negative emotions and experiences that dementia can trigger, a literature review by de Boer *et al.* (2007) highlighted that people do not just succumb to dementia passively. Many employ active coping strategies to overcome the challenges it presents; often working with family members, carers and others to find new approaches for dealing with different circumstances (Nygård and Öhman, 2002). Some people simply adjust their approach to daily activities: writing lists, using memory aids, and devising systems to help maintain a sense of order (Phinney, 2010). People also reduce the demands on themselves by finding easier ways of doing things, for instance buying ready meals rather than cooking from scratch.

2.11.2 Maintaining Independence

Bamford and Bruce (2000) explored the perspective of older people with dementia and their carers by conducting a series of interviews, discussions, and informal conversations as means of data collection. The study found that ‘maintaining a sense of autonomy in the

face of unwelcome and increasing dependency was an important outcome identified by services users and carers' (Bamford and Bruce, 2000, p. 556).

The study also mentioned concerns around crime and increased vulnerability due to feelings of confusion and consequently the desire to feel safe and secure. Many of the participants considered remaining in their own home as an important symbol of control; this finding is consistent with other studies of the experiences of people with dementia, including Harris (2006), Duane *et al.* (2013) and Hamblin (2014a). All three studies found that their participants were concerned about living independently for as long as possible and that most participants were 'comfortable living by themselves' (Harris, 2006; Duane *et al.*, 2013; Yeandle, 2014a).

Hamblin (2014a), in her paper, 'Lifestyles in Later Life: identity, choice and stigma', discussed the role of 'place', in terms of home, neighbourhood, and community in relation to an older person's sense of identity (Figure 2.8). She also reported that older people identify themselves using four key aspects: 'identity as a family member; as worker, professional or skilled person; as an active, independent or capable person; and as a homemaker, homeowner or local community member' (Yeandle, 2014a, p. 3).

"Most research participants expressed some aspects of their identity in relation to place, especially their homes and neighbourhoods. Many had lived in their present homes for over 30 years, some for as many as 50 years. Their homes were often a great source of pride; the place which some had saved and worked hard to buy; where many had brought up their children; and which, for some, had been a means of overcoming stigmatised circumstances in childhood or early adult life.

For some research participants who described themselves as 'working class', their clean, well-kept homes were an important part of their identity; one who had migrated to England at a time when discrimination was prevalent emphasised that keeping her home immaculate had been a means of combating the racism she encountered.

Neighbourhoods were also places where they had participated in local activities and supported others, where they had felt safe and valued, and where they had experienced a sense of belonging. These homes and neighbourhoods were the sites of memories, and had been spaces where the person had agency and made changes (for example, decorating, taking part in community events or activities, or campaigning). Due to their present frailty and ill-health, some participants felt these environments were now increasingly controlling them or constraining their activities and decisions; some were now afraid or unable to go out alone or to access certain areas of their home."

Figure 2.8: Extract from Hamblin (2014a): 'Lifestyles in Later Life: Identity, Choice and Stigma', Discussed the Role of 'Place' (p. 3 – 4)

Bamford and Bruce (2000) also emphasised the importance of personal identity, with many female contributors feeling that their sense of self-worth was tightly bound to their

ability to fulfil their traditional roles within their household, such as cooking and cleaning. Studies examining the lives of people with dementia have had participants report: difficulties with every day activities, a lack of stimuli, social isolation, the lack of a feeling of security, social withdrawal and restrictions of access within their own home or to the outdoors, as impacting on their quality of life (Sabat, 2001; Nolan *et al.*, 2002; Chung, 2004; Harris, 2006).

Bamford and Bruce (2000) reported that many people felt reluctant to seek help as they felt it undermined their sense of autonomy; they wanted to feel valued and be treated with respect. However, willingness to accept support increased if it enabled the individual to remain as independent as possible; furthermore, being presented with a choice as to the form the help would take ensured a feeling of control.

2.12 In Summary

In summary, this chapter explained that dementia is not a single illness but a group of progressive symptoms that occur when the brain becomes damaged by certain diseases. The most common cause of dementia is Alzheimer's disease. Symptoms include memory loss, mood changes, problems with communication, confusion, and disorientation. Each stage of dementia can be characterised by a progressive deterioration in ability to complete activities of daily living, leading to an increased dependency on other people. Consequently 'dependence' has been identified as a suitable marker for staging disease progression. Kahle-Wroblewski *et al.* (2015) identified six discrete levels of dependency associated with dementia advancement; which correlated with declining cognition, increased behavioural disturbances, increased health and social care costs, and increased levels of carer burden.

Another key element to consider from the literature is variability. No two people are affected by their dementia in exactly the same way. The rate of progression can vary greatly between individuals (Musicco *et al.*, 2009; Thalhauser and Komarova, 2012; Alzheimer's Society, 2017a; Barocco *et al.*, 2017). Therefore, variability between rates of disease progression, and levels of dependency, were identified as important concepts to build into the TeleDem Simulation.

Increasing dependency not only captures the advancement of the disease, but also the impact on the person's carer. The behavioural disturbances and memory loss that typify dementia can make the role of caregiver challenging. The burden that many of these carers experience is closely associated with the care receiver's admission to institutional

care. Informal carers are fundamental to dementia care in the UK, with the Alzheimer's Society estimating that at least 670,000 family members and friends are acting as a primary carer.

The financial cost of dementia is over £23 billion a year (Luengo-Fernandez *et al.*, 2010); consequently, as our society ages, carers will be essential in helping health and social services meet the demand for care. It is therefore a national priority to explore options for supporting carers and helping people with dementia to maintain their independence and quality of life. One such option, explored in the following chapter, is telecare.

Chapter 3: The Role of Telecare in Meeting the Social Care Needs of People with Dementia

3.1 Chapter Overview

This chapter, alongside Chapter 2, provides the contextual information for the development of the TeleDem Simulation, and therefore also addresses step one of the modelling framework (see Figure 3.1).

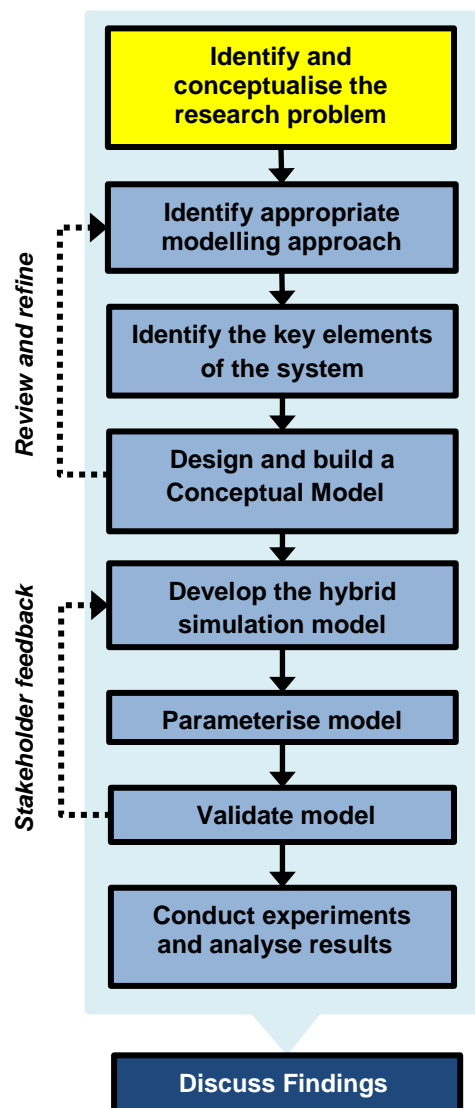


Figure 3.1: Addressing Part One of the Modelling Framework – Telecare Background

To determine the scope of the model and to establish its purpose, it was necessary to explore the existing evidence relating to the use of telecare to support people with dementia and their carers. Search terms relating to ‘ageing’, ‘dementia’, ‘Alzheimer’s

disease', 'cognitive decline', 'remote care', 'telecare', and 'technology' were combined to maximise the number of matches. The identified literature was grouped into broad themes, and the papers for inclusion in the thesis were reviewed and refined as the scope of the model evolved.

This chapter covers how telecare works, when it is offered, how much it typically costs, and offers a brief overview of how research in the field has developed. It examines the 'benefits of' and 'barriers to' the technology, as well as considering evidence regarding its effectiveness and cost effectiveness. The chapter concludes by considering the evidence gap and how modelling could potentially assist in addressing this.

This chapter aims to set out key themes and perspectives within this research area, but does not attempt to provide a comprehensive overview of all published literature. As highlighted by Botsis and Hartvigsen (2008), the concept of remote care has been demonstrated for a broad range of chronic conditions associated with the ageing population, including: diabetes, heart failure, chronic obstructive pulmonary disease, chronic wound management, hypertension, mobility disabilities, and dementia. However, for this review, the scope of the evidence considered for inclusion was restricted to papers relating to technology or telecare for supporting 'people with dementia', or 'in old age' in general. Papers focusing on a specific medical condition that is not related to cognitive function, were excluded.

The body of literature examining the role of telecare within a social care setting is growing, however much of the research is still based on pilot studies or exploratory projects; consequently, findings are often tentative or preliminary (Powell, 2009; Fry and Buse, 2013; Goodridge *et al.*, 2016). Therefore, it was necessary to draw on a broad range of sources, both within the academic and grey literature when composing this chapter, in order to explore the evidence currently available for the use of telecare to support people with dementia. Furthermore, a fundamental component of this research was engaging with stakeholders involved in the development and delivery of telecare (see Chapter 5 for further details). This involved working with Dorset County Council, talking extensively with telecare commissioners, service providers, and experts involved in the design of the technology. Consequently, the knowledge gained through these engagement activities has helped to structure, build, and inform this chapter, particularly when describing the benefits of, and barriers to, telecare uptake.

3.2 How Telecare Works

A typical telecare service incorporates a series of sensors installed around the home or worn by the user which can send an alert to a remote monitoring centre in order to initiate a response (Bayer *et al.*, 2007). Possible sensors include: movement/non-movement sensors, falls detectors, flood detectors, exit sensors and gas detectors; each device is connected to a home unit.

If a problem occurs a signal will be sent to the home unit, either manually for example by a personal alarm being triggered, or automatically by a sensor, such as a flood detector. The home unit then sends an alert to the monitoring centre. The centre's role is to acknowledge the alarm, respond according to protocol, and coordinate an appropriate response. The response will depend on the nature of the alarm and any previously agreed actions (Siotia and Simpson, 2008). Figure 3.2 illustrates this system.

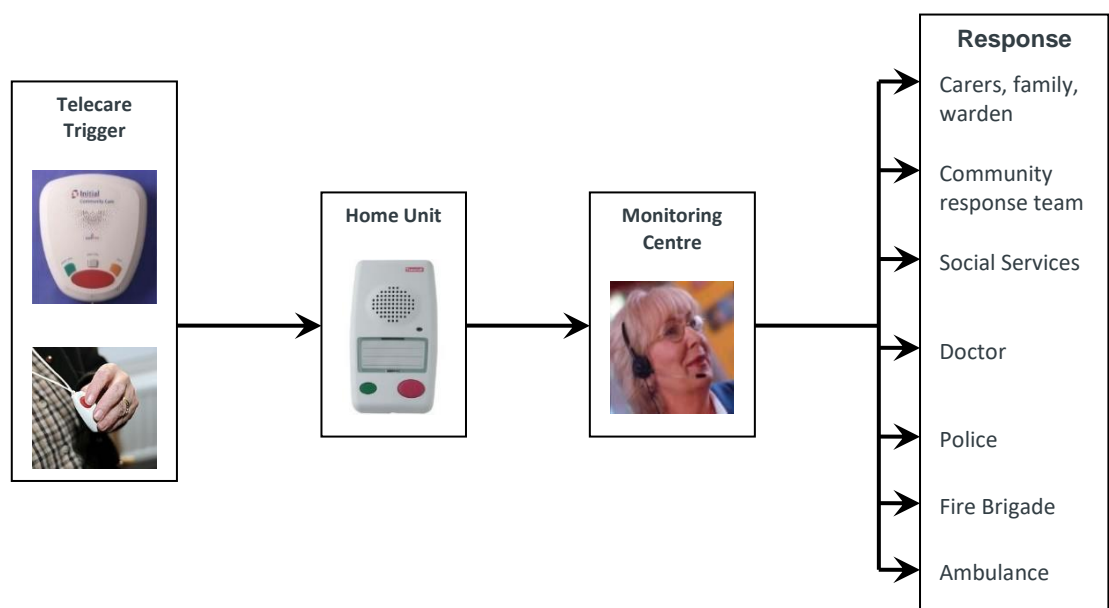


Figure 3.2: The Telecare System (adapted from Brownsell and Bradley, 2003)

Depending on the level of sophistication of the technology, telecare can be grouped into three distinct generations (Brownsell and Bradley, 2003; Siotia and Simpson, 2008; The Scottish Government, 2008; Jarrold and Yeandle, 2009). First generation telecare is exemplified by community alarms, such as pull cords, wall mounted units, or personal triggers carried by the individual. This generation of equipment is user activated, with no embedded intelligence. These devices are entirely reliant on the user triggering them in order to call for help (Brownsell and Bradley, 2003).

Second generation telecare includes all the features of first generation telecare, but also incorporates 'intelligent' components that use sensors, so they do not require physical activation (Brownsell and Bradley, 2003; Siotia and Simpson, 2008). Second-generation telecare relies on the event and not on the user to initiate an alarm; for example, fall detectors, activity/inactivity sensors, flood detectors, exit sensors, and gas detectors. Each device is connected to a home unit, which can immediately report a problem to the monitoring centre. These sensors can collect and transmit information continuously. The home unit is connected to the person's phone line, which allows two-way speech through a loudspeaker, so that the monitoring centre operator can reassure the caller and facilitate an appropriate response (Siotia and Simpson, 2008). 'This provides a much more sophisticated and comprehensive support to managing risk and improved quality of life.' (Kerr *et al.*, 2010, p. 6).

Third generation telecare builds on second generation, by utilising broadband, wireless, and audio-visual technology. It introduces the concept of the 'virtual neighbourhood' (Brownsell and Bradley, 2003). It creates the possibility of tele-consultations between the service user and care professionals, thus reducing the need for home visits or hospital appointments. It also increases opportunities for people who are unable to leave their homes. It enables them to maintain interaction with friends and family through video conferencing and also supports activities such as banking and shopping (Kerr *et al.*, 2010).

The currently available telecare being used across the UK falls into the second-generation category. An overview of the telecare equipment available in 2017 to support social care in the UK is described in Appendix 7.

3.3 When is Telecare Offered?

This section considers why and when telecare is provided in terms of care need. Details of the funding and eligibility criteria for telecare is provided in Section 3.5.1: 'Local Authorities and Telecare Provision'. Brownsell *et al.* (2007) examined 'The role of telecare in supporting the needs of elderly people' by exploring the 'trigger factors' that result in older people taking the step to increase their levels of care and support. The trigger factors relating to the uptake of telecare are summarised in Figure 3.3.

- A fear of falling
- A major health event – such as support following a stroke or hip replacement
- A perceived decline and concern for own health
- A person feeling lonely
- Abuse (physical or mental)
- Consequences of admission to hospital
- Depression, mental breakdown or deterioration
- Deteriorating physical functioning
- Difficulty cooking for themselves
- Difficulty toileting/continence management
- Family, friends or neighbours can no longer provide support at home
- Family/caregiver stress
- Inability to care for self at home
- Managing pressure sores
- Medication management – such as compliance problems
- Multiple minor longstanding illnesses
- Occurrence of falls
- Person feels isolated
- Poor nutritional/dietary intake
- Presence of chronic disease (such as Parkinson's, heart problems)
- Requiring regular trips to hospital
- Self-perceived inability to manage alone or care for oneself
- Self-management of health conditions (regulating insulin, dealing with the pain of arthritis)

Figure 3.3: Trigger Factors for Telecare Uptake Adapted from Brownsell et al. (2007)

Furthermore, O'Sullivan (2011) conducted a four year evaluation of the Telecare Development Programme (TDP) for Scotland. They recorded the reasons for offering telecare to new clients; these are listed in Table 3.1 along with the proportion of clients within each 'offer category'.

Table 3.1: Recorded Reason for Offering Telecare to New Clients

Reason	2010/2011
Prevent admission to a care home	7.5%
Prevent/lessen hospital admission risk	17.2%
Facilitate hospital discharge	8.7%
Improve carer piece of mind/respice	22.2%
Meet a low level need	33.0%
Other reason	11.4%
Total	100%

Source: O'Sullivan (2011)

Telecare is not the answer for everybody. 'People have different needs, abilities and preferences and 'one size does not fit all' (AT Dementia, 2016, p. 1). Technology should only ever be provided as an addition to human contact and care, not as a replacement

(AT Dementia, 2016). Brownsell *et al.* (2007) recommends an approach to care that draws upon a variety of services to best address the individual's needs. Both Brownsell *et al.* (2007) and Cash (2003) agreed with the importance of a carefully conducted assessment; Cash (2003) pointed out that dementia presents with a range of different symptoms, so the equipment that works for one person may not work for all. For their 2003 paper, Cash conducted interviews with 28 service users with dementia, their carers, and their care workers. The study highlighted the importance of the early introduction of telecare and found that if it was installed too late it was ineffective.

Furthermore, telecare should only be offered to someone with dementia if there is an appropriate response protocol in place; for example, if the individual has a carer available to assist if an alert is raised or alternatively if a 24/7 responder service is provided. Telecare should not be offered if it would rely solely on a response from emergency services. For instance, both Oxfordshire and Lincolnshire County Councils offer a response service, which provide trained responders, who will attend 'non-medical emergencies' any time of day (Lincolnshire County Council, 2016).

3.4 A Brief History of Telecare for Dementia Care

Telecare in the UK developed as a service from the social alarm technologies widely introduced during the 1960s and 1970s (Fisk, 2003). A social alarm is a system that is installed in a user's home and makes it possible for the user to call for help in urgent situations by pressing a button on a small portable alarm trigger (Sjölander and Avatare Nöu, 2014). Due to their 'user activated' design, social alarms were initially perceived as unsuitable for people with dementia (Woolham *et al.*, 2006). Health and social care professionals often dismissed the technology as it could not be reliably operated by someone experiencing cognitive impairment (Woolham and Frisby, 2002). However, technological progress, in particular through the development of passive sensors, alongside demographic shifts and increasing service pressures, resulted in a rapid growth in interest in telecare as new options for meeting the social care needs of an ageing population were sought (Woolham *et al.*, 2006). Therefore, the technology has quickly evolved from its humble beginnings into a multi-million-pound industry (Leroi *et al.*, 2013).

Research into the role of telecare has quickly gained momentum; with telecare attracting attention from academics, policy makers, and organisations appraising their own equipment or services (Fry and Buse, 2013). Consequently, numerous telecare trials have been established across the UK. The ever growing number of pilot studies has led some to joke that telecare 'has more pilots than British Airways' (Poole, 2006). In 2008 Clark

reviewed telecare pilot studies across 150 local authorities in England on behalf of the Telecare Learning and Improvement Network. He found that 48 social care authorities referred to dementia in their strategic plans; while 22 made reference to dementia when discussing mainstreaming and sustainability. He also noted that several social care authorities conducted localised evaluations of their pilot studies. These evaluations indicated that telecare, when used for people with dementia, can: (adapted from Clark (2008, p. 3))

- Reduce the need for residential care, in particular through delayed admissions.
- Offer increased choice and independence for service users.
- Reduce the burden placed on carers and offer them more personal freedom.
- Reduce the potential for accidents and falls in the home.
- Contribute to the development of a range of preventative services.

However, due the small scale of most trials, and their 'characteristics as pilot projects (where additional resources are often made available to ensure their success)' (Barlow *et al.*, 2007, p. 9); there is deemed to be a lack of robust evidence. In an attempt to address this, in 2008 the Department of Health launched a large scale randomised control trial (RCT), referred to as the Whole Systems Demonstrator (WSD) Programme (see Appendix 8 for further details). Its purpose was to examine the role of telecare and telehealth in supporting integrated delivery across both health and social care (Department of Health, 2009b); providing the necessary evidence required for the widespread mainstream launch of this technology across the UK. However, when results from the WSD were eventually released, they were heavily caveated. The main implication was that evaluating telecare had been far more challenging than expected.

Newman *et al.* (2014), highlighted several problematic areas regarding trial design. Firstly, the time frame for the study was cited as a significant barrier to effective evaluation. The 12 month time frame for data collection was insufficient to draw meaningful conclusions regarding the impact of technology on residential care home admissions; yet this was also one of the main areas where telecare was proposed to deliver its greatest cost savings (Newman *et al.*, 2014). Secondly, because the study did not examine how the effects of telecare might vary depending on the unique characteristics of each participant, the researchers felt that some important effects may have been masked. For instance, the impact of a fall detector on hospital admissions for someone who had been experiencing falls was not specifically examined; the impact of telecare for these individuals may have been far greater than for others within the sample (Newman *et al.*, 2014). Thirdly, inconsistency between sites regarding the delivery of the service, made extrapolating

meaningful results for the cost effectiveness of the service challenging. In addition, many of the participants already had a lifeline and pendant, which would have impacted the perceived benefit to quality of life when receiving additional peripheral devices (Lowe, 2013).

Finally, another of the earlier publications from the WSD discussed organisational level challenges faced by the programme. Hendy *et al.* (2012), highlighted the difficulty of implementing such a 'complex innovation' with so many variables under the restrictive conditions of an RCT; suggesting instead that a system such as 'remote care' needs to organically evolve, driven by support from front-line staff and management. Newman *et al.* (2014) stated that attempting to deliver a major service change during a time of austerity further impacted the success of the project; suggesting that staff enthusiasm diminished as organisational priorities shifted and workloads increased.

Despite being a large and rigorously designed study, the short comings described above, have led to many policy makers and local authorities disregarding the findings of the study. Nonetheless, the WSD has put further emphasis on the need for greater exploration and organisational change. (Newman *et al.*, 2014). Consequently, progress for developing telecare into a mainstream service has been modest. In part, due to the fact that exploration of the 'personal, organisational, cultural, ethical, and legal implications of telecare has fallen significantly behind technological development' (Greenhalgh *et al.*, 2012, p. 2).

Furthermore, a lack of public awareness of the technology has stifled demand. In July 2013, Carers UK commissioned YouGov to examine public attitudes to using technology to support caring for older and disabled people (Carers UK, 2013b). They surveyed 2,069 UK adults (aged 18+) and found that while 70% use technology for banking, paying bills, shopping, or communication; fewer than 30% use technology to support health and social care. Carers UK found that 'lack of awareness' was a significant barrier to interest in telecare; the survey found that 80% were unsure what telecare was. Once survey participants were presented with a definition of telecare, they found that interest in using the technology to support care delivery rose dramatically. The results showed that the group most interested in using the equipment was the over 65s, with 85% saying they would consider using it (Carers UK, 2013b). Section 3.12, later in this chapter, considers the necessary steps for overcoming the barriers to mainstreaming telecare.

3.5 Telecare Policy Background

Since the late 1990s telecare has been a key feature of UK Government Policy discussion (see Appendix 9), including: the Wanless Review (Wanless *et al.*, 2006), and The National Dementia Strategy (Department of Health, 2009a). Furthermore, the National Strategy for Carers, entitled 'Caring about Carers', has made reference to the role of technology for supporting carers since as early on as 1999 (HM Government, 1999). A later update in 2008 made direct reference to 'telecare', highlighting that it can provide carers with peace of mind and a degree of freedom.

In 2012 the Department of Health published the 'Prime Minister's Challenge on Dementia', which set out to deliver major improvements in dementia care and research (Department of Health, 2012). One of the key themes was Dementia Friendly Communities, and as a consequence of this campaign, the Alzheimer's Society established a task force in October 2013 to focus on dementia-friendly technology. The 'Dementia- Friendly Technology Charter' was published by the Alzheimer's Society in 2014. The charter, which was developed in partnership with Tunstall Healthcare, provides people with dementia and their carers information on how to access technology. It also provides a range of case studies and offers guidance to 'health, housing and social care professionals on how to make technology work for people based on their individual needs' (Alzheimer's Society, 2014).

More recently, the 'Prime Minister's challenge on dementia 2020' builds on the achievements of the 2012 edition. It aims to identify what needs to be done to make sure that dementia care, support, awareness, and research are transformed by 2020. This document makes reference to the 'Dementia-Friendly Technology Charter' and also acknowledges the contribution that technology has made to the evolution of dementia care in the home (Cabinet Office *et al.*, 2015).

3.5.1 Local Authorities and Telecare Provision

Lloyd (2012) describes local authorities as 'key agents' in telecare policy, as they have a significant role in the delivery of telecare services in England. Local authorities (as presented in Lloyd, 2012):

- Administer public funding on telecare;
- Commission or directly provide telecare services;
- Oversee local care markets, including telecare services;
- Assist individuals in the procurement of telecare services.

The provision of telecare is complex, telecare policy over the last decade has been built around a mixed economy (Lloyd, 2012). The service is commissioned and overseen by local authorities, but can be funded by the NHS, the council, or the individual. The individual might pay in full or may pay a subsidised charge.

“Some councils, such as Kent, will not charge for telecare services in any circumstances. Others will not charge for services costing less than £1,000 per year to those eligible for council support, while others may charge for telecare services at a low rate.” (Lloyd, 2012, p. 9)

In April 2015 ‘The Care Act 2014’ was released, setting out guidelines for local authorities in relation to assessing people’s needs and their eligibility for publicly funded care and support. The eligibility framework for social care support is graded into four bands: critical, substantial, moderate, and low (further information is provided in Appendix 10). These classifications describe the seriousness of the risk to independence and wellbeing, or other consequences if needs are not addressed (Department of Health, 2010). Some social services may only provide telecare to those with ‘substantial’ or ‘critical’ needs (Disabled Living Foundation, 2013, p. 3). Individuals wishing to use telecare can either be referred to a provider through Adult Services or other agencies, or they can go to the provider directly. Until relatively recently, those eligible for help with social care from their local authority, would receive a care plan, with limited choice regarding the services they could receive (Age UK, 2016). However, the government is now encouraging councils to move towards Self-Directed Support, which is likely to transform social care into a much more personalised service. The move towards ‘personalisation’ reflects the shifting expectations of today’s society; people expect to exercise choice and control over any support they may require (The Scottish Government, 2010).

The government document ‘Putting People First’ published in December 2007, emphasises the importance of a person-centred approach (HM Government, 2007). Self-Directed Support, allows individuals receiving care to take control of how their personal budget is allocated. For instance, they may wish to receive their budget as a direct payment or they may want to let the council arrange services for them. This shift in care delivery has seen an increase in telecare uptake (Roulstone *et al.*, 2013b) as people can now choose the installation of telecare over more expensive and intrusive forms of support.

3.6 The Cost of Telecare

Henderson *et al.* (2013b) calculated the cost of telecare across the three sites used in the WSD programme. The cost estimation method is published in the Personal Social Services Research Unit's 2013 report on Unit Costs of Health and Social Care. A summary of how the equipment costs were calculated is provided in Figure 3.4.

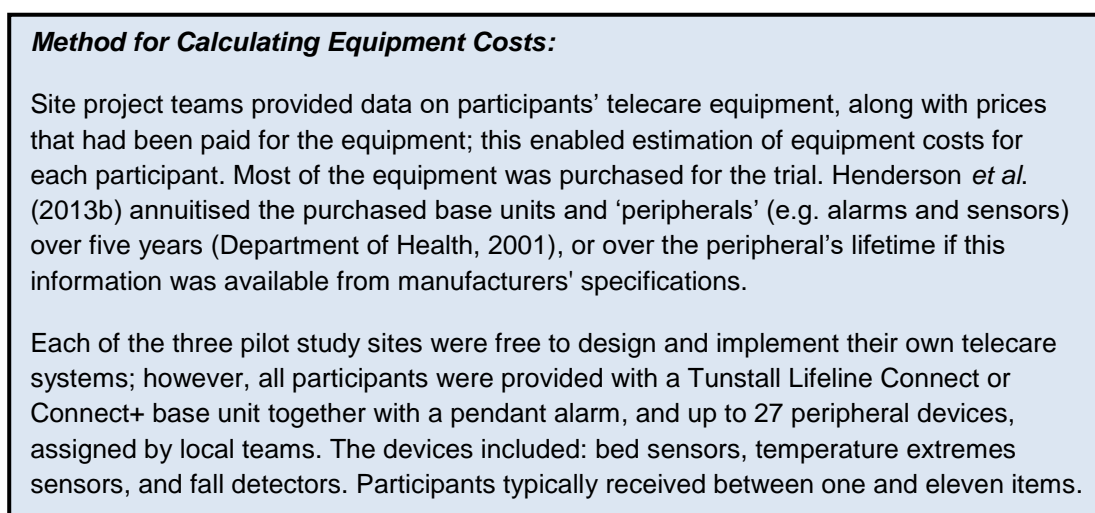


Figure 3.4: The Method used by Henderson *et al.* (2013b) for calculating telecare equipment costs across the WSD Programme

Henderson *et al.* (2013b) also calculated telecare support costs per participant, which included costs for: monitoring, infrastructure, installation, and maintenance. The results showed that the costs for supporting the delivery of telecare varied substantially between sites. The total direct support costs ranged from £437 to £1004 per participant, per year; while the average cost of equipment per participant ranged from £73 to £93 per year. The mean intervention costs are shown in Table 3.2.

Table 3.2: Mean Annual Intervention Costs of Telecare in the Whole System Demonstrator Programme

Component of the Intervention	Mean Cost Per Person Per Year (Standard Error)
Equipment and support package costs	£792 (13.4)
Equipment costs	£81 (1.9)
Intervention costs	£711 (12.6)

Source: Henderson *et al.* (2013)

3.7 Exploring the Benefits of Telecare for People with Dementia

There is a broad range of literature that refers to the potential benefits of telecare for people with dementia and their carers. It is frequently suggested that telecare can help vulnerable people to remain living independently by reducing the risks of living in the community (Siotia and Simpson, 2008; Beale *et al.*, 2009). Tang and Venables (2000) infer that telecare can improve service delivery and therefore lead to an improved quality of life for the service user. Brownsell and Bradley (2003) suggest that the technology can provide reassurance for the individual and their carers, delaying or even avoiding admissions to residential care. Taylor and Agamanolis (2010) propose that being monitored increases perceptions of safety and therefore reduces anxiety. Beale *et al.* (2009) reported that telecare can reduce carer stress and therefore improve quality of life for informal carers supporting people with dementia. It helps care workers to better manage their time, as telecare systems flag up when their assistance is required, thus eliminating unnecessary and potentially disruptive checks (Tunstall, 2008b). Moreover, including telecare as a care option offers people a greater choice, providing more options for the management of their condition (Knipscheer, 1994). Wey (2004) outlined the potential ways telecare can assist people with dementia to live independently and maintain their sense of identity; these include:

- Supporting and facilitating memory, orientation, and other cognitive abilities that are central to the person's everyday life.
- Enabling the person to continue to carry out tasks and activities that were becoming increasingly challenging.
- Facilitating meaningful activities and helping the person to remain connected to their family and social networks.
- Ensuring safety.
- Providing reassurance and support to carers. (adapted from Wey (2004))

Appendix 11 offers more specific examples of types of telecare equipment that can help meet the challenges posed by dementia.

In 2011, the AKTIVE (Advancing Knowledge of Telecare for Independence and Vitality in later lifE) Project was established. It set out to explore how various types of telecare technology may benefit those who are susceptible to falls or who have cognitive impairments (AKTIVE Consortium, 2013; Yeandle, 2014b). The findings from the project, which collected data from 60 individuals, suggested that telecare can positively impact on

the daily activities of older people providing enhanced feelings of safety by offering reassurance and confidence (Fry, 2014). Telecare was felt to be beneficial in maintaining older people's identity as active, independent, and capable individuals; helping them to hold on to highly valued aspects of their lives, such as continuing to live within their own home and retaining sufficient independence to feel in control of their everyday life (Hamblin, 2014a).

Telecare was also found to help strengthen weak social ties when neighbours, friends, and contacts within local associations (for instance the church or community group) agreed to become a nominated responder (Yeandle, 2014a). Although the equipment did not provide significant social interaction, many service users and their family members felt the connection it provided was important (Koivunen, 2014). One respondent commented:

“If anything happens, you're not on your own, you can just press the button and somebody will come” - Mrs Tyne, aged 94, living alone in Oxfordshire (Koivunen, 2014, p. 13).

Hamblin (2014b) identified some instances where telecare had limited older people's freedom, with some participants, who were not able to do what they wished, feeling disempowered by the steps taken to reduce risk on their behalf. Hamblin (2014b) acknowledged that it can be challenging to strike an appropriate balance when it comes to risk:

“Complete freedom and control for participants may at times entail a significant amount of risk, while removing all risks, without their consent, would limit their freedom and independence in unacceptable ways.” (Hamblin, 2014b, p. 17)

The paper concluded by highlighting the importance of striking a balance that is appropriate to the individual's unique circumstances by ensuring the person is involved in the decision process.

3.8 Informal Carers' Perspective

Providing care for someone with dementia can have a profound effect on family carers (Gitlin *et al.*, 2010a). Challenges for carers, as discussed in Chapter 2, Section 2.9, can include attending to physical needs, dealing with behavioural and psychological symptoms, and addressing the need for constant vigilance (Vitaliano *et al.*, 1991; Wright *et al.*, 1999; Gitlin *et al.*, 2010a). While factors associated with dementia, such as

cognitive decline, cannot be greatly modified, telecare does have the potential to mitigate some of the challenges that carers face (Siotia and Simpson, 2008).

The impact of telecare on reducing carer burden has been referred to in numerous studies (Miskelly, 2001; The Audit Commission, 2004; Department of Health, 2005a; Woolham, 2006; Gitlin *et al.*, 2010b). The ongoing randomised controlled trials currently examining telecare for dementia (see Section 3.13 for more detail), all include measures for the impact of the equipment on carer burden; either using the ZBI or in the case of UP-TECH: the Carer Burden Inventory (CBI). This is because carer burden is an important measure. As outlined in Chapter 2, Section 2.9, improving carers' physical and mental health, by reducing burden and stress, results in a better quality of life, which in turn can delay admission into institutional care for their loved one (Chiatti *et al.*, 2013). In response to receiving telecare, carers frequently describe the 'peace of mind' that the equipment offers (Sixsmith, 2000; Alaszewski and Cappello, 2006; Reeves *et al.*, 2007; Beale *et al.*, 2009; Dunk and Schuette, 2009; Jarrold and Yeandle, 2009; Koivunen, 2014). The following case study (Figure 3.5) comes from the previously mentioned Aktive project, and highlights the reassurance that telecare can provide for both carers and service users.

"Mr Lindsay was provided with a GPS tracker as part of his support arrangements, to take with him when we walked the dog. Mr Lindsay and his wife held differing views as to how well he was able to manage when he was out walking alone; Mr Lindsay felt the device was unnecessary, but Mrs Lindsay would worry about him. ***'It would help with peace of mind of [my wife], just to be quite honest really'***. Later Mr Lindsay was out walking, had a fall and became confused. ***'I turned round quickly and, you know, for that (snaps fingers), that little second, I didn't know where I was.'***

After that experience he said he would not go for a walk without his GPS tracker. For this couple, the telecare device initially caused friction, Mr Lindsay initially changing his behaviour only for his wife's 'peace of mind', but eventually his experience of feeling confused when out alone made him see the GPS tracker as an important part of his daily routines."

Figure 3.5: Mr & Mrs Lindsay's experience (adapted from Koivunen (2014, p. 12))

Telecare can help carers to manage the risks to the person they care for (Dunk and Schuette, 2009). Carers interviewed as part of a Telecare Pilot run by Kent County Council felt telecare provided reassurance that if an incident occurred, alerts would be triggered automatically and help would be available quickly through the alarm system (Alaszewski and Cappello, 2006). The study reported that the overwhelming majority of those interviewed felt that telecare provided users with support 24 hours a day, every day of the year, helping them to live safely and independently (Alaszewski and Cappello, 2006). Carers also described feeling better supported in their role, which was mirrored in

the findings of Jarrold and Yeandle (2009) and Beale *et al.* (2009). Recipients of telecare and their carers in the WSD programme also reported that they:

“Valued the sense of reassurance gained by presence of the various sensors and alarm systems.” (Newman *et al.*, 2014, p. 27)

Pilotto *et al.* (2011) conducted a multicentre international survey of relatives and/or caregivers of 223 Alzheimer’s disease patients. The survey formed part of the Smart Home for Elderly People - HOPE Project, which was funded by the European Commission. The aim was to investigate the potential role of Information and Communication Technology systems for people with Alzheimer’s disease. Participants were recruited from Italy, Spain, and Greece. Carers reported that the technology could be very useful to improve: ‘quality of life (66.4%), care (56.1%), and safety (87.0%), monitoring bed rest and movements (80.7%), medication use (87.4%), ambient environmental conditions (85.2%); and emergency communication (83.4%)’ (Pilotto *et al.*, 2011).

In 2009, CIRCLE (Centre for International Research on Care, Labour and Equalities) at the University of Leeds conducted a study in Scotland to explore carers’ experiences of telecare (Jarrold and Yeandle, 2009). The research was commissioned by Carers Scotland, with funding from the Scottish Government’s, Telecare Development Programme. The researchers held 30 interviews with carers and ran a focus group with a further 13; they conducted informal interviews with professional stakeholders and observed various aspects of the telecare service. Although the sample of carers encompassed a range of caring circumstances, it was not designed to be representative of all carers in Scotland. It did, however, include carers from a range of geographical locations, with just over half living in the same household as the person they cared for (Jarrold and Yeandle, 2009). The study aimed to:

“Explore the impact (both positive and negative) that telecare has on carers in diverse circumstances and identify the benefits and challenges associated with telecare for carers, and their perceptions relating to the impact of telecare on those they care for.” (Jarrold and Yeandle, 2009, p. 15)

Carers in the study reported the following benefits (adapted from Jarrold and Yeandle, (2009, p. 5)):

- Feeling more relaxed and less stressed.
- Feeling more confident about the safety and wellbeing of the person they cared for.

- Having more opportunity to get away from their caring situation and take a break from caring.
- Feeling better supported in their caring role.
- Improvements in some aspects of their relationship with the person they cared for.

One carer interviewed for the study stated:

“We were at the point where we needed more home care. I was totally stressed out. But once we got telecare it made a massive difference, it relieved a lot of pressure.”

(Jarrold and Yeandle, 2009, p. 24)

Jarrold and Yeandle (2009) also reported that for some carers, having telecare meant they were able to remain in paid employment and therefore the equipment meant that they were able to maintain their family's financial stability. Some carers in the study stated that they no longer felt like they were 'constantly on call'. Greater independence for carers has been a reported benefit of telecare in a number of studies (Alaszewski and Cappello, 2006; Rahimpour *et al.*, 2008; Cullen *et al.*, 2016). One carer interviewed by Jarrold and Yeandle (2009) explained:

“It has allowed me to do more things at home, like crafts and reading a book. Before I would have to be constantly aware of my husband, it really invaded my own time.” (P. 29)

An evaluation carried out in Ireland by Cullen *et al.* (2016), looked at telecare and assistive technology initiatives implemented by four demonstration sites funded under the Genio Dementia Programme (2012-2015). The evaluation involved 24 individuals with dementia and their family carers, each with a tailored mix of telecare sensors and devices. All 24 reported positive benefits, including the following comments from carers (Cullen *et al.*, 2016, p. 3):

“Number one I can sleep in my own bed again, which is marvellous. I mean at 60, sleeping on the floor on an airbed is no joke... And I've got the added benefit that I can go out for a bit of fresh air and sit down on my bench with a cup of tea.”

“This gives her independence. You can monitor but she still feels she is doing her own thing... Otherwise I'd have to be going in and out of the room all the time and that would drive her cuckoo altogether.”

As stated in Chapter 2, Section 2.9, caring for long periods can impact negatively on a person's health and wellbeing. Carers of people with dementia are particularly susceptible to mental ill health, distress, depression, and guilt (Luengo-Fernandez *et al.*, 2010). Telecare may help to alleviate these issues by providing reassurance (Fry and Buse,

2013) and improving mental wellbeing. Carers in several studies have reported feeling reduced levels of stress and anxiety thanks to telecare (Strawn *et al.*, 1998; Alaszewski and Cappello, 2006; Woolham, 2006; Jarrold and Yeandle, 2009; Keogh and Delaney, 2009; Hamblin, 2014a; Cullen *et al.*, 2016). Both Jarrold and Yeandle (2009) and Keogh and Delaney (2009) also reported an impact on sleep patterns, with carers feeling less tired and reporting a better night's sleep when telecare was in place.

Alaszewski and Cappello (2006) found that carers who did not live with the person they cared for felt that telecare reduced the need to 'check-up' on the person as frequently, thereby reducing what they described as their 'surveillance' or 'monitoring' of the person. It has also been suggested that telecare increases flexibility in the caring role and enables 'care at a distance' (Powell *et al.*, 2010). An evaluation of the lifestyle monitoring equipment (see Appendix 7), Just Checking, in Nottinghamshire, found that the equipment played an important role for family members who lived abroad, allowing them to check on relatives and engage with the planning of their care from a distance (Schneider *et al.*, 2010).

Robinson *et al.* (2007) explored the perspective of carers, care workers, and the cared for, on the management of wandering in dementia. The paper combined a systematic review, with stakeholder interviews and focus groups. The findings of the qualitative study showed considerable consensus with the findings from the literature; with the management of risk and risk assessment being identified as a key theme for all carer groups. Both family members and care workers were mindful of the need to balance a person with dementia's right to autonomy, with their duty to minimise harm (Robinson *et al.*, 2007). However, it was established that overall, family care givers are more tolerant of risk than professional carers, who favoured 'safety over autonomy due to a fear of litigation' (P. 400). Carer focus groups prioritised quality of life and independence for the person with dementia above the potential risks, commenting that health and social care professionals were often overprotective (Robinson *et al.*, 2007).

Research examining the use of GPS tracking devices to manage the risks of wandering behaviour has shown positive responses from carers (McShane *et al.*, 1998b; Altus *et al.*, 2000; Miskelly, 2004; White *et al.*, 2010); with the main benefits being increased confidence and peace of mind (Altus *et al.*, 2000; Miskelly, 2004), and a reduction in time until their relative was found (McShane *et al.*, 1998b).

3.9 Effectiveness and Cost Effectiveness

In addition to claims that telecare can support independent living, cut hospital admissions, and improve quality of life for older people and their carers (Bowes and McColgan, 2006), there are also, what some have described as 'grandiose' and 'radical', claims that, telecare can solve workforce shortages and lower the cost of care delivery (Bowes and McColgan, 2006; Pols and Willems, 2011). The development of telecare has not only been driven by technological advances, but also by a need for policy makers to find new cost-effective ways of addressing the supply and demand of health and social care within an ageing population.

It has been suggested that telecare can provide cost savings in a range of ways. Early hospital discharge thanks to telecare reduces the costs of hospitalisation (Curry and Norris, 1997); while a reduction in the number of people entering residential care cuts social care expenditure (Brownsell *et al.*, 2001). It has also been proposed that telecare can help care workers to better manage their time, therefore reducing work force pressures.

O'Sullivan's (2011) evaluation of the Scottish Telecare Development Programme (TDP) which launched in 2006, aimed to support more people to live at home for longer by providing them with telecare. The evaluation combined case studies, user and carer questionnaires, and quarterly returns by health and social care partnerships (O'Sullivan, 2011). Around 60% of the study cohort were categorised as 'older people' and a further 9% were diagnosed as having dementia, however O'Sullivan suggests that the proportion of people with dementia within the study was likely to be higher in reality, due to undiagnosed dementia within the older population.

Overall the evaluation reported that the telecare service helped almost 44,000 people during the period of study; avoiding around 8,700 unplanned hospital admissions and over 3,800 care home admissions, as well as speeding up 2,500 hospital discharges. These outcomes lead to the partnerships saving (O'Sullivan, 2011, p. 2):

- 546,000 care home bed days.
- 109,000 hospital bed days through facilitated discharges and unplanned admissions avoided.
- 48,000 nights of sleepover/wakened night care.
- 444,000 home check visits.

Therefore, over the life of the programme, O'Sullivan (2011) calculated that TDP funding helped to generate a gross benefit with an overall value of almost £79 million.

Furthermore, the Renfrewshire Project in Scotland, examined the cost savings of a telecare project in relation to admissions and length of stay in hospitals and care homes for 325 telecare users with dementia. The project took place over a five year period between 2007 and 2012. It was reported that providing telecare avoided 88 admissions to care homes, and a further 114 admissions to hospital. Extensive sensitivity analysis was employed, and the findings demonstrated a cost saving of over £2.8 million, the equivalent to approximately £8,650 per service user (Craig *et al.*, 2013). Craig *et al.* (2013) verified the effectiveness of the Renfrewshire Council's Telecare Service through examples of clients who remained living safely in their own home despite their dementia, over several years. They reported that telecare 'prevented, or at least delayed, admission to residential care for many people' and 'provided carers with reassurance, support and peace-of-mind' (Craig *et al.*, 2013, p. 1).

However, several articles have previously suggested that the cost saving claims made in relation to telecare, due to the lack of clear evidence, are often over exaggerated (Bowes and McColgan, 2006; Pols and Willems, 2011). Bowes *et al.* (2013) conducted a literature review on behalf of the Dementia Services Development Trust examining the cost effectiveness of assistive technology in supporting people with dementia. Despite exploring a large literature base, the authors only identified 59 articles for full examination, concluding that:

“The literature shows a real dearth of rigorous costs analysis of assistive technology for people with dementia and their carers. Nevertheless, there are clear indications of cost effectiveness in many respects, albeit from indirect evidence.”
(Bowes *et al.*, 2013, p. 20)

O'Sullivan (2011) caution against over-simplifying the cost analysis for telecare. The TDP evaluation process had unavoidable limitations, which are discussed as part of Section 3.10, in particular its reliance on end-of-year figures reported by the various care partnerships. Many of the partnerships found some of the outcome and efficiency measures hard to assess due to the absence of a strong data collection, reporting and evaluation culture (Beale *et al.*, 2009). Consequently, the authors stressed the need for caution when interpreting the gross financial benefits. Nonetheless, O'Sullivan (2011) concluded that telecare can have a transformational effect on service user and carer quality of life; and that going forwards, telecare has an important role to play in enabling people to remain living in their own homes.

Similarly, Henderson *et al.*, (2013a) cautioned policy makers against characterising telecare as a ‘magic bullet’ in the absence of robust evidence of its cost effectiveness. Henderson *et al.* (2013a) carried out a cost effectiveness analysis for the WSD programme and concluded that telecare was no more cost effective than ‘usual care’. However, as previously stated in Section 3.4, the time frame of the study was insufficient to measure the impact of telecare on institutional care admissions, which was considered a significant limitation of the study. Furthermore, the study excluded consideration of the potential benefits of telecare for carers, when measuring the interventions benefits. The following section explores the challenges of measuring the impact of telecare in more detail.

3.10 The Challenges of Measuring the Outcomes for Telecare

The challenge of measuring the outcomes of telecare has, so far, had a detrimental impact on building an evidence base to support its mainstream implementation. The lack of evidence continues to be one of the main barriers preventing widespread uptake of the technology. As previously mentioned, the WSD programme was established in 2008 to address this gap in evidence, but has since been widely disregarded, largely due to its shortcoming in terms of study design (Woolham *et al.*, 2018). The limitations of the WSD programme were explored in Section 3.4; Table 3.3 considers the challenges discussed in the wider literature.

Table 3.3: An Overview of the Challenges of Measuring Outcomes for Telecare

Challenge	Findings from the Literature
Limitations in the data available	<p>The way data is collected, structured, stored, transmitted, and accessed varies not only between local authorities, but also between health and social care bodies. The lack of shared standards and an ability to integrate data and information leads to fragmentation and represents a significant weakness (Giordano <i>et al.</i>, 2011).</p> <p>Yeandle <i>et al.</i> (2014) indicated that the Active project had experienced some difficulties with data analysis. This was due to inconsistencies between Local Authority systems, and added complexity due to organisational changes occurring during the study which related to the telecare services and data recording methods.</p> <p>Beale <i>et al.</i> (2009) reported an absence of strong data collection processes and a limited ‘reporting and evaluation’ culture within the care partnerships they worked with.</p>
Challenges of quantifying measures of success	<p>Looking at the system as a whole, the telecare users and their families are the ones most likely to benefit from the equipment, through improved quality of life, reduced carer burden, greater security, independence, confidence, and the ability to remain living in one’s own home (Barlow and Hendy, 2009). Reduced risk and increased independence are highly</p>

	valued benefits for service users, which also sit in line with national objectives for older people, however they are hard to quantify, particularly in financial terms (Beale <i>et al.</i> , 2009).
Predicting and measuring 'prevented situations'	Prevented situations are inherently difficult to quantify. Beale <i>et al.</i> (2009) measured the impact of telecare based on Quarterly Returns from Care Partnerships. Consequently, a number of outcomes were based on what Partnerships think might have happened if telecare had not been available, for instance 'admission to a care home or an extended stay in hospital' (p. 98). Therefore, the quality of the estimates provided by the Partnerships will be heavily reliant on the knowledge and background of the person or people involved in completing the returns (Beale <i>et al.</i> , 2009).
Valuing qualitative data	The reported experiences of telecare users are incredibly insightful when considering the success of the intervention. Beale <i>et al.</i> (2009) found a few respondents from a user questionnaire had indicated that they felt telecare had 'saved their lives', although this consequence is clearly very important, it is also inevitably subjective.
Difficulties with extracting the costs and benefits between different care sectors	Health care services within the UK are largely free to those who use them, whereas Social Care is means tested. The costs and benefits of telecare may sit with different stakeholders and the boundaries between 'health' and 'social' care may be blurred (Barlow and Hendy, 2009).
Differences in the cost of providing telecare between individual service users	<p>Social care means testing will alter how much telecare costs for different individuals. For instance, someone reliant on benefits, with no savings, may receive telecare for free; whereas someone living within their own home on an occupational pension, is likely to be required to make weekly contributions towards the cost of the equipment.</p> <p>Furthermore, there is likely to be variation in the level of sophistication of the systems installed for each individual and consequently a significant difference in the cost implications. For instance, one person may only require a simple pendant alarm, while another may require a far more complex set of peripheral devices and passive sensors (Barlow <i>et al.</i>, 2005a).</p>
Differences between Local Authorities in what telecare equipment is provided and how the service is delivered	If considering more than one site at a time, extrapolating meaningful results can be challenging due to inconsistencies in service delivery. The range of telecare equipment and the service provided varies between local authorities and therefore there are different cost implications (Pleace, 2011). For instance, charges for telecare can vary between authorities and some offer additional services such as a responder service.
Attributing costs	The costs associated with training staff to use telecare are frequently excluded from cost assessments (Bowes <i>et al.</i> , 2013). Also, cost implications for informal carers in terms of their potential ability to return to the labour market have rarely been considered in the literature (Bowes <i>et al.</i> , 2013).
Telecare is rarely the sole solution	Telecare is frequently used in combination with other health or social care services as part of a package of care, therefore assessing impact and capturing costs savings can be challenging (O'Sullivan, 2011).

Source: Various (see text for specific references)

3.11 Factors Influencing the Uptake of Telecare for People with Dementia

In addition to the lack of evidence, there are also a number of other barriers to the uptake and adoption of telecare that impact on the success of the service. These range from individual level aspects, to higher level design and implementation factors. Telecare uptake is explored in more detail in the following sections.

3.11.1 Individual Level

For telecare to be appropriate for someone with dementia, there needs to be someone willing and able to respond the alerts raised. ATDementia (2016) states that sufficient carers or care support must be available for people with dementia to have telecare installed. If a response service is available locally, then telecare may still be an option for someone without informal care support. However, if there is no such response service, then telecare would not be deemed appropriate.

There are also environmental barriers to telecare adoption. Simple factors such as the type of property a person lives in, for instance whether it is rented or privately owned, may influence the extent to which adaptations can be made (Hagen, 2004; Roulstone *et al.*, 2013a). Furthermore, uptake will be limited to the available equipment, which is dependent on the nature and extent of telecare services within the person's local area (Hagen *et al.*, 2004).

According to Hagen *et al.* (2004), the willingness of an individual with dementia to use assistive technology can be influenced by five independent variables, relating to 'the person with dementia, the carer, the environment, the product, or the researcher' (P.4). Hagen *et al.* (2004) set out an assessment protocol for assistive technology, as part of the previously discussed ENABLE project. They indicated the potential influence of: age, education, previous occupation, ethnicity, dementia diagnosis and stage, co-morbidities, cognitive functioning, nature, duration and degree of the problems, acceptance of condition, and attitude to technology (Hagen, 2004). The attitude of the person towards the technology is directly linked to how they perceive the equipment. Table 3.4 outlines the concerns that may contribute towards telecare being viewed negatively by an individual or their family.

Table 3.4: Concerns that may Influence How a Person or their Carer Perceive Telecare

Concern	Description
Exacerbate isolation	Telecare can generate a fear that human interaction will be replaced by machines (Roulstone <i>et al.</i> , 2013a). There is a concern that a reliance on 'remote care' may compound issues relating to isolation in old age for both the service user and their carer by reducing their face to face contact with care workers (Marshall, 2000; Tang and Venables, 2000). Dewsbury and Edge (2000) warn of the risk that technology may allow people to 'function in society, rather than actively participate in it' (p. 11).
Intrusion / loss of privacy	Invasion of privacy and the sense of being 'under surveillance' have been cited as two of the main issues associated with remote care/monitoring (Percival and Hanson, 2006). When considering telecare some people feel the "perceived benefits are not sufficient enough to outweigh the feeling of intrusion" (Brownsell and Bradley, 2003, p. 75).
Threat to feelings of identity and independence	Sanders <i>et al.</i> (2012) examined the reasons why people withdrew from or chose not to participate in the Whole System Demonstrator trial. They found that the perceived threat of telecare to identity, independence and self-care, posed a barrier to uptake. Respondents saw self-reliance as a component of positive ageing, they viewed the acceptance of equipment as undermining their ability to cope and to care for them-selves (Sanders <i>et al.</i> , 2012). Roulstone <i>et al.</i> (2013b) refer to people's concern that telecare, such as a pendant alarm, may be seen by others as a 'badge of vulnerability' (p. 66). Lebbon and Boess (1998) suggest that older people are more likely to want the technology if they see it as benefiting their health and wellbeing rather than as a symbol of dependency. Sixsmith and Sixsmith (2000), proposed that adoption of telecare relied on perceived need, usefulness and whether the equipment supported the individual's sense of personal identity.
Embarrassment and stigma	Hamblin (2014a)'s working paper from the Aktive project, found that some participants saw the telecare equipment as a source of embarrassment and stigma. They appeared to associate telecare with other adaptations and aids that they perceived to be markers of old age. Consequently, Hamblin (2014a) concluded that there was a 'trade off' between how telecare impacted the way people felt they were perceived, and the contribution of the equipment to their identities as 'active, independent and embedded in places and communities which they valued' (Hamblin, 2014a, p. 15). The paper concluded that telecare could be redesigned and repackaged as something more desirable, rather than being seen as the 'least bad option' among alternatives.
Technical competence	Sanders <i>et al.</i> (2012) found that people were deterred from using the equipment if they believed it would require learning special skills to use it. Roulstone <i>et al.</i> (2013a) also refer to the difficulty of frail older people, with cognitive decline, learning about new equipment.
Disrupt or change existing service	Sanders <i>et al.</i> (2012) also found that people were reluctant to take on telecare if they thought they might lose their current package of care. Respondents often stated that they valued their current service and preferred to maintain the existing care relationships that they had with their care providers (Sanders <i>et al.</i> , 2012).
Cost	If a contribution is required from the service user, this can deter people from accepting the equipment.

Sources: Various (see text for specific references)

Findings from the Aktive project, examining telecare for people with dementia, highlighted the importance of the installation situation and first impressions of the equipment (Koivunen, 2014). These elements within the process were identified as particularly significant in shaping how the equipment was perceived and understood, which in turn influenced whether the equipment was embraced by the intended user. Furthermore, experiences relating to the responses of monitoring centre staff, nominated responders, and emergency or medical staff also impacted how the telecare was viewed. Koivunen (2014) reported that one negative experience had the potential to discourage use of the equipment going forward. These findings echo that of Horton (2008), where a pilot study in Surrey examined the role of telemonitoring devices for 35 older people with dementia. Horton (2008), found that some users considered the devices intrusive, and disliked that they were unable to control when the call centre was alerted; this therefore impacted their willingness to continue using the equipment.

Careful assessment is crucial, if the individual's needs and preferences are not taken into consideration when they are first assessed for telecare, then the equipment may be ineffective or even cause further confusion or distress. The AT Dementia website (2016), which provides information on assistive technology for people with dementia, points out that telecare may not be the answer if:

- The person switches off or unplugs the equipment.
- The person is confused or distressed by the equipment or by any alarm sound or response it raises.
- There are insufficient carers to respond to an alert.

Koivunen (2014) emphasised the importance of engaging family members and social contacts with the equipment and ensuring they themselves felt confident in the telecare system and its purpose, enabled them to support the older person to feel more confident in the system and to view any false alarms as 'test runs' (Koivunen, 2014). Finally, Koivunen (2014) concluded that an understanding of an older person's needs, social situations, and abilities was essential, as was recognition that these elements are varied and changing. Therefore, any form of support needs to be flexible, reviewed regularly, and implemented, wherever possible, with the engagement of the person's significant others.

Lebbon and Boess (1998) suggest that older people are more likely to want the technology if they see it as benefiting their health and wellbeing rather than as a symbol of dependency. Sixsmith and Sixsmith (2000), proposed that adoption of telecare relied on perceived need, usefulness, and whether the equipment supported the individual's sense of personal identity.

3.11.2 Carer and Care Worker Resistance

Little is known at present regarding the influence that the personal characteristics of carers and care workers may have over their engagement with or resistance to telecare (Roulstone *et al.*, 2013a). Nonetheless, both can play a significant role in telecare uptake. Hagen *et al.* (2004) outlined some of the key factors concerning a carer's status that may impact on their influence over the adoption of assistive technology:

- The person with dementia's relationship to the carer,
- The nature of the caring role,
- Whether he/she was cohabiting,
- The carer's employment status,
- The carer's perception of the character of the individual they care for,
- The importance of the memory problem of the person being cared for,
- The expected outcome of implementing the assistive device.

Family and carer anxiety regarding the use of technology can form a barrier to telecare (Siotia and Simpson, 2008). Alaszewski and Cappello (2006) reported that some carers and care workers were concerned about the use of telecare, due to a lack of knowledge and training. Powell *et al.* (2010) found that carers were concerned that they may lack the necessary skills to use the equipment. A survey of local authorities, carried out between November 2016 and January 2017 found that although training for telecare assessors was offered, this was usually provided by the equipment manufacturers and suppliers, and was often very short (for 24% of respondents the duration was between half a day and one working day) (Woolham *et al.*, 2018). They also found that 'the percentage of training formally accredited by an external organisation like a university or college was very small, and almost none of the training provided led to a formal qualification of any kind. (Woolham *et al.*, 2018, p. 4). Therefore, training for both carers and care workers is important in order to reduce anxieties about the equipment and to address barriers relating to a lack of knowledge (Powell *et al.*, 2010; Yeandle and Fry, 2010).

A further barrier relates to insufficient information and awareness, as both carers and care workers are often unaware of the range of telecare available, or they do not know how to access the service (Roulstone *et al.*, 2013a). Therefore, it is important to promote telecare effectively and raise awareness. Clark and McGee-Lennon (2011) suggest that there is an urgent need to provide training, 'supplier neutral' information, and raise awareness of currently available telecare, as well as upcoming technology, as a means of addressing many of the barriers that currently limit the uptake of the equipment.

Care workers often have reservations about telecare when it is first introduced, fearing that it may impact job security, or that it may reduce their contact time with people (Kerr *et al.*, 2010). Hibbert *et al.* (2003) reported that nurses involved in the implementation of a home telecare services were concerned that they were being replaced with technology. This was echoed in Clark and McGee-Lennon (2011) who noted that the introduction of technology was perceived by some as a cost cutting exercise. Mainstream services have been slow to embrace telecare, putting a greater emphasis on formal care, despite numerous authoritative reports promoting its use (Brownsell *et al.*, 2007). The mainstream introduction of telecare would require a cultural shift, as many informal carers and health professionals continue to hold the view that human care is the only appropriate form of support for people with dementia (Siotia and Simpson, 2008). Clark and McGee-Lennon (2011) suggest that in order for telecare to be successful, care professionals need to build their confidence with the technology, they need to understand that telecare can be used to support rather than replace existing packages of care.

There is also the risk that care professionals can under prescribe telecare based on the assumption that the majority of older people have 'technophobia' towards advanced home care technologies (Clark and McGee-Lennon, 2011). However, there is evidence in the literature (Brownsell *et al.*, 2000; Tinker and Lansley, 2005) to suggest that the belief that technology is feared by older people is a misconception, with many older users welcoming technology. Clark and McGee-Lennon (2011) reported that many of the older people participating in their focus group, which discussed the current barriers to uptake for home care technology in the UK, considered 'technophobia' as less relevant to them and as more of an issue for the previous generations.

3.11.3 Ethical Considerations

Problems in obtaining informed consent can also create a barrier to using telecare for people with dementia (Siotia and Simpson, 2008). Care workers may be more reluctant to use telecare for someone who is cognitively impaired if they cannot actively engage in the decision-making process.

“However, if the individual lacks capacity to consent, the views of people involved in their care, including family, friends and other professionals, should be taken into account and a decision taken in the patient’s best interests.” (Siotia and Simpson, 2008, p. 5)

There are also ethical considerations regarding intrusion into service user’s privacy. It is important to carefully select the aspects to be monitored to ensure that privacy is not

otherwise invaded; it is also important to put in place confidentiality guidelines regarding the data that is gathered (Siotia and Simpson, 2008).

GPS tracking devices raise particular ethical questions as tracking a person's movements impacts upon their liberty, particularly if they are restricted to an area that a carer deems as safe. Critics of the technology feel that it poses a threat to the user's human dignity and freedom (Cahill, 2003; O'Neill, 2003). There is a risk of stigmatisation and prejudice; O'Neill (2003) suggests that electronic tagging and tracking 'evokes unfortunate metaphors: infantilisation, custody and a subhuman existence' (p. 1). However, when considered against alternative measures to mitigate the risks of wandering, GPS could be considered as one of the least restrictive interventions. Counsel and Care's publication in 1993 of 'The Right to Take Risks', detailed 20 forms of restraint regularly used in care settings to prevent wandering, which ranged from tying someone down, to the use of pharmacological interventions, locks, curtains, concealing doors, threats, and poverty. Another publication mentioned the use of restrictive seating such as bean bags, which trap the individual in a seated position (Hughes and Louw, 2002).

3.11.4 Providers and Commissioners

Goodwin (2011) refers to financial pressures on local authority budgets, alongside resistant organisational cultures, as creating a major barrier to wider telecare adoption.

“Many implementation difficulties relate more to the organisational and structural conditions within which telecare is deployed than the technology itself.” (Barlow *et al.*, 2005a, p. 50)

Barlow *et al.* (2005a), identified several major organisational level problems in the planning and implementation process for telecare. Firstly, the absence of an identifiable 'local policy sponsor' lead to confusion over funding responsibilities. Secondly, there was a lack of engagement from senior managers. Thirdly, organisational restructuring further exacerbated confusion over responsibilities and resulted in high staff turnover, which had knock on consequences for momentum and morale; and finally, bringing together teams from a range of sectors, including health and social care all with different working practices, meant that no one had an overview of the entire process (Barlow *et al.*, 2005b).

The number of different agencies involved in assessing and supplying telecare can cause problems, with misunderstandings particularly between engineers and health services (Dewsbury *et al.*, 2002). Buckle *et al.* (2014) reviewed the human factors that influence the performance of telecare. The paper discusses a range of examples of problems that

occurred during the Aktive study, which resulted in failures within the system. These problems can occur at any point, from procurement and installation, to assessment and review; problems can be caused by the person's use of the equipment, or by the monitoring centres, or even during the response to an alert.

“Latent failure types were commonly identified during the study. Latent failures are made by people whose tasks are removed in time and space from operational activities, e.g. designers, decision makers and managers. Examples of latent failures are: poor design of equipment; ineffective training; inadequate supervision; ineffective communications; and uncertainties in roles and responsibilities.”

(Buckle, 2014, p. 25)

3.11.5 Functionality and Design

The acceptability of telecare equipment relates to its design, function, and reliability (Hagen, 2004). Putting equipment into people's homes is not a guarantee that it will be used (Roulstone *et al.*, 2013a). If the equipment does not fit with the person's needs, is too challenging to use, is unsafe, unreliable, or is not delivered in a timely way, then these factors will negatively impact compliance and uptake (Wielandt and Strong, 2000; Lansley *et al.*, 2005). Dewsbury (2001) notes that the functionality of the equipment is of particular importance for people with dementia, who may easily become distressed or confused.

Once telecare has been installed, the issue of compliance can play a key role in its continued use. A study by Taylor and Agamanolis (2010) of 1,324 individuals provided with a personal alarm in North East Scotland found that one third of the participants only wore the pendant 'some of the time'. The reasons people gave for removing the pendant included: concern around accidentally triggering an alert, because the pendant did not work outside the house, or because they felt the pendant was too bulky or conspicuous (Taylor and Agamanolis, 2010).

Both Sanders *et al.* (2012) and Hamblin *et al.*, (2014a) promote the importance of incorporating feedback from older people in the design and implementation process for telecare. Hamblin (2014a) highlights the fact that modern society is full of technology that is not only needed, but wanted; suggesting that telecare manufacturers, designers and service providers need to deliver devices that are not just tolerated, but are instead seen as desirable and essential for supporting wellbeing in later life.

3.12 Overcoming Barriers

In order to overcome the previously discussed barriers to telecare, feedback from service users should be included in the design and implementation of the equipment to ensure it meets their requirements (Roulstone *et al.*, 2013a). Furthermore, careful, person-centred assessments need to be conducted to ensure equipment is deployed appropriately. Siotia and Simpson (2008) emphasise that telecare will not be the right solution for everyone. Telecare assessments need to take place prior to the installation of equipment, and the assessment should be carried out in the person's home, otherwise needs that could be met by the technology may be overlooked (Woolham *et al.*, 2018).

“Assessment in non-home environments is also potentially problematic because it does not enable the assessor to observe how the individual interacts with their home environment, which could lead to devices being inappropriately chosen or sited.” (Woolham *et al.*, 2018, p. 45)

Telecare applications must be tailored and reliable, with the adequate inclusion of social and health care services (Topo, 2009). Rigorous assessment requires a deep level of understanding; telecare assessors need to have the appropriate skills and experience to carry out effective assessments. Investment in training for assessors, installers, call centre staff and paid responders is essential; training for informal carers may also be beneficial (Clark and McGee-Lennon, 2011). Furthermore, the quality of the training is important (Woolham *et al.*, 2018).

The UTOPIA (Using Telecare for Older People In Adult social care) project, led by the Social Care Workforce Research Unit at King's College London, surveyed all 152 English local authorities with social care responsibilities (Woolham *et al.*, 2018). The survey took place between November 2016 and January 2017 and received a 75% response rate. The study emphasised that the use of telecare to support carers is part of its potential. Therefore, they recommended that older people and their carers should be involved as fully as possible in decisions regarding telecare provision to reduce the risks of the technology being subsequently abandoned. Koivunen (2014) also asserted that engaging family members and carers with the equipment is important for ensuring a telecare installation is successful.

Efforts must be made to raise awareness of telecare equipment amongst care professionals and the wider population (Clark and McGee-Lennon, 2011). Steps should be taken to address the shortage of 'objective' information about telecare devices (Woolham *et al.*, 2018).

Organisational boundaries need to be reconfigured to allow telecare services to be integrated effectively into existing care systems (Barlow *et al.*, 2005a). Examples of good practice should be circulated and standards should be agreed and shared between local authorities, as this would support appraisal and benchmarking (Woolham *et al.*, 2018). Nationally recognised accreditation should be sought, for instance the 'Telecare Services Association practice standards for telecare and telehealth'. These steps would ensure that a good quality and more consistent standard of service is offered.

Telecare needs to be viewed as part of a bigger picture. Savings from telecare investment should be considered in respect of other local accounts outside of local authority social care (Barlow and Hendy, 2009). For instance, investment from social care may create potential savings for the NHS in terms of hospital admissions, or reductions in the number of calls to the emergency services, such as the fire brigade. The UTOPIA project suggests that it could be beneficial for a national organisation, such as the National Audit Office or NHS England to provide a wider overview of broader of the cost effectiveness of telecare. They also caution that 'telecare manufacturers should not be considered appropriate organisations for such a review because of their vested interest in encouraging telecare use' (Woolham *et al.*, 2018. P. 47).

Telecare funding in terms of eligibility criteria should also be reviewed. The UTOPIA study found that some local authorities do not permit telecare under direct payments (refer to Section 3.5.1 for further information on direct payments), this is something that should be investigated (Woolham *et al.*, 2018). Consistent processes and standards for service delivery across localities would facilitate deployment of the equipment and evaluation of its impacts.

Person-centred provision of telecare requires that devices be carefully matched to assessed needs, therefore local authorities should ensure they are offering a sufficiently wide range of telecare and electronic assistive technology devices to meet potential needs (Woolham *et al.*, 2018). Once the equipment is installed it should be monitored and reviewed on a regular basis. Cowan and Turner-Smith (1999) highlighted the importance of 'follow up' visits after an installation, in order to monitor changes in user's needs, as technology can easily become redundant as a person's physical status changes. Equipment must be regularly checked and maintained to ensure that it continues to work properly, mechanisms should be put in place to ensure the upkeep of the equipment.

Finally, as mentioned in Section 3.11.3, the use of telecare involves various ethical considerations, especially when it is being used for people with dementia. Guidelines for the key ethical considerations associated with telecare are set out in Appendix 12.

Recommendations for providing an ethical telecare service are outlined in Penny (2009). It is 'essential that professional practice develops in parallel with the expansion of telecare, to ensure the benefits are realised and the risks are managed' (Francis and Holmes, 2010, p. 2).

3.13 In Search of Robust Evidence for Telecare in Dementia Care

Despite the broad range of evidence available in relation to the use of telecare for people with dementia, much of the available literature refers to pilot studies, service evaluations, observational findings, and short term assessments of impact (Bower *et al.*, 2011). Qualitative evaluations typically provide insight into people's experience of an intervention and their beliefs about it, rather than attempting to objectively measure its outcomes (Davies and Newman, 2011). Furthermore, the short term, small scale assessments and evaluations, that are often conducted in relation to Pilot Studies, present issues regarding the generalisability of their findings.

Barlow *et al.* (2007) highlighted the lack of high quality evidence for the effectiveness of telecare when used for safety and security monitoring. Martin *et al.* (2008) completed a Cochrane Systematic Review entitled 'Smart home technologies for health and social care support'; which considered a substantial amount of published literature, but was unable to find a single paper that met their strict inclusion criteria. The paper concluded that:

"The current available published studies lack the application of robust empirical methodologies to validate smart home technologies as an effective intervention to support health and social care." (Martin *et al.*, 2008, p. 6)

Furthermore, Leroi *et al.* (2013) refer to the 'relative dearth' of dementia specific studies in this area of research, resulting in a significant gap in the evidence. This lack of, what is termed as, 'robust evidence' led to the establishment of a series of large scale RCTs across Europe: ATTILA in the UK, UP-TECH in Italy and the TECH@HOME study in Sweden (see Appendix 13 for further details). Each of these studies specifically examines assistive technology and telecare for supporting people with dementia; and all three examine the impact of the technology on carer burden. However, at the time of writing, none of the studies had published their findings.

An RCT is frequently portrayed as the optimum method for assessing effectiveness; it allows the researcher to establish whether, under examination, a cause and effect

relationship exists between telecare and the outcomes (Davies and Newman, 2011). However, some commentators argue that RCTs are inappropriate when examining an intervention as complex as telecare (Williams *et al.*, 2003). Delaney (2011) suggested that it would be difficult to conduct an RCT of telecare effectively, as it has so many different technical, clinical, social, and organisational components. Furthermore, Barlow and Hendy (2009) argue that those who are likely to benefit most from telecare are service users and their families, and they are far more likely to value outcomes that relate to quality of life that are hard to quantify.

For telecare to move forward it is important to consider the impacts of the intervention as a whole and to continue building the evidence base. In the absence of robust empirical data, simulation modelling has previously been utilised effectively to provide insight into a range of complex health and social care systems. Chapter 4 will explore this theme in more detail.

3.14 In Summary

Information and communication technologies have become integrated into many aspects of our everyday lives; but while technology may have become integral to our social lives, it also offers enormous potential for the delivery of health and social care. In this chapter, it has been proposed that telecare can help people with dementia to maintain their independence, delaying or even eliminating the need for residential care (Brownsell and Bradley, 2003; Siotia and Simpson, 2008). Evidence has been discussed which indicates that telecare can reduce the potential for accidents and mediate risks in the home (Clark, 2008); provide service users with increased choice, offering more options for condition management (Knipscheer, 1994). Furthermore, there is evidence demonstrating that telecare has a role to play in reducing carer burden.

Telecare can alleviate carer stress by providing 'peace of mind' (Brownsell and Bradley, 2003; Alaszewski and Cappello, 2006) and allow carers greater personal freedom, reducing the pressure placed upon them (Clark, 2008; Beale *et al.*, 2009). In some instances, permitting them to pursue their own interests or continue in full time work (Jarrold and Yeandle, 2009). Telecare can also enable carers and care workers to remotely monitor an individual's daily activities. Therefore, the equipment can help maintain the person's health through the early detection of signs of deterioration; thus, facilitating accelerated diagnosis and treatment (Wright, 1998).

Despite the growing body of literature describing the benefits of telecare, much of this is based upon anecdotes and short-term trials, which has been insufficient to encourage nationwide implementation. Even with enthusiastic backing from the UK government many seemingly successful telecare pilots fail to take off as a mainstream service (Hendy *et al.*, 2012).

The latter half of this chapter explores the barriers to telecare that have limited its uptake and spread. It then discusses at length the steps that could be taken to overcome these barriers and ensure the successful delivery of telecare as a mainstream service. The chapter concludes by outlining three large scale randomised control trials that have been set up with the aim of providing robust evidence for telecare as a form of dementia care; each including a measure of the impact of the technology on carer burden.

However, the success of the RCTs is yet to be reported and therefore there is still little known of the possible effects of telecare on the wider dementia care system. This gap in knowledge was identified in Barlow *et al.* (2005b) as an area of research that simulation modelling could help to address. This chapter provides the context for model development; any results produced through modelling would need to be considered against this backdrop.

The following chapter explores the Operational Research literature on simulation modelling applied to health and social care, and provides evidence of the suitability of the hybrid simulation method chosen to achieve the research objective of this thesis.

Chapter 4: Literature Review - OR Modelling in Health and Social Care

4.1 Chapter Overview

This chapter forms the main literature review of the thesis, examining previous examples of modelling applications in the fields of health and social care. Conducting a literature review and understanding the methods available is the second step of the modelling framework outlined in Chapter 1, see Figure 4.1.

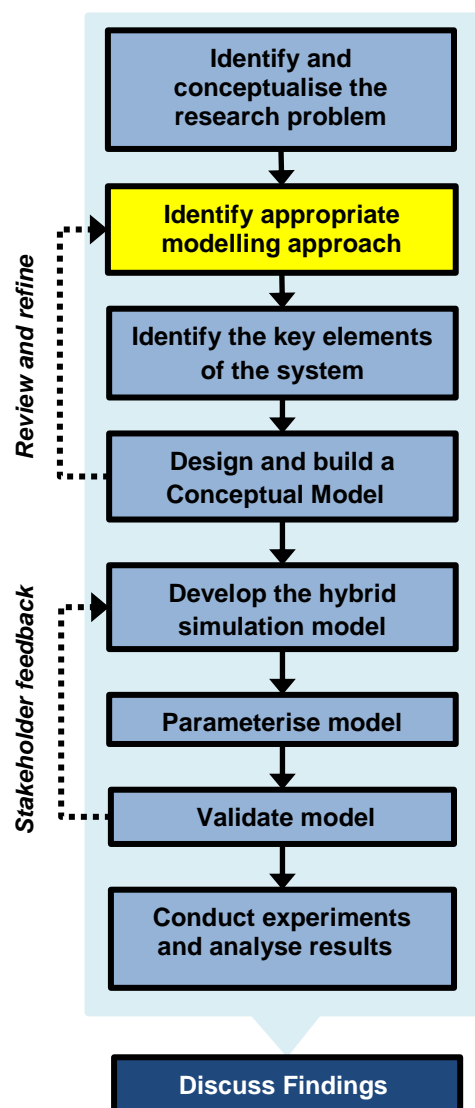


Figure 4.1: Addressing Part Two of the Modelling Framework

Search criteria for this chapter started broad, using terms such as 'Operational Research modelling' or 'simulation' paired with 'health', 'health care' or 'social care'. A second-round

of searches were then conducted for different OR techniques, such as 'discrete event simulation', 'system dynamics', 'statecharts', and 'agent based simulation'; searched in combination with 'health care', 'social care', 'aged care', 'long-term care', or 'ageing' / 'ageing population'. The final round of searches focused on more specific terms relevant to the research, including: 'dementia', 'Alzheimer's', 'cognitive decline', 'telecare' or 'remote care', paired with the various modelling terms.

Initial searches on Web of Science for 'Operational Research modelling' with 'health' generated over 1,400 items. By comparison, combining 'health' and 'simulation', generated over 22,000 items. Literature was excluded if it did not use some form of simulation modelling. The articles were then filtered further so that only simulations recognised as forms of OR modelling were included.

The search was conducted using the Web of Science and JSTOR journal databases, alongside Google Scholar, and the University of Southampton's TDNet. Google was also used to identify 'grey' literature relating to modelling examples which were reported outside of the academic literature. Many articles and books were identified through references from the bibliographies of other publications; this process is referred to as 'snowball tracking' by Brownsell et al. (2007).

Priority was given to studies that related to dementia or ageing; where examples from this area were absent, they were included from broader searches relating to progressive diseases or new models of care. In some instances, examples from outside of health or social care were also incorporated if they provided an illustration of a particular concept. For example, when exploring hybrid modelling, papers covering a wider range of human centric systems were also considered.

Literature of interest included journal articles, conference proceedings, book chapters, and where relevant, non- academic reports. The final literature review presented in this chapter focuses on 114 publications. The chapter is made up of five distinct parts. The first section of this chapter provides a brief overview of Operational Research (OR) modelling for healthcare. The second section details the most commonly used simulation approaches in OR. The third component looks at implementing OR models in social care. The fourth section considers the published examples of modelling in social care for the ageing population, and the final summary section highlights the existing research gap, and the chosen modelling approach with which this thesis aims to make its contribution.

4.2 OR Modelling in Healthcare

The number of journal articles detailing applications of OR Modelling for the UK Healthcare System has grown substantially since the 1950s (Royston, 2009). OR has been applied successfully to assist 'clinical decision-making, facility location and planning, resource allocation, evaluation of treatments, and organisational redesign' (Brailsford, 2007, p. 1436). Healthcare systems are large, costly, and multifaceted. They are characterised by uncertainty and variability (Katsaliaki and Mustafee, 2011), and as such, they require an approach capable of dealing with complexity (Brailsford, 2007). Decision trees, Markov models (Barton *et al.*, 2004), and simulation models (Brennan *et al.*, 2006) are the main techniques used in healthcare evaluation.

Decision trees are a fairly simple form of modelling (Barton *et al.*, 2004). They are aggregate level models, and therefore follow a cohort over time rather than individual people (Squires and Tappenden, 2011). A decision tree outlines all possible decision alternatives, the probability of each event, and assigns values to each outcome, such as, a cost or net benefit measure (Brennan *et al.*, 2006). Decision trees are useful when a decision process can be broken down into a branched structure, with each event of interest occurring once; however they are not appropriate when a problem is more complex or when variability between individuals is important (Squires and Tappenden, 2011).

Markov models are typically stochastic models used to represent randomly changing systems (Gagniuc, 2017). A Markov model is particularly useful when 'a decision problem involves a risk that is ongoing over time, when the timing of events is important, and when important events might happen more than once' (Sonnenberg and Beck, 1993, p. 322). All events of interest are modelled as transitions from one Markov state to another (Nikfar, 2012, p. 13). Markov models are commonly used in healthcare modelling to describe movement between discrete health states (Sonnenberg and Beck, 1993). For example Dowd *et al.* (2018) developed a Markov model to represent the progression of a patient through the stages of dementia in order to estimate the cost-effectiveness of a Connected Health Intervention. They modelled the dementia pathway as five discrete health states: mild dementia, moderate dementia, moderate-severe dementia, severe dementia, and death, to examine the changes in costs of care and quality of life over time. Although there are many examples of Markov models within the healthcare modelling literature (Tennvall and Apelqvist, 2001; Hurley and Matthews, 2007; Shechter *et al.*, 2008; Garg *et al.*, 2010; Gillespie *et al.*, 2011; Deo *et al.*, 2013; Dowd *et al.*, 2018), other modelling methods are preferable when the model must accommodate individual patient histories, multiple

simultaneous events, and variability between patients (Squires and Tappenden, 2011; Standfield *et al.*, 2014).

Consequently, simulation has become the method of choice for many OR healthcare modellers. Simulation can accommodate complexity and uncertainty in a way that empirical models, such as Markov models, cannot (Standfield *et al.*, 2014). Simulations allow stakeholders to conduct experiments to examine different courses of action (Pidd, 2004) in a safe, efficient, and cost effective manner (Squires and Tappenden, 2011), offering an appealing alternative to empirical research (Royston, 1999). A further benefit of simulation is that it facilitates communication between a diverse range of stakeholders by generating a shared representation of the system of interest; this can be particularly beneficial when dealing with stakeholders from different organisations or professions (Ferlie *et al.*, 2005).

Simulation has developed rapidly in recent years as computer technology has become more widely used and computers have become increasingly powerful (Fone *et al.*, 2003). Furthermore, the introduction of more user-friendly software has opened up simulation to a much wider range of users (Barlow and Bayer, 2011). Under the umbrella term 'simulation', there are a range of different approaches. The most commonly applied simulations include Monte Carlo Simulation (MCS), System Dynamics (SD), Discrete Event Simulation (DES), and Agent Based Modelling (ABS), with DES accounting for the overwhelming majority of applications within healthcare (Brailsford *et al.*, 2012a). For the purposes of this research the latter three approaches will be explored in more detail from Section 4.3 onwards.

4.3 Selecting a Simulation Approach

Selecting a simulation technique to model a system is dependent on the system being modelled. The modeller will need to understand the system and the data available. They will also need to understand the various modelling structures and the circumstances in which they are appropriate. Furthermore, they may be influenced by software availability, personal preference, and their own modelling ability (Brennan *et al.*, 2006). Various taxonomies of healthcare modelling have been proposed within the academic literature, including those outlined by Barton *et al.* (2004), Brennan *et al.* (2006), Cooper *et al.* (2007), and Brailsford (2007), with each offering guidance on which modelling approaches are suitable in particular situations, highlighting the advantages and disadvantages of various methods.

One such taxonomy, proposed by Brailsford (2007), grouped healthcare simulation models into three categories. Firstly, ‘models of the human body’, although frequently referred to as ‘disease models’, can also represent biological processes in healthy humans. Models produced by Davies *et al.* (2000); Rauner *et al.*, (2005); Getios *et al.*, (2010); Guo *et al.*, (2012) and Tong *et al.* (2017), provide a selection of examples. Secondly, ‘operational or tactical models’ form a traditional area of OR modelling. The literature presents a vast number of examples within this category, particularly using DES (Bailey, 1952; McGuire, 1997; Harper and Shahani, 2002; Miller *et al.*, 2004; Katsaliaki and Brailsford, 2007; Pilgrim and Chilcott, 2008; Lebcir *et al.*, 2017). Finally, ‘strategic models’, of which there are relatively few published examples, typically use System Dynamic modelling, which lends itself to strategic planning (Royston *et al.*, 1999; Atun *et al.*, 2007).

Brennan *et al.*’s (2006) modelling classification is based on whether a model is cohort-based or individual-based, dependent on discrete time or continuous time, and whether or not it allows for interactions between individuals. As an example Hoang *et al.* (2016) provide a simplified classification of some typical modelling paradigms according to two criteria proposed by Brennan *et al.* (2006) as shown in Table 4.1.

Table 4.1: Classification of Modelling Paradigms

	Cohort-based	Individual-based
No interaction allowed	Decision tree / Cohort Markov model	Individual-based microsimulation / Markov microsimulation
Interaction allowed	System dynamics model	Agent based model / Discrete event simulation

Source: Hoang et al. (2016) p.3

In November 2013, the International Society for Pharmacoeconomics and Outcomes Research (ISPOR), established a ‘Dynamic Simulation Modelling Emerging Good Practices’ Taskforce to focus on dynamic simulation modelling methods that can be applied in health care delivery research. The taskforce produced a two-part report providing guidance for comparing and selecting an appropriate simulation method for addressing a particular problem scenario in healthcare, see Marshall *et al.* (2015a) and Marshall *et al.* (2015a). The taskforce focussed on comparing DES, SD and ABS, which are explored in further detail over the following sections.

4.3.1 System Dynamics

SD was developed by Forrester (1961), and combines both qualitative and quantitative aspects. SD is a ‘top down approach’, the fundamental principle is that ‘structure

determines behaviour'. Therefore 'if we can understand the structural relationships between the elements within a system, then we will be able to understand the emergent behaviour of the system as a whole' (Brailsford, 2007, p. 1437).

SD models a system as a series of interacting variables. It is able to handle direct causal links, such as growth in population leading to increased depletion of resources, and feedback loops, whereby a growth in population would depend on the supply of food, but food supply would depend on population size (Sterman, 2000). The main concepts in SD are feedback, accumulations (stocks), rates (flows), time delays, and non-linearity (Sterman, 2000). Stocks are accumulations, they represent the difference between an inflow to a process and its outflow (Sterman, 2000); they represent aggregations of something, for example food, products, people, or oxygen. Flows determine how fast a system changes; they are rates that feed in and out of stocks. For example, food consumed per day, shipments per week, people per hour, or oxygen per minute. The concept of non-linearity is tied to the existence of feedback within a system; 'it means that an effect is seldom proportional to the cause' (Marshall *et al.*, 2015b, p. 7).

The main outputs from an SD model are trends and patterns, as well as mean values. SD models are relatively quick to run, and they are less concerned with parameter estimation and validation than DES (Brailsford and Hilton, 2001). They tend to be used at a strategic or conceptual level to enhance the understanding of a system and the interacting relationships within it (Desai *et al.*, 2008). Its characteristics mean that SD modelling has been particularly useful in the evaluation of policies relating to healthcare interventions. In 2009, the Department of Health published a paper deeming SD a useful tool for examining operational and strategic choices.

However, SD has its disadvantages. Individuals cannot be identified within the model as it treats simulated objects as a continuous mass (Brailsford and Hilton, 2001); this has potentially limited its appeal among health or social care professionals who are trained to focus on the individual (Brailsford, 2007). Furthermore, SD models are deterministic, this limits the ability of SD to capture certain elements of uncertainty and variability that can easily be incorporated into a stochastic model.

4.3.2 Discrete Event Simulation

DES was developed in the 1960s to help analyse and improve industrial and business processes (Karnon *et al.*, 2012). DES is characterised by its ability to represent complex behaviour, capturing interactions between individuals, populations, and their environments (Pidd, 2004). A DES represents a system as an ordered sequence of well-defined events

or activities. The main concepts within a DES are: entities, attributes, activities, resources, queues, and time. Table 4.2 is adapted from Karnon *et al.* (Karnon *et al.*, 2012, p. 702), Squires and Tappenden (2011, p. 8) and Brailsford *et al.* (Brailsford, 2014a); it provides an overview of the core components of a DES.

Table 4.2: The Components of a Discrete Event Simulation

Component	Description
Entities	Passive objects that have attributes, experience events, consume resources, and enter queues, over time. They are individual items that flow through the system, for example orders in a supply chain, vehicles in a transport system, or people in a service system or hospital (Robinson, 2014).
Attributes	Specific features that can be assigned to each entity allowing it to carry information. For example, an entity may represent a patient and therefore the entity can be assigned attributes that reflect the required human characteristics, such as age, gender, diagnosis, marital status, and quality of life. The assigned attributes can be used to determine how an entity responds within the model. Attribute values can be updated over time, aggregated with those of other entities, or analysed further outside the simulation.
Activities	Also known as events, perform work on the entities. They are what happens to an entity travelling through the represented system. Activities can occur, and recur, in any logical sequence. An activity could be a treatment, or a hospital admission for example, or the progression of a disease to a new stage, or a change in medication.
Resources	Objects that provide a service to an entity, such as staff, equipment, or hospital beds. They are required to be present to operate the activities (Robinson, 2014).
Queues	If a resource is 'occupied' when an entity needs it, then that entity must wait in a queue for the resource to become available. A queue in the model can represent a waiting area, a waiting list, a store or phone call queuing for example. A queue can have a maximum capacity and rules can be applied that alter how entities are 'called' from queues.
Time	Time is explicitly modelled by calculating when the next event will occur following the occurrence of each event (Pidd, 2004). Time forms a central component to DES, and consequently the model can examine length of stay in hospitals, time spent with symptoms, or survival, for example.

Sources: Various (see text for specific references)

One of the many advantages of DES is the ability to vary the duration of activities for entities according to their individual characteristics (attributes) and previous history by sampling from parametric or empirical distributions (Brailsford, 2007). In Karnon and Brown's (1998) paper, comparing the use of DES to Markov chain models and Decision trees for economic evaluation in health economics, they argue that this ability to model an

individual's pathway by sampling probabilities from a distribution, allows the model greater realism in the depiction of patient experience, and a greater flexibility in terms of data requirements.

Complex logical rules can be applied to entities to determine their routing through the system. The stochastic nature of DES enables it to capture the randomness, variability, and uncertainty of real world situations. Many DES software packages also offer the advantage of incorporating animation and graphics into the model implementation. This can therefore make DES into a relatively visual form of modelling, aiding communication with stakeholders, and encouraging dialogue between interested parties (Brailsford and Hilton, 2001). The visual element can also aid validation, as individual entities can be followed through the simulated processes enabling event traceability. The modeller can therefore monitor whether the system is behaving as it should (Marshall *et al.*, 2015b).

The outputs of DES include mean values, and distributions of values. They can be used as system performance indicators, for example: resource utilisation, wait times, number of entities in a queue, and throughput of services or products (Marshall *et al.*, 2015b).

DES models have traditionally been used in OR at an operational level, and healthcare is no exception, with hundreds of applications for A&E departments and clinics. Gunal and Pidd (2010) stated that almost every year, the Winter Simulation Conference proceedings include at least one paper detailing a simulation of an A&E department; Ferrin *et al.* (2007) and Miller *et al.* (2004) are just two examples. However, DES has also been used at the 'human body' model level to examine the cost effectiveness of health interventions. For example, Getios *et al.* (2010) used DES to evaluate the cost effectiveness of Donepezil in the treatment of Mild to Moderate Alzheimer's disease. They used a range of data sources to develop the simulation which predicts the progression of Alzheimer's disease through correlated changes in cognition, behavioural disturbance, and function. The study concluded that Donepezil is a highly cost-effective treatment for mild to moderate Alzheimer's disease within the UK. Similarly, an article by Guo *et al.* (2012) used a DES model to explore the potential value of Florbetaben PET (a beta amyloid tracer which can be used to detect neuropathological changes) in early diagnosis of Alzheimer's disease.

In 2016, Tong *et al.* published details of a patient-level cost-effectiveness model using DES to estimate the cost effectiveness of different cognitive screening tests for use by General Practitioners (GP). Three screening tests were examined: Mini-Mental State Examination (MMSE), 6-Item Cognitive Impairment Test (6CIT), and General Practitioner Assessment of Cognition (GPCOG). The model, which focuses on Alzheimer's disease,

was developed to follow individuals through the dementia pathway from pre-diagnosis to post-diagnosis, disease progression, and death (Tong *et al.*, 2017). They developed the clinical disease and service pathways through interviews with clinicians, commissioners, and other experts in dementia care.

The model updates characteristics of each patient each year until they die. They can move between four health states: normal cognition, Mild Cognitive Impairment (MCI), dementia, and death (Tong *et al.*, 2017). Each year the model checks the status of each patient to see whether they have already had a dementia diagnosis, and then the model routes them accordingly. Those without dementia or MCI return to the population, whereas new cases of dementia receive medication, and newly diagnosed MCI patients are followed up after two years. All patients face an annual mortality rate based on their age, gender, and dementia status (Tong *et al.*, 2017). Surviving patients cycle through the model for the following year; while those that have died exit the model and have their costs and Quality Adjusted Life Years (QALYs) calculated. The model, which was built using SIMUL8 and Visual Logic Application, provided evidence to suggest that using any of the three screening tests in primary care could be considered cost effective compared with a GP's unassisted judgement. However, GPCOG was considered the most cost effective with the 'highest Incremental Net Benefit (INB) at the threshold of £30,000 per QALY from both the National Health Service and Personal Social Service (NHS PSS) perspective (£195,034 per 1,000 patients), and the broader perspective that includes private social care and informal care (£196,251 per 1,000 patients)' (Tong *et al.*, 2017, p. 1).

Despite what its prolific use in OR would suggest, DES does have its drawbacks. DES models can be expensive to develop, can take a long time to run (Brailsford and Hilton, 2001), and usually require a certain level of expertise to build (Squires and Tappenden, 2011). DES models produce a broad range of outputs, showing the whole distribution of possible outcomes. However, the model requires many iterations in order to obtain statistically significant results; subsequently model validation forms a fundamental part of the modelling process (Brailsford and Hilton, 2001).

Furthermore, when compared to SD models, which have the capability of using 'fuzzy' descriptive data alongside numerical inputs (Sweetser, 1999), DES is associated with being data hungry (Brailsford, 2007). Quantitative data requirements are high because DES requires 'the assignment of numerical values to all parameters of the theoretical distributions from which stochastic behaviour is to be generated' (Fishman, 2013, p. 513). However, the use of these theoretical distributions allows flexibility in terms of data

requirements (Karnon and Brown, 1998). 'In the absence of historical data, expert opinion provides the most useful guidance for setting parameter values' (Fishman, 2013, p. 513). In these instances, DES can be used to run 'what if?' scenarios (Lehaney and Paul, 1994), which allow the modeller to explore the interactions between model parameters and their impact on the outputs of interest (Karnon and Brown, 1998).

4.3.3 Agent Based Simulation

ABS is the most recently developed method, with its first applications dating from the mid-1990s. While DES and SD have historically always been associated with OR modelling, there have been relatively few publications relating to ABS from within the OR community. Unlike SD and DES, ABS has been developed by a large number of different disciplines, including computer science, economics, biology, and the social sciences; with each discipline bringing their own set of goals and objectives (Siebers *et al.*, 2010). There is a growing body of literature across the disciplines demonstrating applications of ABS to various modelling scenarios, including traffic and transportation, financial markets, human migration, supply chains, urban design, energy usage, health and social policy, and market forecasting (Siebers *et al.*, 2010; Marshall *et al.*, 2015a); see also North and Macal (2007) and Macal and North (2010).

ABS models the actions and interaction of autonomous individuals (agents) in a network (Katsaliaki and Mustafee, 2011). An ABS model is formulated around the creation of a cohort of agents, which are placed within an environment and assigned individual attributes and behaviour rules (Day *et al.*, 2013). Consequently, a typical ABS can be seen as having three key elements: 1) a set of agents, including their attributes and behaviours; 2) the agent's environment; and 3) a set of mechanisms of interaction, specifying how the agents relate to one another and how they interact (Bandini *et al.*, 2009; Brailsford and Taylor, 2014b). ABS is therefore the process of identifying, designing, and programming these three elements in computer software in order to create an Agent Based Model (ABM) (Siebers *et al.*, 2010; Brailsford and Taylor, 2014b).

The agents within an ABM are able to adapt their behaviour according to interactions with their environment and other agents (Squires and Tappenden, 2011). Unlike SD and DES, which take a 'top down' approach by mapping a system or process, ABS models a system from the 'ground up' – 'agent by agent and interaction by interaction' – which allows self-organisation to be observed (Macal and North, 2010). Therefore the structure of an ABS model is emergent from agent interaction (Marshall *et al.*, 2015a). An 'agent' can

represent numerous different concepts; for instance, an agent could be an individual in a population or a cell in the human body.

Outputs from an ABM can include health outcomes, disease patterns and trends, costs, resource utilisation, and labour productivity; ABM is particularly well suited for providing insights into the health of large populations over time (Marshall *et al.*, 2015b, p. 8). ABS allows scenarios to be modelled where assumptions at an individual level may appear very simple, but their impact at a collective level may not be obvious (Katsaliaki and Mustafee, 2011, p. 1432). For instance, ABS has been found to be particularly useful for modelling the spread of infectious diseases (Bagni *et al.*, 2002; Perez and Dragicevic, 2009; Meng *et al.*, 2010).

Macal *et al.* (2014) developed a ABS model to identify where to target interventions in Chicago to reduce the transmission of community-associated Methicillin-resistant *Staphylococcus aureus* (MRSA). The model captures heterogeneity in population locations, behaviour, and contact patterns, which are all relevant to transmission and control. Each agent has a daily activity profile which determines when they occupy locations, such as homes, workplaces, schools, hospitals, and gymnasiums. Hospitals and gymnasiums are assigned based on geographical proximity to the agent's household. Social contact between agents occurs when multiple agents occupy the same location at the same time (Macal *et al.*, 2014). Algorithms are used to calculate transmission probabilities between agents. The model then uses statecharts to represent the transitions between disease states. Each agent can be in one of three states at any time: 'colonised' (i.e. carrying the infection, but not infected), 'uncolonised', or 'infected'. Results from the model showed that colonised agents, rather than infected agents, were the primary source of disease spread. This has important implications for targeting interventions in MRSA control.

As previously mentioned, when defining the behaviour of agents, modellers use mathematical logic-operators, ranging from simple 'if-then' rules, to highly complex algorithms (Brailsford and Taylor, 2014b; Marshall *et al.*, 2015a). One such 'operator' typically used in ABS, as illustrated in the above example from Macal *et al.*, is the statechart. In Day *et al.*'s (2013) paper describing an agent based template for modelling a cohort of veterans with diabetic retinopathy, they also used statecharts to capture the progression of the disease within each agent. A statechart graphically represents the condition of an agent over time; it includes a collection of 'states', which an agent may inhabit, and transition rules for how an agent exits one state and enters another (Day *et al.*, 2013). Similarly, Vickland and Brodaty (2008) used statecharts to describe the disease

states, and the progression of dementia and depression in Alzheimer's disease for their ABS. The states are represented as nodes on a graph, and transitions are shown as lines, with arrowheads showing their direction of motion (Day *et al.*, 2013).

Statecharts can be considered as a powerful tool; their compact, yet expressive nature means that they are able to capture complex behaviour with relatively few elements (Vickland and Brodaty, 2008). 'They offer formal and logical representation of states and transitions that may occur during the dynamic performance of the system under consideration' (Vickland and Brodaty, 2008, p. 94). In Vickland and Brodaty's paper, the statecharts were used as the 'blueprint' for the behaviour of the virtual patients. The authors used the knowledge and experience of senior clinicians to create the series of hierarchical statecharts, with each state representing one symptom or characteristic of various degrees of intensity. The model was developed in the multi-method simulation modelling software, AnyLogic. An agent-based approach was selected to 'allow relative autonomy of the virtual patients and non-deterministic behaviour of the model' (Vickland and Brodaty, 2008, p. 94). The behaviour of each agent was governed by the statecharts and the emergent behaviour was monitored by examining results clustered by age group, gender, and level of depression.

Although ABS can be applied to problems at multiple levels, including operational and strategic planning, it is most suited to individual level problems (Marshall *et al.*, 2015a). It enables modellers to explicitly model the complexity arising from individual actions and interactions that arise in the real world in ways that 'were either not possible or not readily accommodated using traditional modelling techniques, such as DES or System Dynamics (SD)' (Siebers *et al.*, 2010, p. 205). In 2010, a plenary panel session at the UK Operational Research Society's Simulation Workshop was held to discuss why ABS is underutilised in OR when compared to DES. As a consequence of the panel session, the paper '*Discrete-event simulation is dead, long live agent-based simulation*' was published, detailing the discussions that took place (Siebers *et al.*, 2010). The paper concluded that ABS is a more natural approach to simulation, with better engagement from stakeholders. It was felt that ABS opened up opportunities for simulation to be applied to a new range of problems in a more robust manner, without the need for the 'work arounds' commonly employed in DES and SD modelling. However, the paper also acknowledged that the highly technical nature of ABS software is a significant barrier to its wider acceptance. The authors were keen to see future applications of ABS, and combined DES/ABS in OR. They reported feeling encouraged that software vendors actively engaged with the workshop discussions and the idea of developing drag-and-drop interfaces for ABS applications (Siebers *et al.*, 2010).

In 2012, Brailsford responded to Sieber's *et al.* (2010) with the paper: '*Discrete event simulation is alive and kicking!*' (Brailsford, 2014c). Brailsford argued that, due to the individual level resolution and handling of time characteristic of both DES and ABS modelling, in many instances both modelling approaches can be applied to examine the same problem situations. Therefore, until a point is reached where 'someone develops an ABS model which cannot be represented as a DES or conversely, a DES model which cannot be represented as an ABS, then the jury will remain out' (Brailsford, 2014c).

Increasing computer power and developments of user-friendly interfaces have meant that DES software has moved progressively towards 'drag and drop' packages, such as SIMUL8. This has greatly facilitated model building and increased its accessibility for business users (Siebers *et al.*, 2010). By contrast, ABS requires an understanding of programming techniques, and the modeller needs to be comfortable with computer languages, such as Java (Brailsford, 2014c). Furthermore, there are relatively few undergraduate, postgraduate, or executive courses available for ABS. This does little to raise awareness of the approach and reinforces low adoption, as modellers tend to apply the techniques they know best, regardless of the problem (Siebers *et al.*, 2010). Also, as previously stated, DES software packages offer the advantage of transforming DES into a relatively visual form of modelling, which can aid stakeholder engagement. By contrast, not all elements of an ABM can be so easily communicated. Although statecharts can provide a general talking point for feedback and refinement, the source code used in an ABM cannot (Marshall *et al.*, 2015a).

Bonabeau suggested that simulating the behaviour of all agents can be highly computational and therefore time consuming; 'although computing power is still increasing at an impressive pace, the high computational requirements of ABM remain a problem when it comes to modelling large systems' (2002, p. 7287). For instance, it has been suggested that any SD model could be modelled using ABS. Although the two approaches appear fundamentally different, with ABS a stochastic, bottom up approach, and SD a deterministic, top down perspective; Macal (2010) demonstrated that a SD model could be translated into an ABS by using the probabilistic elements as explicit probabilities. The paper suggests that any well formulated SD model can be reconstructed as an ABS model (Macal, 2010). However, the trade-off is time; SD can provide results relatively quickly, whereas an ABM equivalent is time consuming to build and run. Siebers *et al.* (2010) suggested that simulation has 'benefited from the ability to do quick and dirty models that get 80% of the answer in a short time frame' (p. 209), and that therefore, the slow time-consuming nature of ABS would represent a step backwards compared to using the more established methods.

Finally, verification and validation can be difficult to achieve in ABS (Nianogo and Arah, 2015), whereas DES has established rules for verification and validation (Siebers *et al.*, 2010). Bonabeau (2002) argues that the very nature of systems involving human agents, with 'potentially irrational behaviour, subjective choices and complex psychology', makes the models hard to quantify, calibrate, and justify. Although this can pose a problem when interpreting the model results, Bonabeau (2002) states that in complex scenarios that focus on human behaviour, ABM is the most appropriate modelling approach to use. Siebers *et al.* (2010) reiterate this, emphasising that ABS allows simulation to be robustly applied to a new range of problems without many of the 'work-arounds' required when using SD and DES. Nonetheless, Brailsford would argue that many of the distinctions made between agents in an ABM and entities in a DES are artificial, and that DES models are equally capable of capturing human behaviours (Brailsford, 2014d). In Brailsford *et al.* (2012b), the authors describe a three-phase DES, that models screening for breast cancer which includes behavioural factors in order to capture a woman's decision whether to attend a mammography or not.

4.3.4 Hybrid Models

The idea behind hybrid simulation is to overcome the limitations of individual simulation paradigms, by combining different modelling approaches to symbiotically enhance each other's capabilities. The concept of using a combination of different simulation paradigms to capture different components of a larger system is not new (Viana, 2014); 'simulation practitioners have long recognised that many real world problems do not fall neatly into the domain of one single and obvious modelling paradigm (Brailsford, 2014d, p. 1544). Consequently, there is a growing body of literature which look at combining techniques. For instance, in Jun *et al.* (1999), the authors discussed the combination of simulation alongside optimisation techniques, such as linear programming, in order to marry together the strengths of each approach. Chahal and Eldabi (2008) proposed combining DES with SD, and Siebers *et al.* (2010) advocated the evolution of DES to include agent based components.

In the proceedings of the 2014 Winter Simulation Conference, Brailsford (2014d) discussed hybrid simulations combining ABS and DES in the paper '*Modelling Human Behaviour – An (ID)entity crisis?*'. The paper described this form of modelling as a slowly increasing trend, identifying 49 publications of hybrid ABM-DES models from the Web of Science over the previous 15 years. As the field of OR has begun to shift its attention from classic manufacturing scenarios towards the service industry, Siebers *et al.* (2010) has

suggested that combining both DES and ABS is the way forward for tackling ‘behavioural OR’.

At the 7th Simulation Workshop, Siebers⁶ gave a presentation on the subject of agent based modelling (Siebers, 2014), during which he discussed a case study of an ABS/DES hybrid model applied to retail simulation (Siebers and Aickelin, 2011). The paper investigates how different levels of staff pro-activeness impacts on the performance of a department store. The model was developed using AnyLogic, which allowed them to replace the passive entities, typical within a DES, with active agents using the agent-based principle of statecharts. Siebers and Aickelin (2011) concluded that the hybrid approach was more effective than a standard DES model at capturing system performance, as it allowed the consideration of autonomy and pro-activeness, ‘two attributes vital for more realistic modelling of human centric complex adaptive systems’ (Siebers and Aickelin, 2011, p. 11).

The University of Southampton’s Care Life Cycle (CLC) project has also contributed towards the hybrid modelling literature, with a model combining elements from DES, ABS, and SD. The CLC project produced a hybrid model of Age-Related Macular Degeneration (AMD) health and social care provision. AMD is the most common cause of visual impairment in those aged 65 and over in the UK; it is a progressive disease that causes loss of central vision (Congdon *et al.*, 2004). The model combines an ABM representing individuals with AMD with a DES model of Southampton’s Eye Unit (the outpatient clinic) (Brailsford *et al.*, 2013). The Eye Unit DES accepts the individual AMD agents as entities. Embedded in each agent is a pair of simple ‘SD like’ models of sight, representing each patient’s left and right eyes; a detailed description of the model structure is provided by Viana *et al.* (2012). The progression of AMD in each of the eyes is slowed down by treatment, which agents receive in the DES clinic. Each patient has a social care need status, which in conjunction with the level of social care provision, affects their probability of clinic attendance.

Social care provision is represented by a statechart consisting of three states: not required, partly met, and fully met. The agents interact with the DES when they are scheduled to attend the clinic ‘the patient may (or may not) attend the clinic, and may (or may not) receive treatment, depending on the congestion in the clinic and the overall performance of the clinic’ (Brailsford *et al.*, 2013, p. 261). The model was built using

⁶ On his University of Nottingham web page, Piers-Olaf Siebers states that his research goal is to establish Agent-Oriented Discrete Event Simulation (AO-DES) as an ‘alternative to the predominately mathematic methods currently used by researchers and practitioners’ (Siebers, 2017).

AnyLogic, which was unfamiliar to all of the team members at the start of the project. Due to the intertwined nature of the model, the seamless transitions between components, and its construction within a single modelling platform, Chahal and Eldabi's (2008) would define this model as an *integrated* hybrid model. This suggests that Viana and his colleagues achieved what Brailsford *et al.* (2010) had previously referred to as 'the holy grail' of modelling. This highlights the progress made in the field over a relatively short period of time, thanks, in part, to the introduction of AnyLogic.

Brailsford *et al.* (2013) suggest that a stand-alone DES model could have been used for the whole AMD model, however it was concluded, in part through academic curiosity, that a hybrid simulation seemed the more 'natural fit'. Viana *et al.* stressed that the focus throughout the hybrid model development process was to select the 'best tools for the job' (Viana, 2014, p. 1593). This concept has been reiterated by proponents of 'paradigm-free' modelling. Schumann (2016) suggested, that a modeller should not be biased by what their chosen paradigm dictates, instead model objects should be selected that best describe each component being modelled.

In 2014, Gao *et al.* also built, what they described as a 'tripartite hybrid model', combining DES, SD, and ABS elements, to investigate the health and cost impacts and intervention trade-offs for diabetic end-stage renal disease. Gao *et al.* (2014) used system dynamics to model the non-and pre-diabetic population. An ABM was constructed to represent the population of diabetic individuals, capturing time-varying competing risks, social network effects, and geographical information. Finally, DES was used to model the pathways of health care progression for those with diabetic end stage renal disease (Gao *et al.*, 2014).

The literature provides further examples of hybrid modelling, as illustrated by Anagnostou *et al.* (2013), Fakhimi *et al.* (2014), and Kittipittayakorn and Ying (2016). Anagnostou *et al.* (2013) developed an ABM-DES hybrid model using the open source ABM tool, Repast Symphony, to examine emergency medical services. This provided the opportunity to 'study holistically integrated improvement scenarios for emergency medical services and crisis management systems' (Anagnostou *et al.*, 2013, p. 1625). Fakhimi *et al.* (2014) used the approach for sustainable strategic planning in a healthcare context. Kittipittayakorn and Ying (2016) combined DES with ABS to explore how outpatient services could be improved in an Orthopaedic Department.

While hybrid modelling has grown in popularity, it is faced with several challenges. The first of which relates to finding appropriate modelling software. Building each model component in a separate software package and then coding an interface so that they communicate with one another, requires programming skills. Alternatively, a hybrid model

can be coded from scratch using a standard programming language such as C++, or an open source ABM tool such as Repast Symphony, which accommodates additional DES code. However, both approaches require an expert level of coding, which renders them a daunting prospect for any novice modeller. Multi-paradigm software package, AnyLogic, has sought to address the gap in the market. It is the first tool of its kind to allow modellers to build ABS, DES, and SD models within a single environment, enabling them to mix and match components using Java (Brailsford, 2014d). However, Brailsford *et al.* (2013) argue that the flexibility of AnyLogic comes at a price; it still requires familiarity with coding (Java), and there is a 'jack-of-all-trades' effect. For example, an experienced user of DES software will be frustrated by the lack of built-in functions in AnyLogic, whereas, an expert programmer will feel limited by a commercial software package (Brailsford *et al.*, 2013).

The second drawback of hybrid modelling is the time it takes to develop such models. As mentioned in Section 4.3.3, modellers often prefer 'quick and dirty models that get 80% of the answer in a short time frame' (Siebers *et al.*, 2010, p. 209), using a single paradigm they are familiar with. Siebers and Aickelin (2011), while acknowledging the additional effort and cost associated with hybrid modelling, would argue that the additional investment is worth it. Siebers and Aickelin concluded that when modelling systems with a high proportion of human interaction, a hybrid model results in a significant improvement in output accuracy which 'justifies the extra costs for data collection and modelling' (2011, p. 11).

Despite the challenges discussed above, the software available is constantly evolving as it tries to respond to demand. The 2010 paper by Siebers *et al.* ended by suggesting that DES software could be improved with the inclusion of the ABS concept of statecharts for defining entities. Similarly Brailsford (2014d) mentioned the need for a 'drag and drop' graphical interface for hybrid modelling as used in SIMUL8, to improve the accessibility of the approach for those unfamiliar with programming languages. It seems that SIMUL8 was listening. In recent years, SIMUL8 responded to demand by incorporating 'drag and drop' statechart functionality into its professional software package, thus enabling DES modellers to transform passive entities into active agents.

4.4 Applying Modelling Techniques within a Social Care Setting

Although OR modelling in healthcare has been prevalent within the academic literature for many decades, its application in community and social care has been comparatively limited (Desai *et al.*, 2008; Onggo, 2012a). Both health and social care authorities focus

on promoting the health and wellbeing of the people for whom they have a shared responsibility (Harvey *et al.*, 2011). The two systems share many parallels; they are both large and complex systems focused around the care of people. Furthermore, both interact with one another at various points. Therefore, despite the lack of published examples, it can be assumed that the modelling methods commonly applied within healthcare can be of equal value when applied to social care.

Firstly, however, it is important to consider a few of the main differences between the two systems which would be likely to influence the modelling process. For example, as discussed in Chapter 2, Section 2.9.2, healthcare is largely available for free through the NHS, whereas social care is frequently provided by local authority-funded social care services, which are subject to means-testing and rationing through eligibility criteria. On the other hand, health care commissioners are subject to tight guidelines and regulations, whereas local governments may have greater freedom over their decisions (Harvey *et al.*, 2011).

Within healthcare there have been numerous applications of OR modelling to evaluate 'clinical' interventions, such as drugs, devices, or medical procedures. The specific nature of most 'clinical' applications of OR modelling make them less directly transferable to social care. For example, when examining the cost effectiveness of an intervention in the clinical setting, there is often only one specific disease being modelled, where the natural history of the disease and impact of the health intervention upon the disease history are relatively well understood. This aids the extrapolation of data beyond the trial follow up (Squires and Tappenden, 2011).

In contrast, social care modelling appears to face similar challenges to that of the broader public health models (Squires and Tappenden, 2011). Such interventions 'generate very broad costs and benefits, and are frequently directed at populations or communities rather than specific individuals' (Weatherly *et al.*, 2009, p. 86). Social care systems are vast and complicated, involving a number of stakeholders, often with conflicting objectives (Onggo, 2012a). They also tend to interact with other complex systems, such as local government services and the NHS. Consequently, OR techniques, such as the simulation methods discussed in the previous sections, 'can and should play a significant role in helping policy makers understand the dynamics of the care system and deliver better policies' (Onggo, 2012a, p. 1).

4.5 Examples from the Literature of Modelling within Social Care

Fewer than fifteen papers were identified through this literature review as describing examples of OR simulations in social care for an ageing population (these papers are considered in more detail in Sections 4.5.1 and 4.5.2). The identification of a relatively small number of relevant articles is consistent with both the comments made in Desai *et al.* (2008), and with the findings of Onggo (2012a).

Onggo (2012a) carried out a literature review examining ‘Simulation Modelling in the Social Care Sector’ with a particular focus on social care for the ageing population. The review identified 14 articles to illustrate some of the more recent applications of simulation modelling. The articles cited are as follows: (Pickard *et al.*, 2000; Spillman and Lubitz, 2000; Knickman and Snell, 2002; Lubitz *et al.*, 2003; Kemper *et al.*, 2005; Lagergren, 2005a, 2005b; Heffernan and McDonnell, 2007; Wolstenholme *et al.*, 2007; Desai *et al.*, 2008; Chung *et al.*, 2009; Jagger *et al.*, 2009; Fernández and Forder, 2010; Hsiao and Huang, 2012). Onggo identified from the literature that there are four main components that enable the provision of care services, as represented in Figure 4.2.

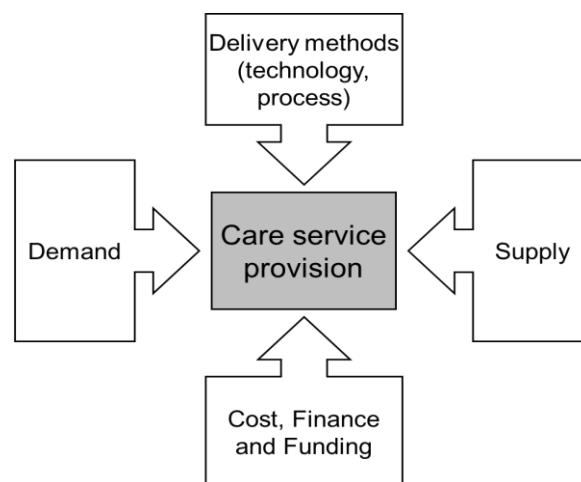


Figure 4.2: The Main Components of Social Care Simulation from Onggo (2012a)

Onggo established that the majority of the identified literature sat within the ‘demand’ and ‘cost and financial modelling’ components, recommending the remaining two areas (supply and delivery methods) for further exploration. Onggo also identified that the literature encompassed by the term ‘simulation’ was dominated by the micro-simulation modelling paradigm, which is a form of modelling used more typically in the Social Sciences. This form of modelling, along with several examples cited by Onggo (2012a), is explored further in Appendix 14. Sections 4.5.1 and 4.5.2 will explore the OR-specific

examples identified by the current research; no examples of ABS applied to social care were found.

4.5.1 System Dynamics Applied to Social Care

Wolstenholme *et al.* (2004b) applied SD at a national level to influence government policy on admission prevention and delayed discharge. The approach was also used to assist UK-based local health and social care services to interpret and apply national policy frameworks for older people (Smith *et al.*, 2004; Wolstenholme *et al.*, 2004a).

Desai *et al.* (2008) published a study entitled, 'Modelling of Hampshire Adult Services – gearing up for future demands', in which SD is used to investigate the challenges of an ageing population in the context of budget limitations. Brailsford *et al.* (2012a) modelled a care system using SD. The model, although considered as a generic model, was developed in part collaboration with an anonymous English council. The model provided an illustrative example of interdisciplinary working between OR modellers, social statisticians, and demographers as part of the Care Life Cycle Project.

Internationally, there were several examples identified of SD models used in the context of social care and the ageing population, produced in Singapore (Thompson *et al.*, 2012, 2013; Ansah *et al.*, 2013). Thompson *et al.* (2012), for instance, built an SD model to estimate the future populations of people with mild, moderate, and severe dementia, in order to examine the impact of changing family composition on likely living arrangements in Singapore.

Further examples of OR modelling within social care can be found outside of academia. The consultancy firm, Whole Systems Partnership, has developed a range of SD models, including the Dementia Simulator. The 'Simulator' was developed to assist Local Authorities in assessing the extent of current National Dementia Strategy implementations, and to test out the potential impact of future interventions. The model takes a whole system approach considering current and future potential use of resources across both health and social care (The Whole Systems Partnership, 2012).

4.5.2 Discrete Event Simulation Applied to Social Care

Campbell *et al.* (2001) provide an early example of a DES model applied within social care. In this study, DES was used to carry out a cost analysis of a 'hospital-at-home' initiative. The objective of the paper was to 'examine whether, from a National Health Service and local authority social services' viewpoint, a hospital-at-home service was cost

saving compared with conventional inpatient care' (Campbell *et al.*, 2001, p. 14). DES was utilised to conduct the economic evaluation because it was not feasible at the time to design a formal evaluation, such as an RCT. Instead, prospective and retrospective observational data was gathered for two groups: one receiving traditional inpatient care, and the other receiving 'hospital at home' care. DES was chosen to carry out this study for its ability to make efficient use of small samples of observational data (Karnon and Brown, 1998). The model was built using SIMUL8 software. From the model results, Campbell *et al.* (2001) concluded that for 'elderly' patients assessed as requiring no more than 14 days of hospitalisation, hospital-at-home care can result in cost savings for the health and social care agencies in comparison with conventional care approaches. Consequently, the study contributed to the health authority's strategic planning.

Katsaliaki *et al.*'s (2005) paper, 'Mapping and planning of care pathways: a case study of intermediate care versus long term care solutions', offers another application of DES. This study was set within Hampshire Social Services and used DES to examine potential care pathways for older people at the point of hospital discharge. The model was used to study the impact of a new range of services called 'Intermediate Care', which was aimed at reducing 'bed-blocking'. 'Bed-blocking' refers to instances where older patients experience delayed discharge from acute beds due to capacity limitations within traditional social care services, for example, due to a lack of available residential care placements. Local Authorities are obliged to financially reimburse the NHS Acute Trusts when delayed hospital discharges are directly caused by inadequate provision of social care assessments and services. The model, which was developed using the simulation software SIMUL8, was used to determine the system capacities and to estimate the likely associated reimbursement costs.

As previously mentioned, Brailsford *et al.* produced a paper in 2010 which presented two case studies of 'hybrid' models. The second case study described two separate models that were manually linked in order to examine the impact of a new call centre, which hoped to speed up access to social care services for people aged over 65 years living in Hampshire. Hampshire County Council (HCC) hoped the model would enable them to establish the 'right size' for the services offered in order to reduce costs. SD was used at a population level to model long term dynamic demographic changes in order to predict the future demand for long term care in the county. DES was used to look at operational issues around the organisation and staffing of the contact centre in order to meet the changing needs of the population it serves over the next 20 years (Brailsford *et al.*, 2010).

Additional examples of DES applied to a social care setting can be found outside of academia. For example, the SIMUL8 Corporation, together with the NHS in Worcestershire, developed a DES to simulate future service needs for dementia care. The model uses SIMUL8 software to support the planning of dementia services in Worcestershire. The model takes population projections by age, gender, and age-banded prevalence for seven types of dementia to create an annual modelled population which is used to simulate patients entering the model each year. Each simulated person is given a set of attributes: age, gender, condition type, severity, progression time, diagnosis, and life expectancy. These characteristics dictate how each person moves through the model, progressing through the stages of dementia over time, and taking into account death from all causes. The simulation is then able to model the services and treatments that the individual is likely to receive at each stage of disease progression. Therefore the model 'enables health and social care planners to answer questions about demand changes, earlier diagnosis of dementia, the implementation of new services, and costs to different parts of the care system' (SIMUL8, 2013).

4.5.3 OR Modelling and Telecare

In addition to examining the literature for examples of OR modelling in social care, a more precise search was conducted to look for OR modelling articles specifically relevant to the use of telecare to support people. Each modelling term described in Section 4.1 was paired with 'telecare' or 'life style monitoring' as a search topic. Although the search initially returned several dozen articles, only one academic article was identified as relevant, which was Bayer *et al.*'s 2007 paper entitled, 'Assessing the impact of a care innovation: telecare'.

Bayer *et al.* (2007) used SD to examine the potential impact of telecare on the numbers of older people in institutional care. The model enabled them to explore different scenarios when examining the effect of implementing telecare. They were able to simulate how the different circumstances would impact patient flows. The study concludes that the benefits of telecare for reducing the size of the population in residential care will not come to fruition until after a significant delay; they suggest that the characteristics of technology-based care and its users prevents rapid change. Further to this, they add that the population residing in institutional care will for a long time, 'largely comprise of elderly people who entered institutional care before telecare was introduced' (Bayer *et al.*, 2007, p. 13).

Outside of the academic literature, one additional example of simulation applied to telecare was identified on the SIMUL8 website. A telecare and telehealth model was built to showcase SIMUL8's Scenario Generator software. Scenario Generator was developed in the UK by the SIMUL8 Corporation in partnership with the NHS's Institute for Innovation and Improvement. The software is a simplified, user friendly package, and is pre-configured with population and disease prevalence data, along with a number of generic pathways of care to enable users to link population needs with health service activity (SIMUL8, 2018a). The telecare and telehealth example they provide looks at the impact of introducing the devices into Social Care Services for people over the age of 65. The model can be configured to the population of a particular area in order to look at resource use. The model provides an interesting illustrative example of what the software can do, however it does not explore the relationship between telecare and delaying admission into institutional care, nor does it consider the specific needs of people with dementia.

In 2009 Royston produced a journal article for the Operational Research Society examining, 'One hundred years of Operation Research in Health – UK 1948-2048'. The article suggested the need for OR to look ahead into the future role of modelling. The paper mentioned both the ageing population and telecare, referring to them as 'the 'white sails' we can clearly see coming over the horizon' (Royston, 2009, p. 174).

4.6 In Summary

In summary, this chapter has looked at previous applications of OR modelling and discussed the strengths and limitations of SD, DES, and ABS, as well as exploring use of these methods in combination. It has looked at examples of simulation applied to health and social care, and considered the challenges of modelling such complex systems.

The examples discussed in this chapter demonstrate the suitability of simulation for testing scenarios relating to the introduction of a care innovation. A simulation provides a safe environment to explore changes to the system without subjecting patients, staff, or services to risk. By building a model to explore the impact of mainstreaming telecare on the number of people with dementia entering institutional care settings, this thesis addresses a gap in the current telecare research, and therefore makes a unique contribution to this field of research.

Furthermore, based on the OR literature explored, this chapter confirms that there have been no previous applications of simulation for this specific group of telecare users. As shown in Section 4.5, the number of OR simulations applied in social care settings is

limited, and although examples have been identified that look at telecare, none have explored the impact of the technology for people with dementia.

Carrying out this literature review, alongside the background research (Chapters 2 and 3) and the stakeholder engagement activities, facilitated the identification of a suitable modelling paradigm to achieve the research aim. Firstly, Chapter 2 highlighted the concept of time as a key construct, as each person's dementia changes and develops over time, as does their need for support. Secondly, both the background research and the findings from the stakeholder engagement (to be discussed further in Chapter 5) highlight the variability between individuals with dementia as another key element for inclusion. This variability is a crucial consideration when modelling care services for people with dementia, as each person may experience a different rate of disease progression, level of care need, and carer capacity to cope.

Therefore, when considering the modelling taxonomies presented in Section 4.3, it was necessary to identify a modelling approach that was both time based, and captured this individual level variation. Consequently, Brennan *et al.*'s (2006) model taxonomy (see Section 4.3) indicates that DES offers a suitable modelling paradigm. Brailsford (2007), highlighted that DES has been widely used for 'operational or tactical models' within the healthcare OR literature; which further indicates its suitability within the current research.

In addition, advances in modelling software capabilities mean that traditional DES modelling can now easily be combined with statecharts. This allows the methodological advantages of both modelling approaches to be combined to capture the variability of disease progression, dependency, and capacity for carers to cope. Capturing this variability allows a more realistic representation of the care system for people with dementia in a way that has not previously been demonstrated for telecare and dementia. It is therefore concluded that a hybrid model, combining DES with statecharts, will be a suitable methodology to achieve the research objective. Full details of the modelling approach adopted, along with the justification for the chosen methodology, are provided in Chapter 6. The following chapter explores the stakeholder engagement process, which helped to identify the key components to be included in the conceptual model on which the final model is based.

Chapter 5: Stakeholder Engagement and Conceptual Model Building

5.1 Chapter Overview

This chapter outlines how the study was initiated and the steps that were taken to understand the problem situation, specifically through stakeholder engagement. It then explains how stakeholders and domain experts were involved in developing the conceptual model on which the TeleDem Simulation is based. The chapter also summarises how the findings from the background chapters, alongside the stakeholder feedback, fed into the conceptual model. Chapter 5 therefore addresses components three and four of the modelling framework set out in Chapter 1, as shown by Figure 5.1. The conceptual model in its final form is then presented in Chapter 6, Figure 6.2.

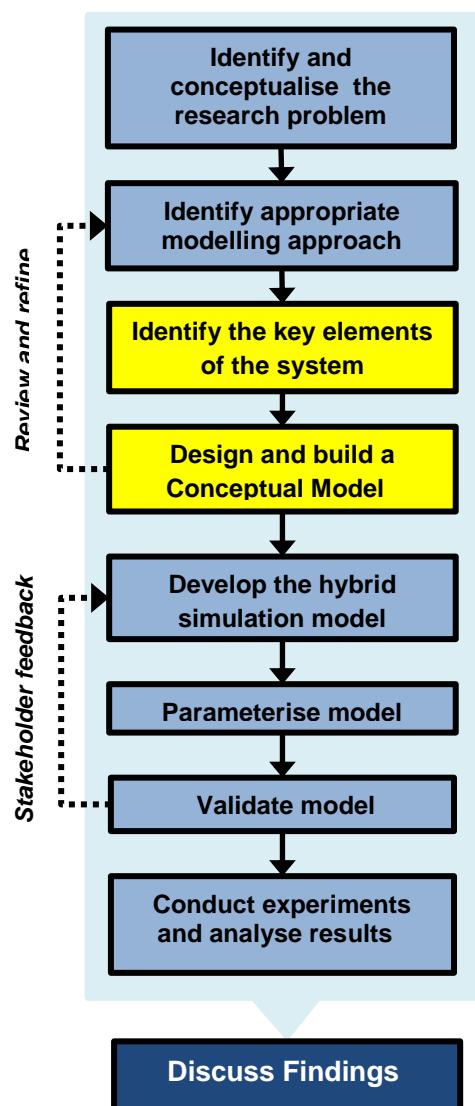


Figure 5.1: Addressing Part Three and Four of the Modelling Framework

For the purpose of this thesis, stakeholders and domain experts are defined as follows (Figure 5.2 and Figure 5.3):

Stakeholders - Individuals who would be involved in, or are impacted by, the mainstream delivery of telecare to support people with dementia. Including:

- Care Service Commissioners
- Care Service Managers
- Telecare Officers
- Care workers, for example occupational therapists and memory advisors
- Telecare providers, involved in product design and supply
- Carers of people with dementia
- People with dementia

They provided context for the research and helped shape the conceptual model for the TeleDem Simulation by providing insight into how the care system currently operates and how telecare would fit within this. Engaging with care workers, carers and people with dementia aided in identifying the social and environmental issues that matter most to them.

Figure 5.2: How Stakeholders are Defined in this Thesis

Domain Experts

For the purposes of this research domain experts are individuals who have specific and detailed knowledge in the field of telecare for dementia, Gerontology, or OR Simulation.

As shown in section 4.3.2, Chapter 4, expert opinion can be used in the absence of historical data to inform model parameters for DES. Therefore, the input and guidance of experts in telecare and dementia can compensate for a lack of robust empirical data by informing the model. Domain experts can also assist in model validation by ensuring the model structure is both rational and functional.

Figure 5.3: How Domain Experts are Defined in this Thesis

5.2 Initiating the Study

Kotiadis *et al.* (2014) recommend initiating model building by attending informal meetings, carrying out one-to-one interviews, and conducting onsite observations, in order to gain a preliminary understanding of the problem situation, and to identify key stakeholders.

Therefore, this study was initiated by developing a working relationship with a county council actively engaged in delivering telecare to people with dementia. Dorset County Council (DCC) includes telecare as one of their community care services, and they were in the process of establishing a pilot study for Lifestyle Monitoring equipment for people with dementia at the point they were contacted.

Working with DCC permitted access to meetings concerned with the countywide delivery of telecare. Monthly meetings were attended over an 18-month period, alongside additional promotional events designed to encourage engagement with telecare. These meetings involved Occupational Therapists, technology developers, service commissioners, people from the monitoring centres, and the people responsible for maintaining and managing the equipment. The lead contact at the Council was the Telecare Project Officer. Working with the Project Officer and attending these meetings facilitated discussion and exploration of telecare for supporting people with dementia.

In addition to facilitating conceptual model building, it was also originally envisaged that this collaboration with DCC would lead to the evaluation of the Lifestyle Monitoring Pilot that was due to launch in February 2012. The pilot involved the provision of ten lifestyle monitoring kits; five of which were provided by Just Checking, and five by another company called Quietcare. The intention of the pilot was to use the kits to aid hospital discharge and facilitate the assessment process for people with dementia. It was felt that using the equipment in this way 'gave people with dementia a voice', and assisted in determining appropriate moves to residential care, whilst reducing or even eliminating unnecessary admissions.

The Telecare Project Officer was dedicated to the pilot study and worked tirelessly. However, issues including staff attrition, resistance to change in practice from within the organisation, slow uptake of the technology, and then the closure of Quietcare's operations in the UK, caused repeated setbacks. The pilot was eventually redefined in 2014, and the Just Checking equipment was reallocated for use for people with learning difficulties. Consequently, the evaluation became beyond the scope of this research.

Nonetheless, the 18 months of working with Dorset County Council provided access to a range of key stakeholder and domain experts. Informal meetings were held with Occupational Therapists to discuss the care pathways for people with dementia; Memory Clinic Advisors were consulted to discuss the challenges of dementia care; and telecare and dementia events and workshops were attended to network with experts in the field. During this initiation stage, additional meetings were also held with representatives from Portsmouth City Council. This provided further opportunity to explore how a mainstream telecare service would fit within the current model of care for people with dementia, and provided valuable insights into the practical realities of implementing such a service.

5.3 One to One Interviews

Once this initial scoping phase was underway, five in-depth one to one interviews were carried out with different stakeholders. Gathering information first-hand makes the research far more immersive. Consultation with ‘individuals who impact upon or are impacted upon within the system to be modelled’ facilitates conceptual model building (Squires and Tappenden, 2011) by enabling the researcher in understanding the complexity of the field from different perspectives.

The interviews provided context, illustrating the human element that is at the heart of this research. Having reviewed the available literature on telecare for dementia it was concluded that these additional interviews would help to address gaps in understanding regarding how the telecare service would fit within the current care model. Furthermore, as a sizable proportion of the information available on telecare for dementia comes from ‘grey literature’, or is based on exploratory studies, conducting interviews with key stakeholders provided an opportunity to verify this information. The interviews sought to clarify the following areas:

- What a telecare service would look like in practice;
- What impact telecare might have on a person’s care pathway;
- Barriers and facilitating factors to telecare uptake, specifically for people with dementia;
- What needs to be in place for someone with dementia to be eligible to receive telecare;
- The perspective of a person with dementia, and the perspective of a carer, in terms of:
 - The day to day experience of dementia;
 - How the person is supported;
 - What their experience of accessing services has been;
 - Their perception of the technology.

5.3.1 Methodological Approach for Interviewing Stakeholders

To conduct the interviews, ethical approval was required from the School of Management and the Research Governance Office (RGO) at the University of Southampton. Further approval was also required from Dorset County Council to attend confidential meetings in which social care clients and their circumstances were discussed. The fully approved

consent form, Participant Information sheets and Debriefing Sheets are included in Appendices 15-20.

A purposive sampling technique was adopted, whereby 'a researcher samples on the basis of wanting to interview people who are relevant to the research questions' (Bryman, 2008, p. 458). Therefore, participants were specifically selected for their expertise in the field of telecare and/or dementia and were identified through their involvement in relevant public events.

Initial contact was made with each participant through informal introductions via contacts within DCC. Each potential participant was provided, in advance, with a consent form and an information sheet, explaining the purpose of the research and how their data would be used. They were given a minimum of a week to decide whether they wished to take part in the interview. They were then asked to initial and sign their consent form and bring it with them to the interview, in order to confirm that they were happy to participate and understood what was involved.

The interviews were semi-structured and took between one to two hours each. Interview schedules, which included 26 possible prompt questions around the theme of using telecare for dementia, were used to guide the conversation, these are included in Appendix 21. Semi-structured interviews were selected because they allow a far greater degree of freedom compared to questionnaires or structured interviews (Denzin and Lincoln, 2005). They are more informal and allow flexibility around how and when the questions are asked (Hammersley, 2013). Questions can be adapted and changed depending on the person's responses, which enables the interviewer and the participant to have a conversation with a purpose (Burgess, 1984).

The interviews were recorded on an audio recorder and hand-written notes were taken. Once the interviews were complete a debriefing sheet was given to the participant, reiterating the purpose of the research and providing contact details, should they have any questions or concerns.

Limitations in terms of time and resources restricted sample size. A full exploration of telecare for people with dementia through interviews with key stakeholders would be a thesis in its own right. Therefore, on the basis that extensive background research was already in progress through exploration of the literature and other forms of stakeholder engagement, it was concluded that five interviews would be sufficient to supplement this work and verify the findings from the grey literature.

The five interview participants can be classified into three categories. The first three participants, who are in category one, are professionals involved in the development and delivery of telecare. The second and third categories describe individuals with lived experience of dementia: a lady with Posterior Cortical Atrophy, and an informal carer providing support for her Grandmother. The participants are described below:

Category One – Professionals involved in the development and delivery of telecare

- ***Telecare Project Officer for Dorset County Council*** - Qualified as an Occupational Therapist in 2006 working with people with dementia, before taking on the role in Telecare service delivery in 2011.
- ***Telehealth/care Programme Manager from the Wessex Health Innovation Education Cluster*** - Extensive experience and knowledge relating to both telecare equipment and dementia. Previously involved with deploying the National Dementia Strategy.
- ***Co-founder and developer of Just Checking*** - Just Checking was established after the co-founders both became involved with the European Research and Development Programme looking at assisted living. Just Checking was developed as a result of talking to the families of people with dementia. During a Masters in Gerontology a prototype of the Just Checking technology was developed and piloted with a County Council. Now over 80% of UK local authorities with adult social service responsibility use the technology (Just Checking, 2017).

Category Two – An individual with dementia

- ***Mrs. P (a 71 year old lady with mild dementia)*** - This lady was diagnosed in 2008 with Posterior Cortical Atrophy (PCA), a rare form of Alzheimer's disease. She shared her experience of dementia and the impact it has had on her life and her perspective on the role that telecare could play for providing support.

Category Three – A Carer's Perspective

- ***Ms. J (granddaughter and carer of an 85 year old lady with dementia)*** - Ms. J, along with her father and uncles are providing ongoing support for Ms. J's Grandmother, who currently lives at home in Sussex.

Once the interviews had been completed, the raw data was transcribed from the recordings and the notes were written up. These notes were then subject to a basic

thematic analysis, whereby reoccurring ideas and concepts were identified. Thematic analysis is an accessible and flexible approach for analysing qualitative data, that is widely used in qualitative research (Braun and Clarke, 2006). A theme represents some level of patterned response capturing something important in relation to the research question (Braun and Clarke, 2006). Notes taken during the interviews are included in Appendix 22. The key themes, along with the main concepts from Chapters 2 and 3, that fed into the design of the conceptual model are summarised in Figure 5.4 in the following section.

Initiating the study by engaging with stakeholders helped to define the system boundaries, and enabled the identification of the key elements for inclusion. Furthermore, findings from the on-site observations, early meetings, and one-to-one interviews helped to inform and verify the background chapter of this thesis (Chapter 3). The key findings from this initial scoping phase of the study are also included in Appendix 22.

5.4 Building the Conceptual Model

Chilcott *et al.* (2010) suggest using diagrams, sketches of model designs and/or disease pathways, representative mocks ups, and written interpretations of evidence, as explicit methods for conceptual modelling. Squires *et al.* (2016) emphasise the importance of producing written documentation detailing the model structure, assumptions, and population, as a point of good practice when conceptual model building. 'Documenting an understanding of the problem before analysing available data sets allows that understanding to be reflected upon and shared' (Squires *et al.*, 2016, p. 590). There is common agreement in the literature that a conceptual model 'should be independent of any implementation paradigm, or software solution, and that it is initiated early in the simulation project life-cycle and iteratively revisited' (Furian *et al.*, 2015, p. 82). A conceptual model can be used to facilitate communication between all parties engaged with the project (Pace, 2000).

Working with Dorset Council in the initial stage of the study, lead to the development of several system diagrams describing the elements of the care system. These diagrams ranged from quick hand drawn flow diagrams to more detailed graphics. They facilitated discussion between domain experts and system stakeholders; with elements deleted and added as the conversations went along. Themes identified in the one to one interviews also fed into the design process. Various iterations of these diagrams were then presented at telecare events and workshops; this provided the opportunity for additional stakeholder feedback. This process helped to refine the model objective.

Stakeholders throughout the engagement process stressed the importance of considering the impact of telecare on the burden experienced by informal carers, and the fundamental role this could play in reducing institutional care home admissions. In addition, a key theme drawn from the interviews, was the distinction between the initial stages of dementia and the moderate to severe stages was highlighted, both in terms of care needs and the types of equipment the person may require. Equipment suitable in the earlier stages focused around supporting independence, with simple solutions to address a specific need, such as medication reminder, or a GPS device. It also included pieces of equipment, such as fall detectors. Each of these pieces of equipment require the person to engage with the telecare to some extent. For instance, a medication reminder can alert a person to the fact that they have tablets to take, but the person requires the capacity to acknowledge that the next step would be to take the tablet. Furthermore, fall detectors and GPS devices rely on the person wearing or carrying the device.

In the later stages it was suggested that people are more likely to remain inside their home, and were less likely to have the capacity to engage with the technology. Therefore, the focus of the equipment shifted towards supervision and more complex arrays of passive triggers that could monitor the risks of activities of daily living. Consequently, it was considered important to draw a distinction within the conceptual model between basic telecare and complex telecare. Both in terms of the level of equipment provided and the person's level of care need.

Feedback also related to the language used in the diagrams; domain experts for telecare and dementia asserted that the conceptual model needed to include the words 'assessment' and 'review', as central components of the care pathway. They felt that the success and/or failure of telecare rested on the quality of the assessment, and regular reviews of the package of care. Therefore, it was considered imperative to flag the role of assessment and regular reviews within the model.

It was also agreed that the model should be generic and simple regarding its depiction of the care system. It was believed that this would add the most value as the model could then be used to explore the impact of telecare for people with dementia, without being 'weighed down' with the nuances of a specific locality or population. It was hoped that if the model results showed a positive impact, then the model could be used to raise public awareness of the technology in an accessible way.

Once a clearer understanding of the care system and scope of the model was reached, a draft conceptual model was drawn up. Figure 5.4 summarises the key themes and concepts from Chapters 2, 3 and 5 that fed into the conceptual model design.

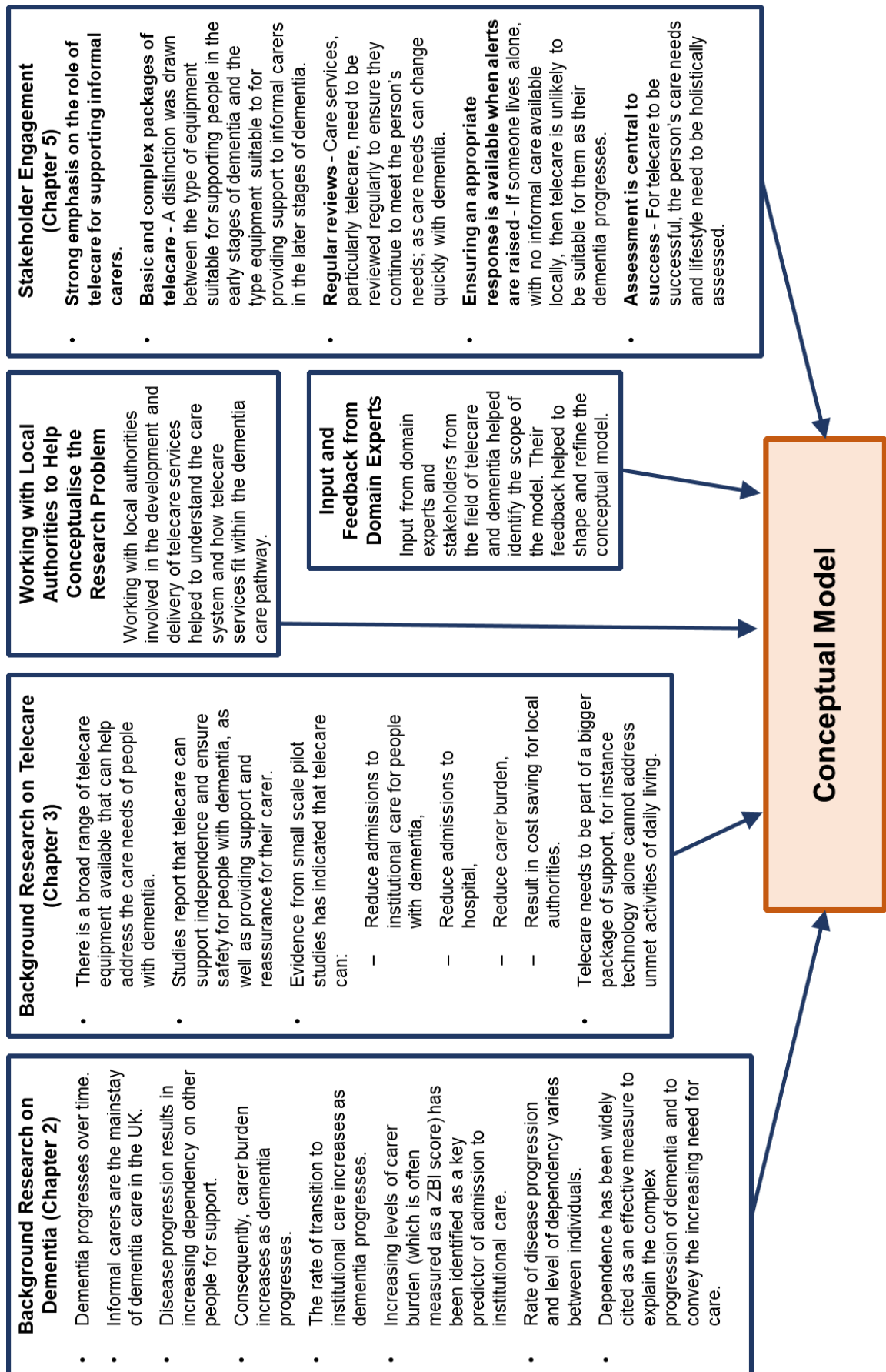


Figure 5.4: Key Themes and Concepts that Informed the Conceptual Model Identified from the Background Research and Stakeholder Engagement

An initial draft version of the model was used as a discussion point to gain further feedback. With input from domain experts in the fields of telecare for dementia, Gerontology, and Operational Research Simulation, a simplified structure of the care system was agreed, and the frequency at which activities should occur was established. It was agreed that the main performance indicators should be measured in terms of days and average utilisation. For example: average number of days spent in institutional care over a decade for a population when telecare is available, compared to the average number of days spent in institutional care when telecare is not offered. By focusing solely on institutional care admissions and measuring performance indicators in terms of days, the model maintains a simplistic and transferable nature, while still providing results that are of value.

Data requirements and data availability were considered during this stage of the process. In the absence of data relating to telecare uptake for different stages of dementia, it was agreed that the model would be used to test a range of different hypothetical scenarios. The preliminary assumptions that would need to be made within the model were also discussed; the final list of modelling assumptions are included in Chapter 7, Section 7.15.

5.5 Validation of the Conceptual Model

Once the conceptual model had been through several iterations of development, the structure was refined, a list of data requirements was compiled, and a list of preliminary assumptions was made. The potential of utilising statecharts as a form of hybrid modelling to capture the variability of disease progression was identified during the review of OR literature, as presented in Chapter 4. Therefore, flow diagrams for dementia progression and carer burden, representing how these statecharts would operate, were also drawn up.

The finalised conceptual model and all of the detailed supporting information was once again presented to the domain experts for validation. It was agreed that the model structure suitably captured the key elements of the real system. The final version of the conceptual model and the statechart diagrams, as agreed with the domain experts, are displayed in Chapter 6, Figure 6.2, Figure 6.4, and Figure 6.6.

5.6 In Summary

Engaging with stakeholders, alongside careful consideration of the literature and background research, facilitated understanding of the problem situation by providing insight into the structure of the system and highlighting the key elements for consideration.

The process also helped to refine the research objective, specifically by increasing focus on the role of carer burden. Figure 5.5 visually summarises the key elements for consideration identified through the background literature and stakeholder feedback in relation to the progression of dementia.

Through on-site observations, interviews, meetings, presentations, and collaboration, it was possible to evolve and evaluate the conceptual model on which the TeleDem Simulation is based. This ensured the suitability of the model to address the core objective of the research:

To examine the impact of telecare on a) the numbers of people with dementia able to remain living within their own homes rather than entering institutional care, and b) the ability of these patients' carers to cope.

Full details of the finalised conceptual model, and the TeleDem Simulation it helped to build, are provided in the following chapter.

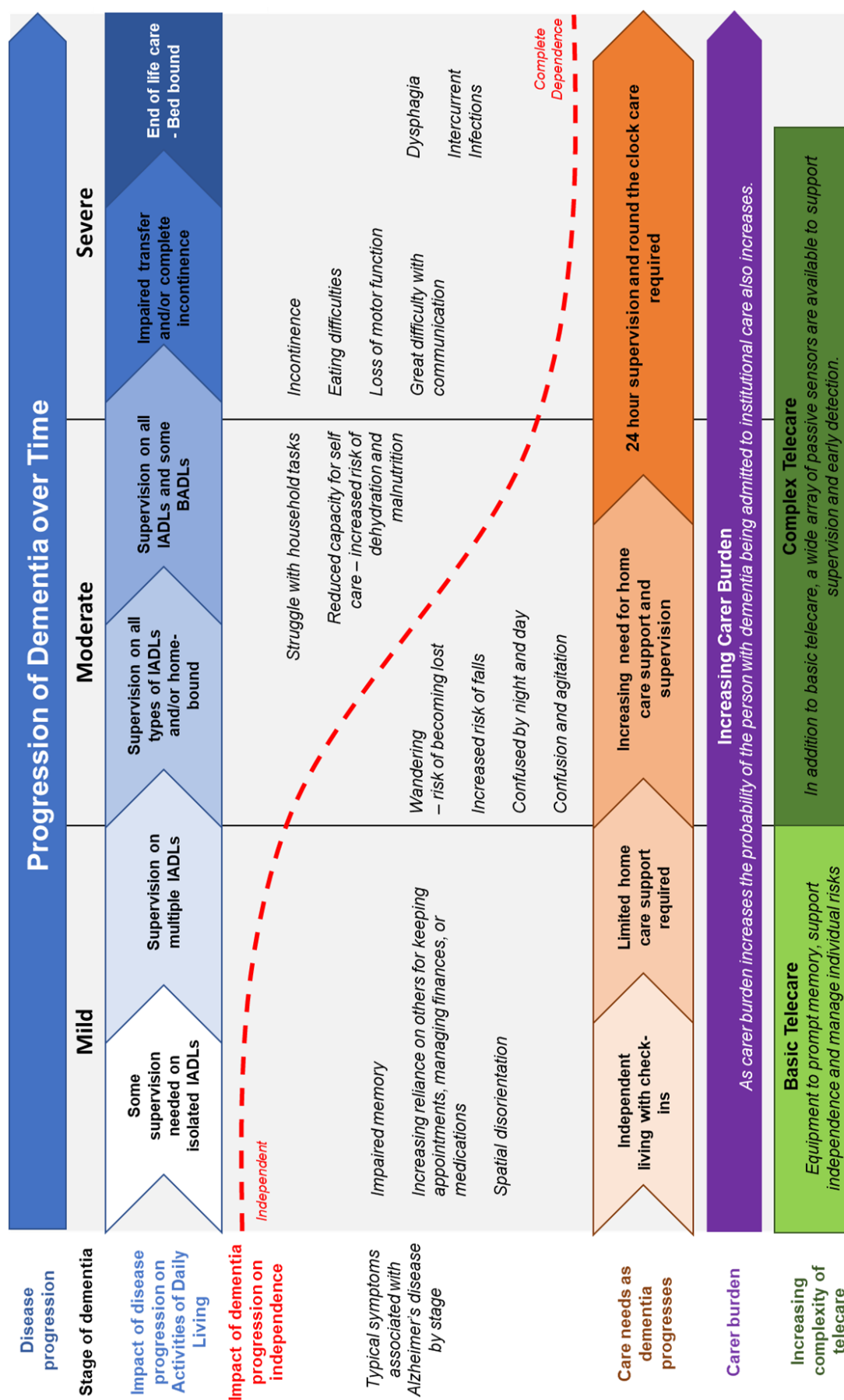


Figure 5.5: Key Elements of the Problem Situation

Chapter 6: The TeleDem Simulation

6.1 Chapter Overview

This chapter describes the modelling methodology of this thesis. It sets out the steps taken to construct the TeleDem Simulation, which is used to achieve the research objective set out in Chapter 1:

Design and build a hybrid simulation model combining discrete event simulation with statecharts to examine the impact of telecare on a) the numbers of people with dementia able to remain living within their own homes rather than entering institutional care, and b) the ability of these patients' carers to cope.

This chapter will cover part five of the modelling framework (see Figure 6.1). Outlining the key features of the TeleDem Simulation and how it was verified.

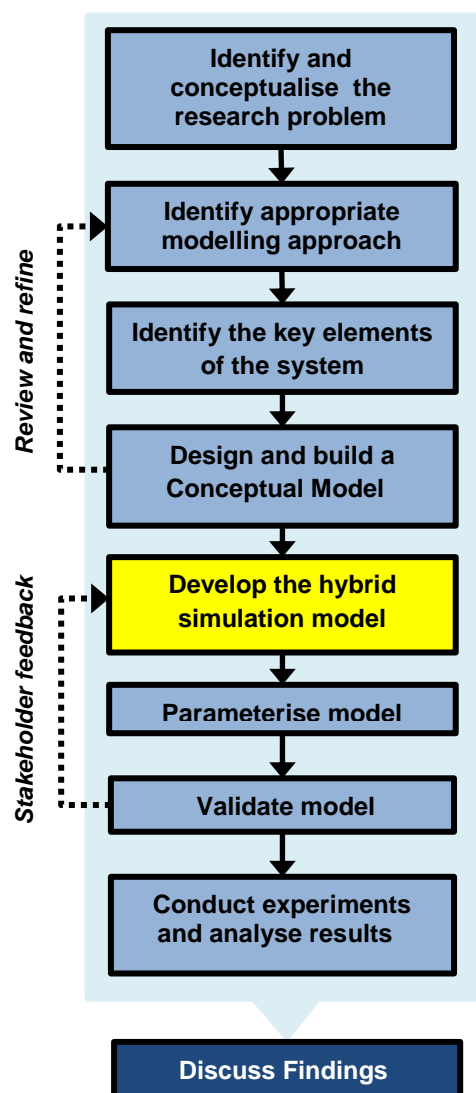


Figure 6.1: Addressing Part Five of the Modelling Framework

6.2 Justification of Modelling Approach Selected to Address the Research Questions of this Thesis

The TeleDem Simulation represents the flow of patients with dementia through different stages in the care pathway, either living at home in the community with varying levels of support, or moving to an institutional setting. The rate of flow, in other words, the length of time a simulated patient remains in any particular stage in this pathway, will be influenced by many factors including their disease status and their carer's ability to cope.

Although each of the simulation approaches discussed in Chapter 4, Section 4.3, could be applied to a broad range of problem domains, the methods vary in their ease and capacity to address particular questions (Marshall *et al.*, 2015a). For instance, person by person variation has been identified as a key concept within this research. Differing rates of disease progression, changing levels of dependency, and the varying of carers' ability to cope, have been highlighted as core influencers over dementia care delivery. Therefore, the model paradigm needs to be able to handle discrete interactions and be structured around individual histories. On this basis, SD models were ruled out due to their aggregate nature.

Advocates of ABS might propose that this methodology would be best suited to capture this individual level complexity. However, as Brailsford (2013; 2014c, 2014d) highlighted, DES can often be deployed with equal effect as its ABS counterpart, without so many of the drawbacks. For instance, the heavy use of coding associated with ABM does not facilitate discussion, whereas DES software packages often include a graphical interface which allows for a more visual modelling process.

DES lends itself to modelling complex systems, such as the social care service for people with dementia, from an operational and tactical perspective. Marshall *et al.* (2015a), when comparing DES to SD and ABS, emphasised the ability of DES to generate insights into the 'impact of resource availability on workflow, efficiency and throughput' (p.153). DES allows you to build in the randomness you see in real life and 'gives you the flexibility to describe events and timings as they actually are' (SIMUL8, 2016). As highlighted in Chapter 4, Section 4.3.2, the ability of DES to sample from distributions also provides flexibility in terms of data requirements. Campbell *et al.* (2001) chose DES as it can make efficient use of small samples of observational data; while Fishman (2013) suggests the use of expert opinion in the absence of historical data for setting parameter values. This

component is useful due to the lack of robust data in the field of telecare. Simulation modelling allows us to test the system repeatedly under different ‘what if?’ scenarios in order to examine its performance. Therefore, even in the absence of data, conclusions can be drawn about the impact of telecare based on hypothetical scenarios devised from the literature and expert opinion.

Furthermore, advances in software design mean that DES can be enhanced with the inclusion of statecharts which, as discussed in Chapter 4, are traditionally an ABS feature. This means that a hybrid model can be constructed within DES specific software (SIMUL8). This allows a modeller to combine the structural strengths of a traditional DES with the individual level realism of an ABS statechart.

Modelling disease progression in traditional DES can be challenging. The progression of dementia in an individual is critical to the care they receive, however, as highlighted in Chapter 2, the rate at which dementia progresses can vary greatly between individuals. Building this into a DES requires complex logic, as an entity can only be in one place at a time. This means there is no efficient way of capturing any parallel processes alongside the progression of the entity through the main pathway. For instance, in the real world a person can die at any point in time and this would obviously result in their care services being withdrawn. For a model to reflect this, the entity (person) would need to exit the system immediately, i.e. the activity (stage in the care pathway) in which that entity was currently engaging would need to be interrupted and terminated. However, a traditional DES could not handle this, the entity could only exit the model at the end of its current activity, which would still have to run for its predetermined time. Using the hybrid modelling approach, the model can describe what is really happening to the patient in a much more realistic way.

A person’s progression through different states in the statechart is independent of their position within the DES, although movement around the DES can be triggered by changes in state. For instance, if a person dies, they can be immediately removed from the DES, which reduces the risk of the model overestimating resource usage. If a person progresses to a more severe stage of dementia, their care needs will change. This aids the ability of the model to reflect the reality of the dementia care pathway, where the outcomes of assessments, reviews, and referrals to care services would be based around each person’s current condition.

Dowd *et al.* (2018) used Markov models to represent transitions between stages of dementia. However, statecharts combine the advantages of a Markov model with a graphical interface that can aid communication with stakeholders. Furthermore, statecharts have the advantage of being simpler to implement, and yet capable of representing highly complex processes. They lend themselves to situations where patients are simultaneously characterised by more than one state, in this instance: stage of dementia, dependency level, and carer capacity to cope. They are also able to record the status of the system, which is challenging to achieve in Markov models due to their 'memory-less' nature (Vijaykumar *et al.*, 2012).

As shown in Chapter 4, Section 4.3.3, Vickland and Brodaty (2008) found statecharts to be a powerful and expressive tool, capturing complex behaviour with relatively few elements. The statecharts, which are relatively straightforward to deploy within the SIMUL8 software, operate independently from the DES model, using probabilities, timings, and rates to represent the current condition of the person. This transforms the work items in the DES from passive entities into intelligent objects that can exert control over the system. The ability of SIMUL8 to include multiple statecharts working together, means the model can capture the varying levels of dependency associated with the disease progression and the changes in carer capacity to cope. Therefore, having reviewed the previous literature and understood the existing applications of hybrid modelling, it was concluded that this is an appropriate approach to positively address research question 1:

- ***How can the use of statecharts enhance the capability of Discrete Event Simulation to effectively take into account the variability associated with the progression of dementia, and also the variation in the ability of carers to cope?***

This question along, with the following broader question (research question 2), will be discussed further in the concluding chapter of this thesis.

- ***What are the advantages and disadvantages of using statecharts in addition to 'standard' DES for modelling patient care pathways?***

Unlike the micro simulations commonly used by social scientists (Onggo, 2012a), DES is able to capture interactions between individuals through wait times and queues. This helps the model to account for factors such as limited equipment availability. Furthermore, being able to examine the system at the individual level makes this hybrid model even more appealing, particularly as a person-centred approach sits at the heart of social care.

Finally, the visual and animated nature of the model lends itself to being used as a communication tool, which could be considered essential in this research, as feedback and input from domain experts has been used to structure model elements where data is sparse.

The individual transitions through the care system in the TeleDem Simulation model can therefore examine the impact of telecare on the numbers of people with dementia able to remain living within their own homes rather than entering institutional care. The model is also able to test the impact of telecare on modifying levels of carer burden by altering transition rates within the statecharts. This allows investigation into how this crucial factor may impact institutional care admissions. Therefore, the results produced by the TeleDem Simulation can answer research question 3:

- ***What can simulation modelling show us regarding the impact of telecare on institutional care admissions for people with dementia?***

Using the results from the TeleDem Simulation and with reference to the literature reviewed, and qualitative data collected, the final research question (research question 4) will be addressed in Chapter 9.

- ***Can OR modelling approaches help local authorities improve the way they plan services for people with dementia? And if so, how?***

6.3 Choice of Software

The model was developed using SIMUL8 Professional 2016. In 2013 SIMUL8 updated their professional software to include statechart functionality; enabling modellers to combine this ABS concept within a traditionally DES platform. SIMUL8's Chief Technology Officer, Frances Sneddon, described this move as a 'game-changer' for DES (Sneddon, 2016).

The SIMUL8 Corporation offers PhD students free access to the professional version of the software, which provides all the additional features and advanced analytical functions. SIMUL8 was therefore selected for its ability to incorporate DES with statecharts in a single user-friendly platform, its free availability to PhD students and because the original software (pre-2013 version) was already familiar to the researcher.

6.4 Model Overview

The TeleDem Simulation is a hybrid patient-level model to examine the effect of telecare equipment on the care pathway for people with dementia. The DES was designed to reflect the care pathway of people with dementia following diagnosis, while statecharts are utilised to follow each person from diagnosis, through disease progression, to death. Statecharts are also used to model stage of dementia, dependency level, and carer burden. The service pathway was developed in consultation with domain experts involved in the development and delivery of telecare, while the statecharts were created with guidance from experts in the fields of dementia and Gerontology. The model was designed to address research question 3:

- *What can simulation modelling show us regarding the impact of telecare on institutional care admissions for people with dementia?*

The model explores this impact by testing a range of scenarios. The scenarios consider the potential influence of telecare over levels of carer burden and the subsequent risk of carer collapse; alongside the effect of varying the number of likely referrals to telecare. The main outcome measure will be the comparative number of individuals who stay living in their own home rather than being admitted to institutional care (residential care or nursing home).

6.4.1 Scope of the Model

The model is not designed to represent a specific locality or population. However, the arrival rate into the model for the main set of scenarios that are tested in this thesis is based on the diagnosis rate for Southampton, so that the model reflects a city with a population of approximately quarter of a million people (see Chapter 8). The TeleDem Simulation is simple and generic in design in order to ensure its transferability when considering planning and policy implications for different areas. The simplicity of the model and its visual nature are two of its main strengths as they make it easy to engage with.

The model is not concerned with service capacities or waiting times within a particular area, therefore the availability of all care services, aside from telecare, are assumed to be unconstrained. This allows the model to focus purely on the impact of telecare on the number of institutional care admissions.

The model focuses on the social care system, as dementia is perceived to be a social care issue (see Section 2.10); therefore, the model does not include any interactions with the healthcare system. The main social care services traditionally available for people with dementia were identified through the stakeholder engagement outlined in the previous chapter. They were simplified down to 'community care', 'residential care' and 'nursing home'.

The model only examines the care pathways for people with Alzheimer's disease. As previously stated in Chapter 2, Section 2.2, Alzheimer's disease accounts for 62% of all cases of dementia. Consequently, there is a significant amount of data and information available on this form of dementia which was used in the development and design of the model; it also means that the model is applicable to a significant proportion of the dementia population. Therefore, the simulated population represents people aged 65 years and older from a city of comparative size to Southampton who have received a diagnosis of Alzheimer's disease.

6.4.2 Conceptual Model

The conceptual model was designed to be as simple and generic as possible, while still addressing the research objectives. Figure 6.2 shows the final version of the conceptual model, which formed the basis of the DES component of the TeleDem Simulation.

The conceptual model represents a simplified version of the care system. The care services depicted are the primary social care packages that each person might receive. The care services are divided into six categories to capture the following differences:

- **Basic Telecare** – For this package of telecare a person would receive a base unit, pendant alarm and up to four additional sensors or devices. For example, a fall detector, linked carbon monoxide detector, medication dispenser, or GPS device. These devices facilitate independent living, by minimising risk.
- **Community Care** – This care service refers to a traditional package of community care, with no inclusion of technology to enhance care delivery. This service, for someone with the early stages of dementia, would involve visits from a care worker to assist with Instrumental Activities of Daily Living (IADLs), such as ensuring that medication has been taken. Then as dementia progresses they would provide increasing assistance with the more basic activities of daily living (bADLs), such as bathing, toileting, and dressing.

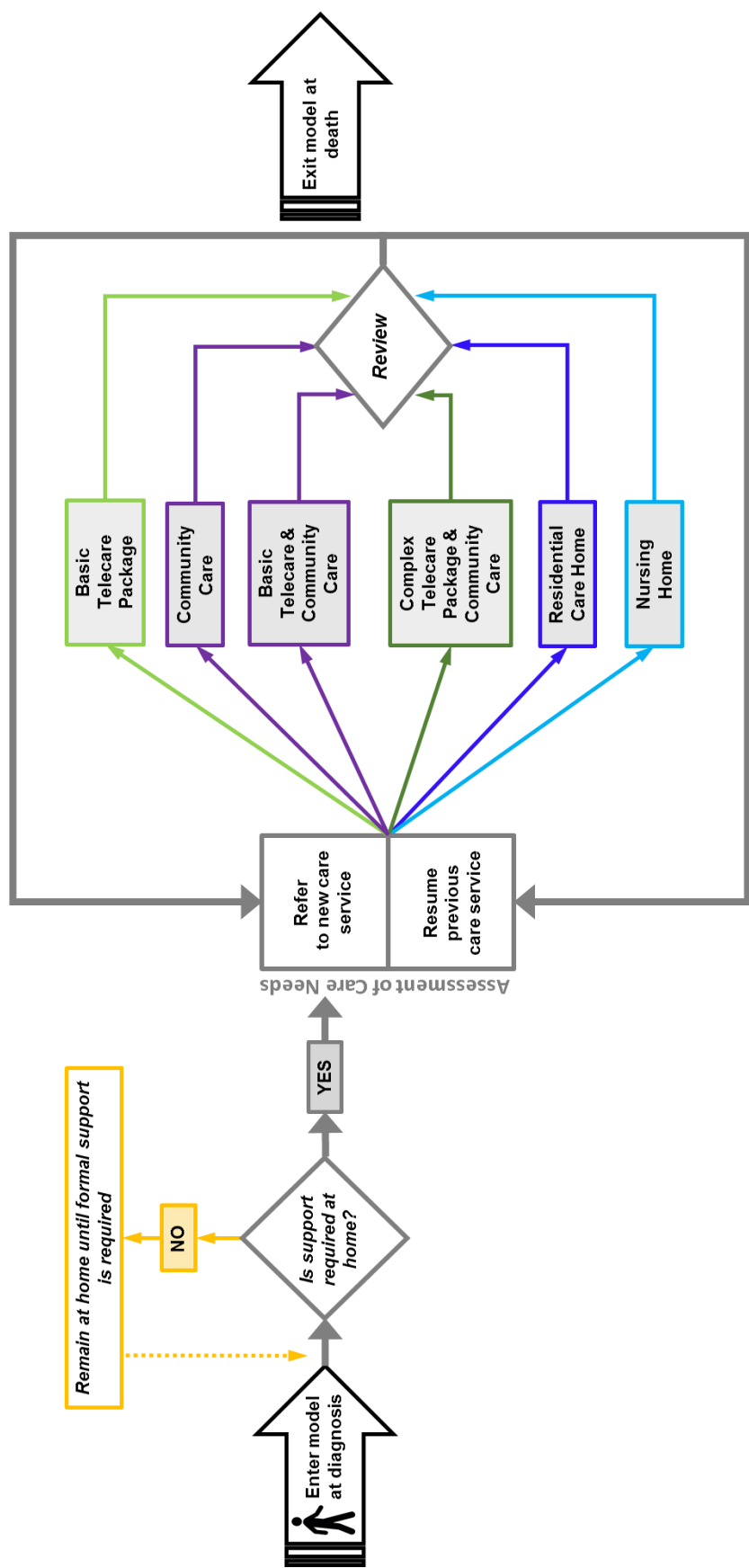


Figure 6.2: The Conceptual Model

- **Basic Telecare & Community Care** – This service combines basic telecare with community care. This can be referred to as a service in its own right, or if someone who is already receiving basic telecare only found they required additional support, they could be referred to this service and have community care added to their existing package of care. During consultation with domain experts, it was felt that including this service was important, firstly, in recognition of the fact that telecare cannot replace human care. If someone requires support with an ADL, a piece of technology will not have the ability to meet those care needs. Recognising this within the model will improve its acceptability for stakeholders who are concerned about technology replacing human support. Secondly, allowing for people to add community care alongside basic telecare, was felt to be more realistic. For instance, an individual may be comfortable with continuing to use a medication dispenser to remind them to take their tablets, but as their dementia advances, they may need help getting dressed in the morning, which is the type of essential care that telecare alone cannot provide.
- **Complex Telecare Package & Community Care** – This care service represents a step up in both care need and equipment complexity. In this category, patients would normally be provided with a full suite of telecare sensors and devices alongside a base unit. Passive activity monitors will be central to this package of care. For instance, in addition to equipment included under basic, people would be offered property exit sensors, lifestyle monitoring equipment, bed and chair occupancy sensors, property exit alerts, and enuresis sensors. The assumption has been made that this care service would be deployed in later stages of dementia and therefore it would be unlikely to be used in isolation, without community care provided by care workers.
- **Residential Care** – This care service is the first of two that can be categorised as ‘institutional care’, as it represents a move out of the community. Residential care offers 24 hour a day, 7 days a week, support from on-site care staff. All meals are provided, and the staff are available to help with all bADLs.
- **Nursing Home** – The final care service is for people who require 24/7 care and nursing support. The main difference between residential care and a nursing home, is that the later has registered nursing staff on duty at all times.

The conceptual diagram shows that people enter the model at the point that they receive their dementia diagnosis. On arrival into the model each person is assigned a set of unique characteristics to reflect the population aged over 65 with dementia in the UK. These characteristics include age, gender, stage of dementia, level of dependency, and informal carer availability. Informal carer availability includes whether the person has an informal carer, their living arrangements (co-habiting with the carer or living alone with a local carer), and the number of hours the carer can spend on caring responsibilities each day.

The person will require a different number of hours of support depending on their level of dependency. The level of dependency also influences the level of carer burden experienced by their informal carer. In turn, the level of carer burden influences the likelihood of the person requiring additional support at home, or transitioning to institutional care due to carer collapse.

The person's unique characteristics govern how they are routed around the model. If they do not require formal support from a care service at the time of diagnosis, they return home. If they do require assistance, the level of care they require is reviewed and they are referred on to one of the six care services.

Characteristics, such as gender, remain fixed, while others, such as age, stage of dementia, and level of dependency, change over time. Stage of dementia, level of dependency, and the level of burden experienced by the person's carer are all controlled by statecharts. Figure 6.3 shows how statecharts fit into the TeleDem Simulation to capture these dynamic characteristics.

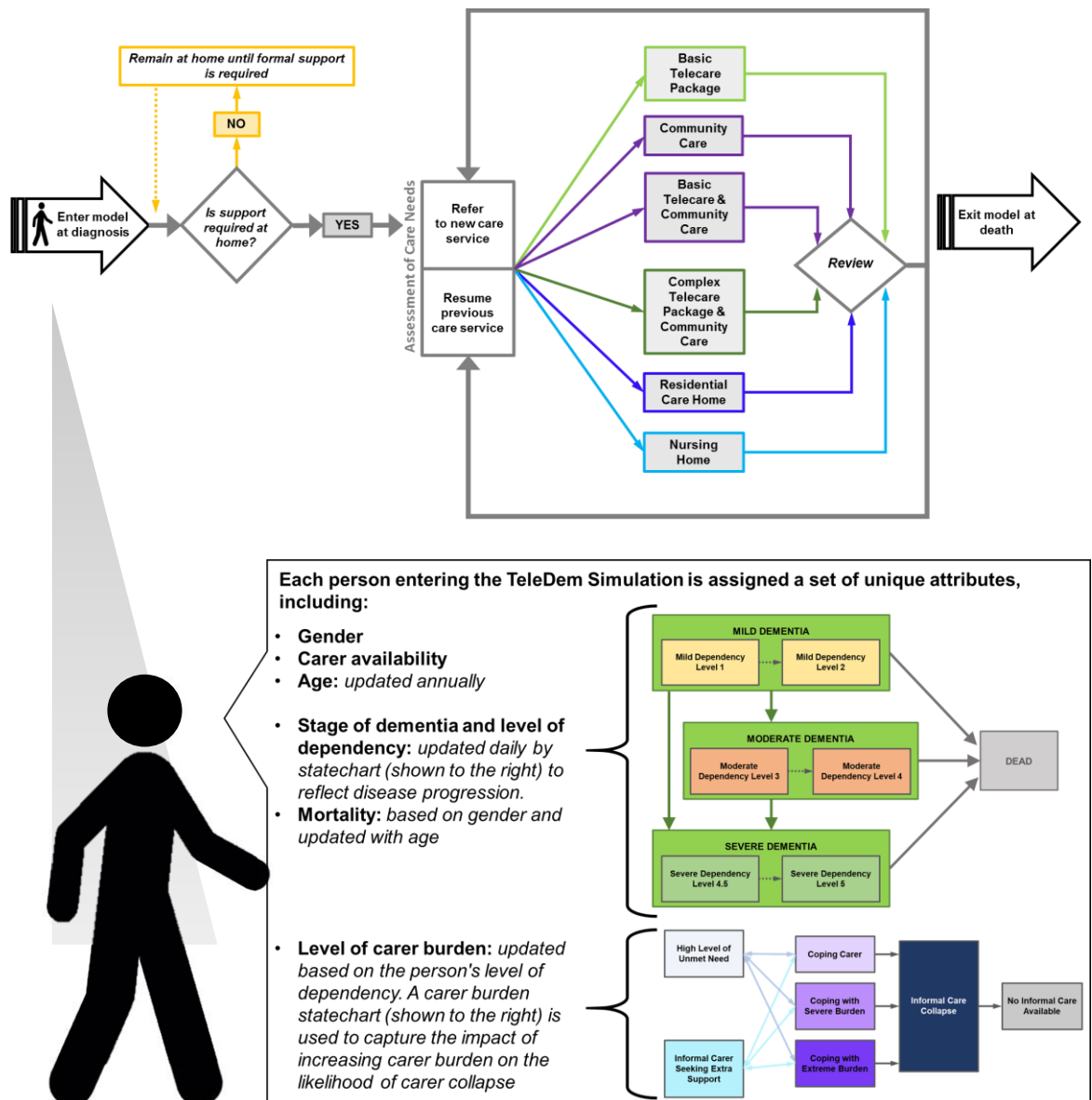


Figure 6.3: The Role of Statecharts in the TeleDem Simulation

Each month the level of care need is reviewed based on the person's stage of dementia, level of dependency, and carer availability. Once in the model a person does not leave until s/he dies. The frequency of review is to reflect how often a person and their support network would be likely to review their care needs, rather than implying a 'formal review' by care workers. A formal review of care needs, under Adult Service Guidelines, is more likely to occur once a year. However, if the model was set to review annually, this would be insufficient to capture the sometimes-rapid changes in level of need. Furthermore, it is highly unlikely that a significant change in 'need' would go unnoticed for twelve months, even for people without a specific informal carer.

6.5 Model Detail

The TeleDem Simulation Model is made up of two key parts, the statecharts and the DES. As previously mentioned, the statecharts focus on specific characteristics of the person that change over time, while the DES models the care pathway. The statecharts update on a daily basis as the DES model runs. Changes within the statecharts govern how people are directed through the DES model. For instance, when someone is referred to a new care service (see the conceptual model in the previous section), the routing decision is based on their statecharts. In other words, the referral to a care service is based on a person's stage of dementia, level of dependency, and carer availability, as would be the case in real life.

6.5.1 Structure of the Dementia and Dependency Statecharts

The following diagram shows the Dementia and Dependency Statecharts (Figure 6.4).

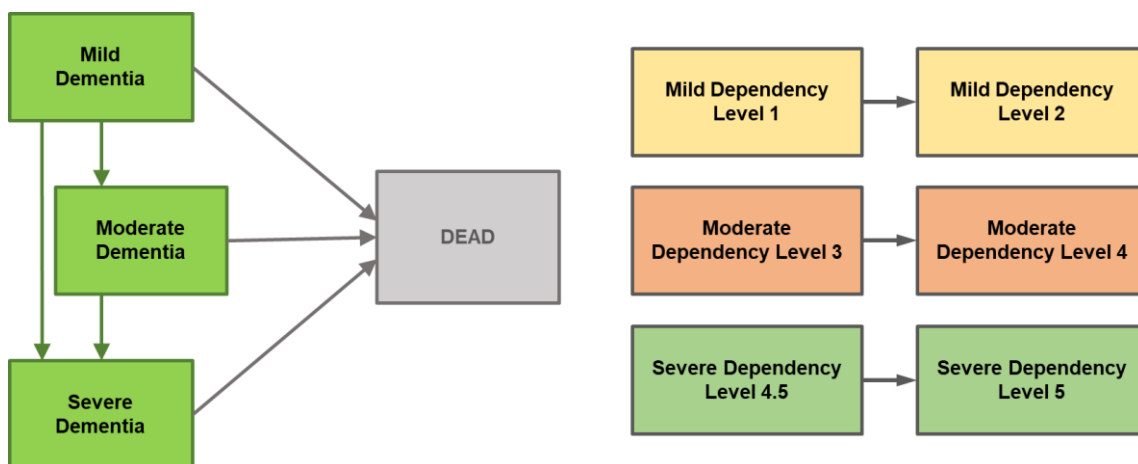


Figure 6.4: Dementia Statechart and Dependency Statechart

When people enter the model, they are diagnosed with mild, moderate, or severe dementia, at which point they are assigned to the relevant node within the Dementia Statechart. The Dementia Statechart is the main driver behind disease progression in the TeleDem Simulation; changes in this statechart directly influence the Dependency Statechart, which in turn controls the Carer Burden Statechart.

Once assigned to their diagnosis state a person then has a daily probability of transitioning between states or to death; the data used to control the rate at which these transitions occur is discussed in Chapter 7, Section 7.4. Although it would have been preferable to have assigned a weekly or monthly transition probability, the largest time unit

in SIMUL8 is 'days'. Therefore, as the DES component of the model operates in days, the statecharts also operate in the same unit of time. The transitions to death are dependent on age and gender. Each day the statechart checks the person's age and then checks the probability of transitioning to death by referring to age related rates, stored in an internal spreadsheet.

At the point that each person is assigned a dementia state, internal code within the statechart node simultaneously assigns them a level of dependency within the Dependency Statechart. The Dependency Statechart is based on the work of Kahle-Wroblewski *et al.* (2015), which mapped activities of daily living onto six categories of dependency; see Chapter 2, Section 2.8.2. For the purposes of this research, the mean MMSE scores from Kahle-Wroblewski *et al.* (2015) were used to match dependency levels to the corresponding CDR based severity stages (mild, moderate, and severe) used in the Dementia Statechart (see Table 6.1 below).

Table 6.1: Matching Stage of Dementia to Dependency Level

CDR (Hughes <i>et al.</i> , 1982).	MMSE Score Mapped to CDR (Perneczky <i>et al.</i> , 2006)	Dependency Level Mapped to CDR Based on Mean MMSE Score (Kahle-Wroblewski <i>et al.</i> , 2015)
1. Mild	21-25	Dependency level 1 Mean MMSE: 23
		Dependency level 2 Mean MMSE: 21
2. Moderate	11-20	Dependency level 3 Mean MMSE: 18
		Dependency level 4 Mean MMSE: 15
3. Severe	0-10	Dependency level 5 Mean MMSE: 10

Sources: Hughes *et al.* (1982), Perneczky *et al.* (2006) and Kahle-Wroblewski *et al.* (2015)

The Dependency Statechart omits dependency level 0 from Kahle-Wroblewski *et al.*'s original work, on the assumption that all individuals arriving into the model will be exhibiting at very least a low level of dependency to warrant a diagnosis. Furthermore, an additional level of '4.5' has been added to the Dependency Statechart, which represents Kahle-Wroblewski *et al.*'s Level 5 data. This is to reflect the GERAS study, on which Kahle-Wroblewski *et al.*'s (2015) work was based (as discussed in Chapter 2, Section 2.8.2). The GERAS study did not include people with very severe symptoms of dementia, as indicated by the mean dependency level 5 MMSE score shown in Table 6.1. Therefore, it has been assumed that someone at dependency level 5 in the general population are likely, on

average, to be experiencing more severe symptoms than reflected in the summary statistics of Kahle-Wroblewski *et al.*'s 2015 paper.

Dependency levels 1 and 2 within the TeleDem Dependency Statechart correspond to mild dementia. Levels 3 and 4 represent moderate dementia, and levels 4.5 and 5 correspond to severe. Figure 6.5 show diagrammatically how the Dependency Statechart sits within the Dementia Statechart.

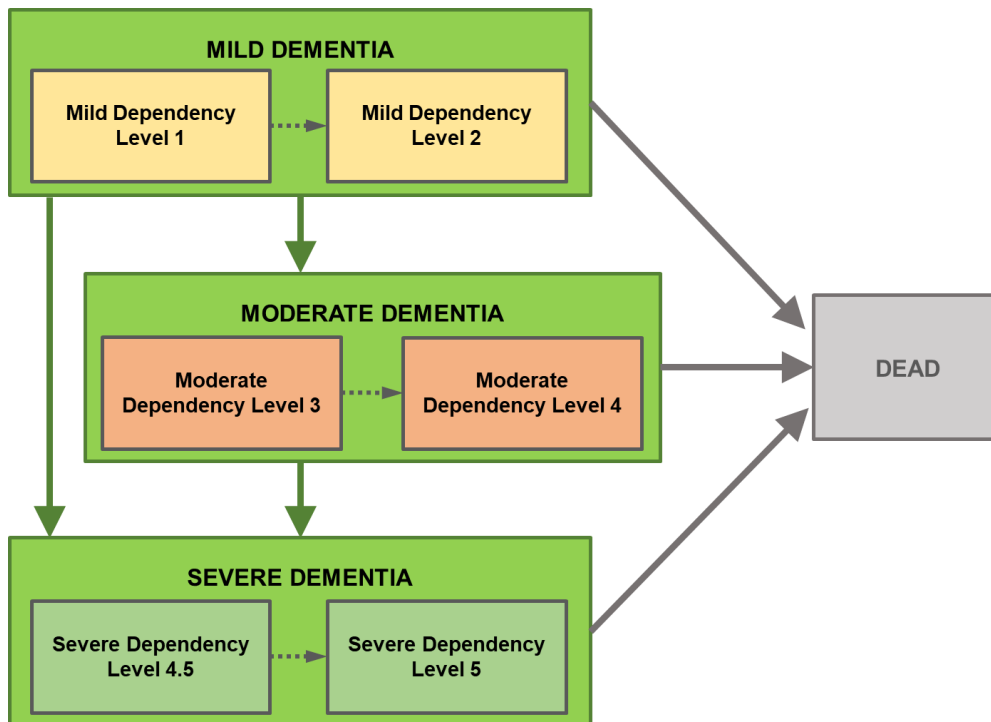


Figure 6.5: Illustrates How the Dementia and Dependency Statecharts Relate to One Another

People are automatically assigned the lower level of dependency for their stage of dementia and then as the model runs they can transition to the higher level. Variation in the rates of transition represents the variation in dependency experienced between different people with dementia.

Within each dependency state, probability distributions are used to assign values to labels relating to the number of hours of support each person requires. If the person has an informal carer, then there are also probability distributions in each dependency level to assign likely level of carer burden, which is recorded as a Zarit Burden Inventory (ZBI) score (Zarit *et al.*, 1985). The ZBI score and care status directly influences each person's position within the Carer Burden Statechart.

6.5.2 Structure of the Carer Burden Statechart

The following diagram shows the Carer Burden Statechart (Figure 6.6).

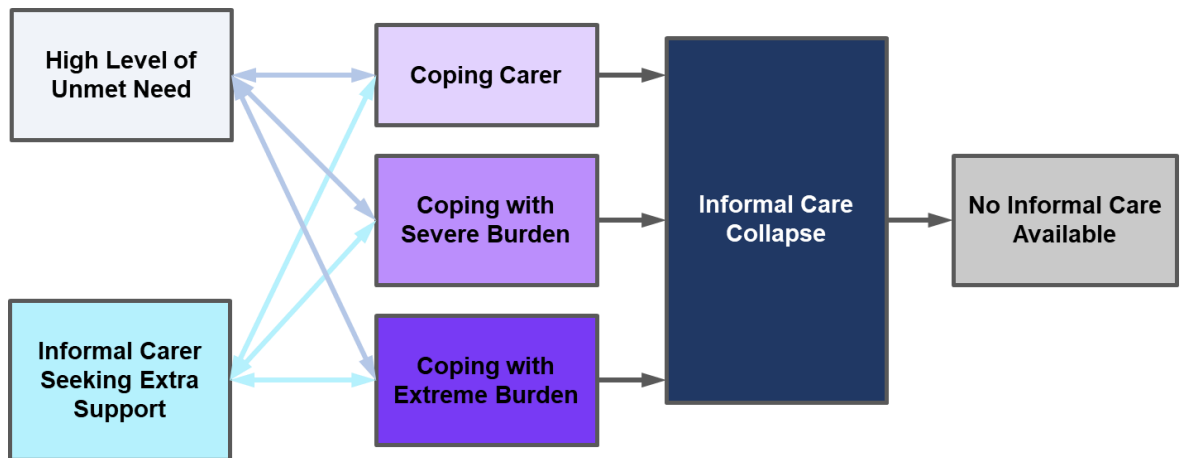


Figure 6.6: Carer Burden Statechart

On entering the model, each person is assigned an informal care status to reflect carer availability. Either patients have no informal support at all, in which case they are assigned to 'No Informal Care Available', as shown by the far-right node of Figure 6.6, or they receive one of three forms of informal care, namely:

- Cohabiting spouse;
- Other co habiting (for instance: son/daughter, other family member, or friend);
- A carer who lives locally.

In this context, 'living locally' means that the carer lives sufficiently close to respond to an incident quickly, should one occur. A carer who lives over an hour away, for example, may be too far away to respond to an alert raised by telecare equipment, and in this case a telecare service would be unsuitable.

People who receive informal care in the model are assigned a ZBI score to represent the likely level of burden being experienced by their carer. As each person moves through the Dependency Statechart they are assigned new ZBI scores based on their current level of dependency. The ZBI score determines where each person sits within the Carer Burden Statechart: 'Coping Carer', 'Coping with Severe Burden', or 'Coping with Extreme Burden'. Each of these nodes signifies a stepped increase in level of carer burden. There are no direct transitional links between the core 'Coping Carer', 'Coping with Severe Burden', or 'Coping with Extreme Burden' nodes, as these are automatically reassigned when a

person's level of dependency changes and their ZBI score is recalculated. Figure 6.7 illustrates how the Dependency and Carer Burden Statecharts link to one another.

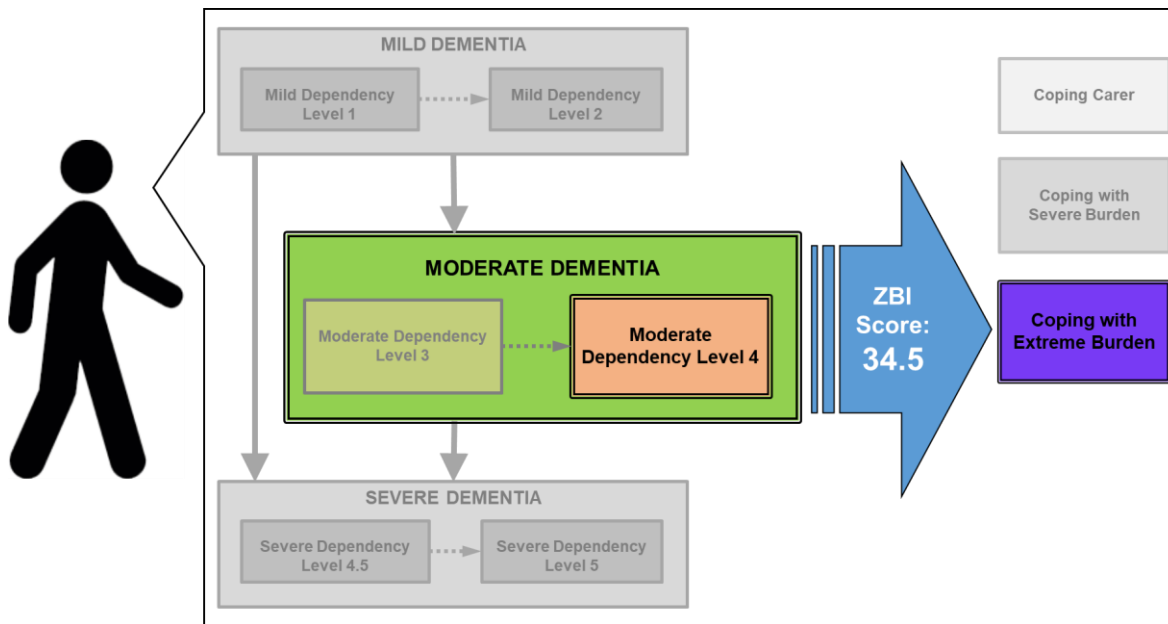


Figure 6.7: Interaction between Dependency and Carer Burden Statechart

ZBI scores within the model are recalculated on referral to telecare based services to reflect the influence of telecare over reducing carer burden. This effect only remains while the person is in receipt of a telecare-based care service.

The transition rates from the core nodes ('Coping' states) and the 'Informal Care Collapse' node increase with level of carer burden, to reflect an increased risk of institutional care admission. Once the transition to 'Informal Care Collapse' is made, the person will be referred to an institutional care setting within the model (either Residential Care or Nursing Home). Upon entering the institutional care, the person is assigned to the 'No Informal Care Available' node. Further information on the role of carer burden and the transition rates for informal care collapse is provided in Chapter 7, Sections 7.10 and 7.11.

People can also transition from each of the 'Coping' states into the state: 'High Level of Unmet Need' if at review it transpires that the number of hours of care required are not being met by the current care provision. The person will then transition back into a 'Coping' state once the unmet need has been addressed. Transitioning to 'Seeking Extra Support' relates to people with informal carers who return home without a community care service following diagnosis. These people are assigned a transition rate that increases in line with their increasing dependency. Therefore the higher their level of dependency, the

more likely the person is to transition to seeking extra support (Scherer *et al.*, 2008). It also relates to people who are referred to basic telecare only. They can transition to requiring additional support and be assigned community care alongside their basic telecare equipment. The transition rates that control movement into this node of the statechart are taken from a paper by Scherer *et al.* (2008), and are discussed in more detail in Chapter 7, Section 7.11. Once an appropriate referral has been made to address the unmet need, or requirement for extra support, then the level of burden experienced by the person's carer is reset to one of the core 'Coping' carer nodes.

6.5.3 Detailed Structure of the Discrete Event Simulation

The DES component of the TeleDem Simulation represents simplified care pathways through the care system. The main concepts within a typical DES are described in Chapter 4, Section 4.3.2; the following table considers what each of those elements represents within SIMUL8 and then the TeleDem Simulation.

Table 6.2: The Main Elements of the Discrete Event Simulation

DES Component	SIMUL8	TeleDem Simulation
Entity	Work Item	Person
Attributes	Labels	Characteristics: age, gender, type of informal care, hours of informal care available, stage of dementia, level of dependency, Carer ZBI Score etc.
Activities, also referred to as Events	Activities	Components of the care pathway: diagnosis, referral, review, and care service.
Resources	Resources	Resources are used to represent the type of care service provided: <ul style="list-style-type: none"> • Simple Telecare Equipment • Community Care Package • Complex Telecare Equipment • Residential Care Home Space • Nursing Home Bed
Queues	Queues	Queues typically represent waiting lists for care services.
Time	Time	Each time unit represents one day.

Source: TeleDem Simulation

6.5.4 Results Available from the Model

There are two categories of result from the TeleDem Simulation: 'population data' and 'resource utilisation'. The population data mostly focuses on 'day counts', which relate to how many days each person spends in each care service. The time spent at home with no support, or informal care only, and the time spent in each of the care services are all measured as days. Labels and Visual Logic commands are used to collect and record this data, which is then exported to csv files at the end of each run. When looking specifically at the care services, the model starts counting the days at the point that the resource is allocated, and then stops counting at the point it is released.

Information regarding people's life span within the model is also recorded in days, and then recalculated into years. In addition to day counts, the population data also includes the number of admissions to institutional care. For instance, for the population who exit the model, the results show how many of those people were admitted to residential care and/or a nursing home over the course of their lifespans. This allows the model to be used to test different scenarios that may impact the number of admissions to institutional care and the number of days people spend in institutional care over their lifespan.

Resource utilisation focuses on the resources used, rather than the number of people using them. This result is recorded for each of the care services listed in Section 6.4. For this result, the minimum, average, and maximum utilisation, are recorded, along with a 95% confidence interval range.

6.5.5 Labels and Information Variables

Labels are a vital component of a SIMUL8 model. They allow the modeller to assign attributes to the work items. In this model, the attributes are personal characteristics (age, gender etc.), and the work items represent people. These attributes and their variability enable the model to capture the complexity of the system. They provide information that can be used to inform how the people move around the model. Labels can contain either text or numbers; however, all of the labels used for this model are numerical.

The three statecharts use a total of 23 labels. 18 of the labels literally describe states that the person may be in e.g. 'Mild', 'Moderate', 'Severe', or 'Dead'. Each person will have three states; one state within each of the three statecharts, for instance a person may be 1) 'Mild', 2) 'Dependency level 1', with a 3) 'Coping Carer'. However, once the person transitions to the state 'Dead' within the core Dementia Statechart, they exit the model and

are removed from all states. Each of the state labels has a value of 0 or 1, which is shown as 'no' or 'yes' within SIMUL8's label viewer; these values mean: 0 = not in this state, or 1 = yes in this state. Transitions, which are shown as arrows on the statecharts, either utilise labels to assign the daily probabilities of transitioning, which then read values from internal spreadsheets, or they are directly parameterised on screen through dialogue boxes. The transition rate for 'Informal Carers Seeking Extra Support' is assigned to a label through the Visual Logic coded in the Dependency Statechart. How the transition rates were derived is discussed in more detail in Chapter 7.

The DES component of the model uses a further 127 numerical labels, which can be divided into five categories: Personal Attribute, Routing, Calculation, Functionality Check and Day Count Result Labels; a full list of all of the labels is included in Appendix 23. Table 6.3 provides a summary of the Personal Attribute labels.

In addition to the Personal Attribute labels used to give each person their unique characteristics, the Routing labels form a principal component of this model. The model contains 13 Routing Labels which ensure that each person follows the correct pathway through the system. The pathway is determined from the personal attributes of the work item, using Visual Logic. Two key Routing labels are 'lbl_First_Referral Routing' and 'lbl_Service routing'. The first of the two directs people to the appropriate care service following referral; the route selected is determined by a series of conditions in the Visual Logic, and in the majority of cases is sampled from one of six distributions, which are discussed in Chapter 7, Section 7.14. The appropriate routing distribution is selected based on the person's level of dependency, whether they receive informal care, and how many hours of informal care they receive. The second key Routing label refers to the care service the person is receiving. The label, which is assigned a value between 1 and 8, is used to route people back to their current care service if their care needs are unchanged at their monthly review. The labels are as follows:

- 1 = Basic Telecare Only;
- 2= Basic Telecare and Community Care;
- 3 = Community Care;
- 4 = Complex Telecare and Community Care;
- 5 = Residential Care,
- 6 = Nursing Home Placement;
- 7 = No Support Sought;
- 8 = Informal Care Only.

The 18 Calculation labels are used in sections of Visual Logic code to update Personal Attribute labels; while the 36 Day Count Result labels are used to count and record the number of days that each person spends in each type of care service. These results are then recorded in an internal spreadsheet, and sent to a csv file at the end of each run of the simulation. The 47 labels categorised as ‘Functionality Checks’ were incorporated into the model design to record data for verification and validation purposes.

Table 6.3: Summary of the Personal Attribute Labels Used in the TeleDem Simulation

Attribute	Label Used	Input	Detail
Identifier	lbl_person	Unique Number	Unique identifier is assigned as the people enter the model.
Gender	lbl_GENDER	Distribution: Probability Profile	Links to a gender distribution. 1 = male, 2 = female.
Age at diagnosis	lbl_Age on Arrival	Distribution: Probability Profile	Ages range from 65 years to 100 years old. Ages are assigned from probability profiles based on the person's gender.
Current Age	lbl_Updated Age at Reassessment	Calculated in Visual Logic	Calculated by adding the number of years the person has been in the model to the age they were assigned on arrival. This is updated each time the person's care needs are reviewed.
Current Stage of Dementia	lbl_Current Stage of Dementia	Statechart	Checks the person's progression through the Dementia Statechart and records the person's current stage of dementia as a number: 111=mild, 222= moderate, 333= severe, 999= dead.
Level of Dependency	lbl_Dependency Level	Statechart	Records the person's progression through the Dependency Statechart as a number that corresponds to their level of dependency: 1,2,3,4,4.5, or 5 This label, along with age and the availability of informal care hours are central to determining the routing people take through the model.
How many hours of support with IADLS, BADLS and/or supervision does the person need?	lbl_hours of care required	Distribution: Average	Updates with each dependency state transition. It details the number of hours of care the person requires based on their level of dependency. The value can range from 0, representing no hours of support required to 24 hours, indicating that the person requires supervision at all times.

<i>Does the person have an informal carer?</i>	lbl_informal carer	Distribution: Probability Profile	Type of informal carer: 0= no carer, 1 = cohabiting spouse, 2 = other co habiting, 3 = local/not cohabiting
<i>If the person has an informal carer, how many hours a day are they available to provide support with IADLS, BADLS and supervision?</i>	lbl_InformCareHrs_AVAIL	Distribution: Probability Profile	The number of hours was sampled from one of three distributions depending on the type of informal carer. As the core time unit of the model is days, the values ranged from 0.03 (representing 40 minutes a day) to 1 (representing available 24 hours a day).
<i>Carer's perceived level of burden, recorded as a ZBI Score</i>	lbl_Carer ZBI Score	Distribution: Normal	The ZBI score was based on a mean value that corresponds to the person's level of dependency. ZBI scores are recorded on a scale of 1 to 88. 0–17 = Low to Moderate burden 18–32= Severe Burden 33-88= Extreme Burden
<i>Impact of Telecare on Carer Burden</i>	lbl_adjusted Carer ZBI	Calculated in Visual Logic	A variable is used to calculate an adjusted ZBI score for people receiving telecare.
<i>Age at death</i>	lbl_age at death	Calculated in Visual Logic	Current age is recalculated when the person transitions into the 'dead' state within the Dementia Statechart. This ages is then recorded as the person's age at death.
<i>How long did the person live from point of diagnosis to death?</i>	lbl_LifeSpan	Calculated in Visual Logic	Calculated by subtracting age at diagnosis (lbl_Age on Arrival) from age at death. Used for recording the dementia life span between diagnosis and death of each person when they exit the model (die).
<i>What is the person's level of unmet need?</i>	lbl_unmet need	Calculated in Visual Logic	This is calculated in the 'Decide whether support is required' and 'Review of Care Needs' work centres to establish whether the person should be routed to referral or not. It is calculated by subtracting the number of hours of care an informal carer can provide from the number of hours of care the person requires. If the resulting value is greater than 0, the person has unmet need and must referred for additional support from a care service.

Source: TeleDem Simulation

6.5.6 Visual Logic

Visual Logic (VL) is SIMUL8's Simulation Language. It allows detailed logic to be built into the simulation describing how the model should behave. VL is used at various key points within the TeleDem Simulation. It is used throughout the model to set labels that capture and record information for collecting results, and for validation purposes. VL is used at points where resources (care services) are released and allocated, and to count the number of days each person remains in each care service. At the end of a simulation run, VL calls and populates a spreadsheet to store the results; it then sends these results to be saved as a csv file. VL enables the statecharts to communicate with each other and the DES, by changing attribute labels. The other key points where VL plays a fundamental role are described in Table 6.4.

Table 6.4: The Role of Visual Logic in the TeleDem Simulation

Location	Purpose
Entry Point	<ul style="list-style-type: none"> The arrival point uses the action interface to attach Personal Attribute Labels for the person's unique identifier, gender, and type of informal care. The Entry Point uses VL to assign age from an age-based probability profile dependent on the assigned gender. VL also sets the hours of informal care available from one of three distributions corresponding to the type of informal care assigned. Finally, initial transition rates to death are assigned based on gender and current age. These are used within the core Dementia Statechart.
Decide whether support is required	<ul style="list-style-type: none"> Calculates whether the person has 'unmet need'. Calls VL to identify the person's carer state within the Carer Burden Statechart, using the carer ZBI score which is set by the Dependency Statechart. Allocates to coping, severe and extreme burden based on ZBI. Uses Before Exit logic to route people based on their unmet need and their carer burden status. If the carer is coping and the person has no unmet need they are either sent home without a referral (i.e. they will be directed to the 'No Support Sought' or 'Informal Care Only' work centres until their dementia progresses), or sent for referral based on distributions derived from Quince (Quince, 2011). These distributions are explored further in Chapter 7, Section 7.14.
Referral	<ul style="list-style-type: none"> Uses VL to call one of six probability profile distributions to direct the work item (i.e. refer the person) to one of the six care services, based on their stage of dementia, level of dependency, hours of care support required, and the availability of informal care. The VL also specifies additional routing out rules relating to instances when telecare equipment is unavailable, or if informal care has collapsed within the Carer Burden Statechart.
Review of Care Needs	<ul style="list-style-type: none"> This work centre uses Action VL to update the person's age and then update their transitions to death based on their age and gender. It also checks for unmet need and updates the Care Burden Statechart. It uses Before Exit Visual Logic to check each person's status. It looks for changes in dependency, unmet need, and changes in the carer state. If further support is required, the logic routes the person back to referral to be referred onto a new care service. Otherwise it routes to a dummy work centre called 'Return to Previous Care Service', which sends each person back to the service they had previously.
Check for Existing [Care Service]	<ul style="list-style-type: none"> A person may be referred to the same service on more than one occasion. The VL in these work centre checks for an existing care service resource and routes the person accordingly to ensure that they do not end up being allocated more than one resource.
Allocate Equipment	<ul style="list-style-type: none"> This work centre releases previous resources (previous care service) and allocates a new care service resource.
Route in Logic for each service	<ul style="list-style-type: none"> If the person is receiving a service that includes telecare, their ZBI score is recalculated to give an 'adjusted ZBI score' which takes into account the 'benefit' of telecare for reducing carer burden. This logic then resets the Carer Burden Statechart by calling the relevant VL.

Source: TeleDem Simulation

6.6 Computer SIMUL8 model

Figure 6.8 is a screenshot from SIMUL8 of the DES component of the TeleDem Simulation. This is followed by a zoomed-out version, showing how the model appears on the screen, in between the statecharts (Figure 6.9). The DES has several layers, which can be switched off to keep the appearance of the model as clean and simple looking as possible. This facilitates communication when showing the model to stakeholders.

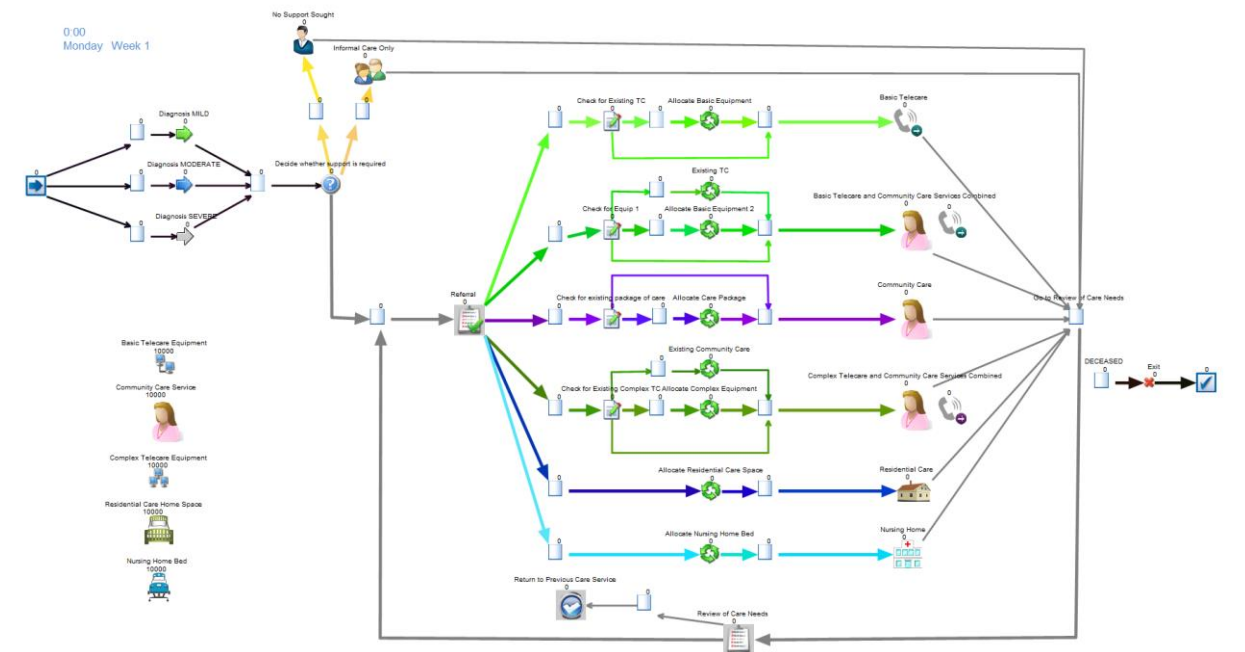


Figure 6.8: A Screenshot of the DES Model as it Appears in SIMUL8

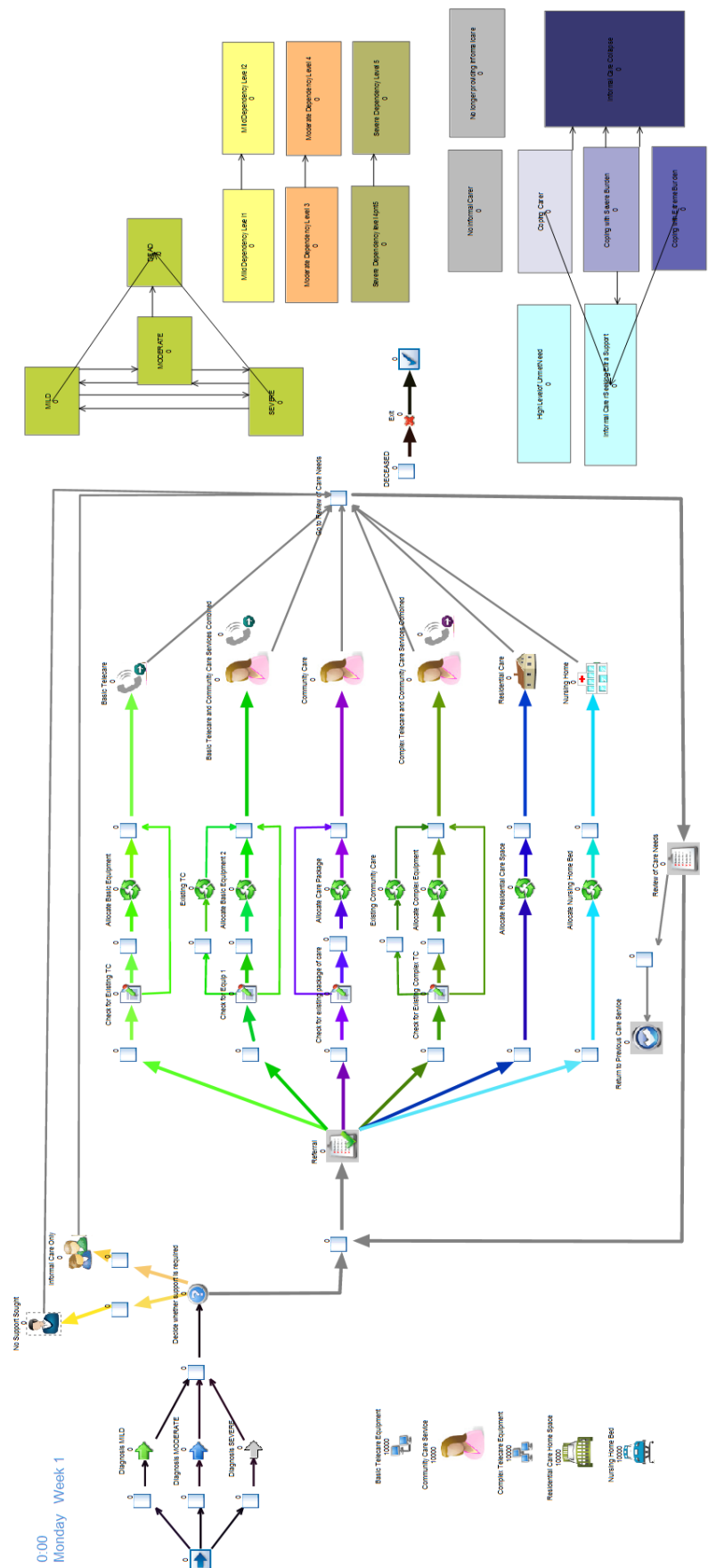


Figure 6.9: A Screenshot of the TeleDem Simulation

As discussed in Section 6.5.1, the TeleDem Simulation uses days as its time unit. A single run of the model simulates a 40-year period (14,600 days) to see how the system performs over time. The model starts collecting results that relate to the population data as soon as it starts each run; whereas results related to resource utilisation are only collected after the first 10 years have elapsed. This warm-up period of 10 years allows the system to reach normal running conditions and prevents the average resource utilisation being underestimated.

A set of simulation runs (iterations) is called a 'trial' in SIMUL8. SIMUL8 contains a built-in trial calculator in order to determine the number of iterations required to achieve a desired level of precision for the confidence limits around the mean of some selected output. For the TeleDem model, the trial calculator determined that 35 runs would achieve a 95% confidence interval for the utilisation of the care service resources. The 'results synchronisation period' of the model is every 14 days, which effectively means that the model results are recorded every two weeks within the simulation run period of 30 years.

The arrival rates into the model are varied depending on the configuration of the scenario being examined. The scenarios that the TeleDem Simulation is used to test, along with a baseline scenario (no telecare), are described at the start of the results chapter (Chapter 8, Section 8.2).

The main components of the TeleDem Simulation screenshot reflect those described in the conceptual model in Section 6.4.2. The colours used in the model were chosen to mirror the conceptual model to help people to follow it and better understand the transition from colour coded diagram (Figure 6.2 in Section 6.4.2) into the operational SIMUL8 model.

The 'work centres' (activities) represented by green cycle icons, are used to check for and allocate resources (care services). The resources are shown to the left of the model. The number of available resources is adjusted at the start of each trial to test different scenarios relating to the availability of telecare services.

6.7 Model Verification

Verification is the process of determining that the model has been properly realised within the modelling software (Pidd, 2004). Anderson *et al.* (2003) describe the process as a 'debugging' exercise to ensure that there are no errors in the computer procedure. To verify the TeleDem Simulation the following steps were taken, as per the guidance provided by Pidd (2004, p. 239):

- The model was then built incrementally, which allowed each part to be run and checked, so that problems could be identified and resolved as quickly as possible.
- The Visual Logic was checked throughout the model building process. Test queues were used at every main routing activity to collect patients to ensure the model was behaving logically.
- Modules of logic were tested individually with extreme input values to ensure that each person's characteristics were changing at appropriate points, and that they were following expected routes.
- The final Visual Logic code was examined line by line, to ensure it provided clear, logical instructions that followed patterns of referral identified through discussion with domain experts.
- The structure and logic of the model were also checked with experts in the field of Operational Research Simulation.
- Finally, the entire model was run to produce an extensive set of results, documenting individual journeys through the model. The relationship between inputs and outputs were tested and checked.

Once it was confirmed that the model was fully operational and behaving as expected, the TeleDem Simulation could be parameterised and validated, as described in the following chapter.

6.8 In Summary

This chapter has described the process of building the TeleDem Simulation; from conceptualising its structure, and selecting the appropriate software, through to model verification. The chapter has outlined the core components of the model and described how the DES and statecharts work alongside one another. The following chapter looks at the input data used to parameterise the TeleDem Simulation.

Chapter 7: Model Input Data

7.1 Chapter Overview

This chapter describes how the TeleDem Simulation was parameterised, outlining the data sources used, and the assumptions that were made. It also sets out how the model was validated. All of the model inputs are summarised in Appendix 24. This chapter addresses parts six and seven of the model building framework, as shown by Figure 7.1.

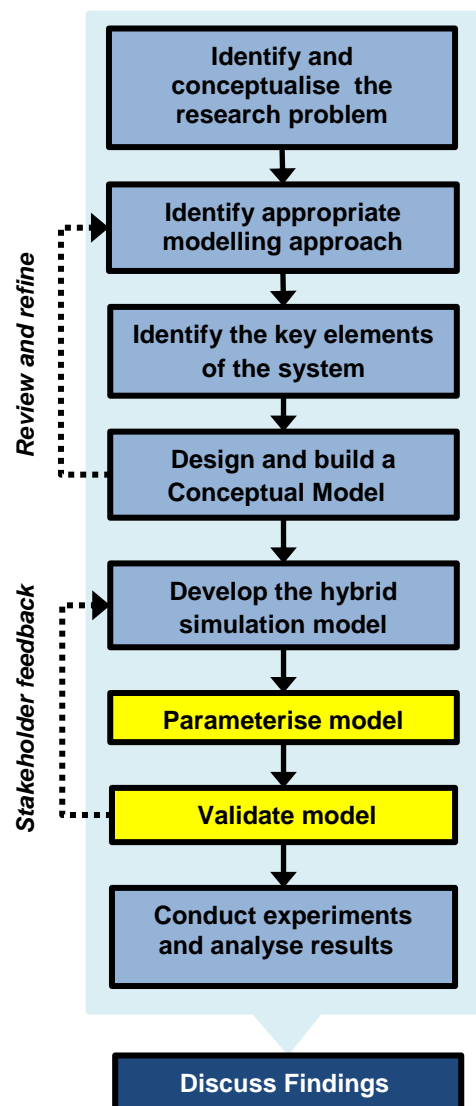


Figure 7.1: Addressing Parts Six and Seven of the Modelling Framework

7.2 The Cohort

The distributions for age and gender were based on the 2013 mid-year figures as estimated by the Office for National Statistics (ONS, 2014). Prince *et al.*'s (2014)

Dementia UK report provided data for the severity and prevalence of dementia by age and gender.

7.3 Diagnosis

People arrive in the model at the point of diagnosis. The arrival rate was varied depending on the scenario being tested (see Chapter 8). In the absence of precise figures, it has been assumed, in line with the literature, that 35% of people will not receive a diagnosis until the later stages of dementia; as Alzheimer's disease can often remain undiagnosed until symptoms become moderate or severe (Bond *et al.*, 2005). However, due to the severity of symptoms exhibited in the later stages of dementia it is assumed that only 5% of people will reach the severe stage without a diagnosis. Therefore, the proportions of people directed within the TeleDem Simulation to each diagnosis point is as follows:

- 65% mild
- 30% moderate
- 5% severe

The large proportion of mild diagnoses is also in alignment with the push towards early diagnosis both nationally (Department of Health, 2009a, 2011a), and globally (Prince *et al.*, 2011).

7.4 Disease Progression

The daily transition probabilities between mild, moderate, and severe states within the core Dementia Statechart are derived from a paper by Spackman *et al.* (2012). Spackman *et al.* (2012) built on the widely cited work of Neumann *et al.* (2001), calculating the probability of transitioning between disease states, and to institutional care, and death. Although both Spackman *et al.* and Neumann *et al.*'s studies were based on data collected in America, it has been assumed for the purposes of this research that UK based patients would show similar probabilities of transition.

Spackman *et al.* (2012) used data from the Uniform Data Set (UDS) from the National Alzheimer Coordinating Center (NACC), which contains demographic, clinical, and specimen data from Alzheimer Disease Centres (ADCs) across the United States. Their main analysis was based on 9,730 observations of 3,852 patients aged 50 years old or over and diagnosed with possible/probable AD. The global Clinical Dementia Rating (CDR) scale was deployed to determine the stage of Alzheimer's; they then calculated the

mean MMSE, NPI and FAQ scores by CDR stage to show the cognitive, behavioural, and physical functioning differences (Spackman *et al.*, 2012, p. 3). They used a multinomial logistic model to calculate transition probabilities between stages of the CDR. Table 7.1 shows the annual transition probabilities produced in the paper.

Table 7.1: Spackman *et al.*'s (2012) Transition Probabilities Between Dementia Severity Levels

	Mild	Moderate	Severe	Dead
Mild	0.774	0.158	0.013	0.055
Moderate	0.07	0.501	0.214	0.215
Severe	0.002	0.027	0.49	0.480
Dead	0	0	0	1

Source: Spackman *et al.* (2012) p.16.

Spackman *et al.* (2012) found that only the previous AD stage of the patient was significantly associated with their current AD stage (2012, p. 5). They concluded in their analysis that age, gender, race, and ethnicity had no significant impact on the likelihood of transitioning between stages of Alzheimer's disease. Therefore, these transition probabilities were used as stated, to calculate daily transition probabilities. To transform Spackman *et al.*'s (2012) annual probabilities (p) into daily probabilities (x) the following formula was applied:

$$x = 1 - (1 - p)^{(1/365)}$$

These daily transition probabilities were applied to the transitions between states in the Dementia Statechart of the TeleDem Simulation as shown in Figure 7.2.

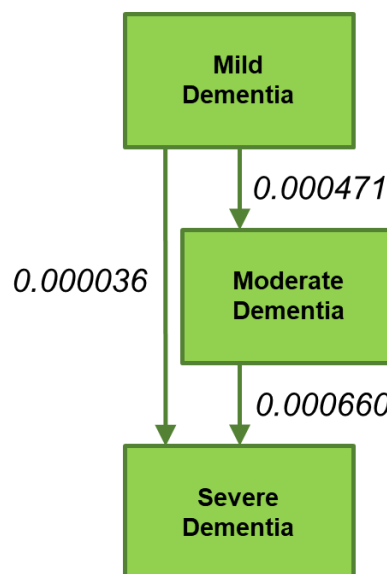


Figure 7.2: Daily Transition Probabilities Between Dementia Stages used in the TeleDem Simulation

The regressive transition probabilities shown in Table 7.1 were not included in the Dementia Statechart. Due to the progressive nature of dementia, significant improvement of symptoms is highly unlikely. The regressive transition probabilities presented by Spackman *et al.* (2012) are very low, and are likely to be due to misdiagnosis in the original data. Removing these transition probabilities was deemed to be an appropriate course of action to reduce the risk of these anomalies impacting the results of the model. Removing these transition probabilities slightly increases the person's likelihood of remaining in their current state, but does not change the probability of progressing to the subsequent state.

7.5 Mortality

Age and gender-specific annual mortality transition probabilities were input into the Dementia Statechart through SIMUL8's internal spreadsheets. For the purposes of this research, Eldon Spackman kindly provided an Excel spreadsheet version of the model used in Spackman *et al.*, (2012), which allowed the transitions to death to be calculated for both genders, and for each age from 65 to 110 years. The maximum age within the model was set to 110 years old, after which point the population transitioned to death. Appendix 25 sets out the full set of mortality transition rates used in the model.

7.6 Daily Transition Probabilities Between Levels of Dependency

At present, there are no data to indicate how long people spend within each level of dependency; Kahle-Wroblewski *et al.* (2015) propose that this is an area of further research. Daily transition probabilities between dependency levels were therefore derived from Spackman *et al.*'s (2012) state transitions, as shown in Figure 7.3. Each stage of dementia is broken down into two levels of dependency. These rates are based on the assumption that a person will spend approximately half their time at each level of dependency, and therefore they are likely to transition twice as quickly between dependency levels as they do between dementia states. The first two transition probabilities were calculated by doubling the daily transition rates between stages of dementia. The final rate was assumed to be the same as level 1 to 2.

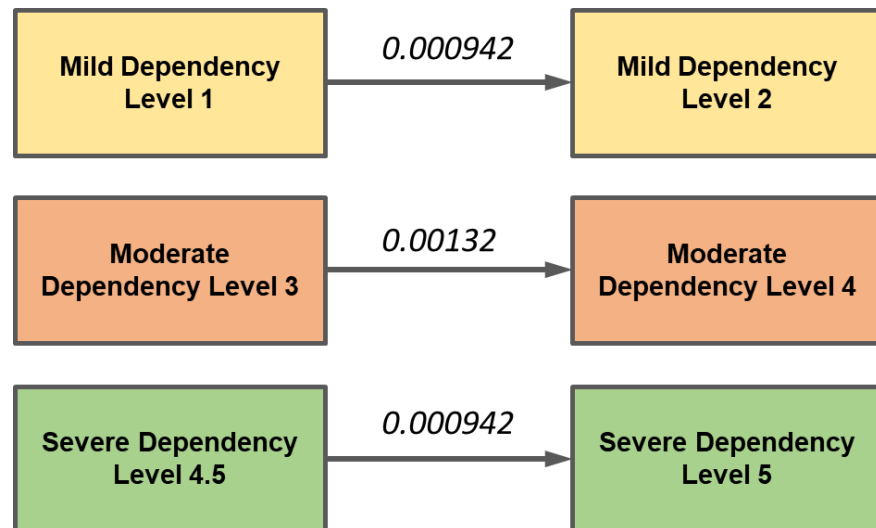


Figure 7.3: Dependency State Daily Transition Probabilities

7.7 Key Milestone and Hours of Care Required

The number of hours of support a person needs changes as their dependency increases, therefore this is allocated to the label: 'lbl_hours of care required', through the Dependency Statechart. For dependency levels 1 and 2, the hours of care required are estimated based on the work of Kahle-Wroblewski *et al.* (2015). This mean 'Caregiver Time' has been used as a proxy for number of hours of support required. This is based on the assumption that in the earliest stages of dementia, the time provided by informal carers is likely to meet the person's overall level of need; whereas in the later stages, additional support will be required to 'top this up'. In dependency level 1 the lower bound of the distribution is set to zero to reflect that some people at this stage of dementia may not require additional support (Caro *et al.*, 2002).

Dependency level 3 is an important milestone in disease progression within the TeleDem Simulation. If people reach dependency level 3 within the model and are receiving basic telecare, they will be flagged for an immediate review of their care needs using the label: lbl_MILESTONE. Caro *et al.* (2002) described people at dependency level 3 or higher as 'dependent'. Caro *et al.* (2002) presented socio-demographic and clinical characteristics of 1,287 patients with mild-to-moderate Alzheimer's disease. They found that approximately 80% of people at dependency level 3 required more than 12 hours of supervision per day. Caro *et al.* (2002) flagged this as a significant milestone, as at this point and beyond people with dementia require 'supervision and assistance with common tasks, for example they need to be watched when awake, or escorted when outside, or accompanied when bathing and eating' (p.2). This corresponds to Kahle-Wroblewski *et al.* (2015) who describe people at dependency level 3 as requiring 'supervision on all types of

IADLs or home-bound'. In their analysis they found that the time spent by informal carers for assisting with ADLs was 2.39 times greater in level 3 than level 2. They also observed a significant change in the utilisation of health care and total societal costs between these levels (Kahle-Wroblewski *et al.*, 2015).

At dependency level 4 it was assumed that people would require over 12 hours of supervision per day, with a larger proportion requiring 24-hour supervision. Kahle-Wroblewski *et al.* (2015) describe people at this level as requiring more extensive supervision, including supervision for BADLs.

As outlined in previous sections, an additional dependency level of '4.5' was included in the Dependency Statechart to represent Kahle-Wroblewski *et al.*'s Level 5 data. At dependencies 4.5 and 5 it is assumed that everyone will require 24-hour care, which reflects comments made within the literature regarding 24-hour supervision being necessary for the majority of people with severe dementia (Draper, 2013; Alzheimer's Association, 2017).

7.8 Type of Informal Care

The distributions for type of informal care were generated from research carried out by Miranda-Castillo *et al.* (2013). They carried out a cross-sectional survey between 2006 and 2007, recruiting a total of 152 people with dementia (aged 60 years and older) living at home, and 128 informal carers. Participants were recruited via health and social services, and voluntary organisations in North East London, Cambridgeshire, and Liverpool. They found that 67% of people with dementia lived with an informal carer, whereas 33% lived alone. Their results showed that 10% of the respondents with dementia had no informal care support (Miranda-Castillo *et al.*, 2013).

Miranda-Castillo *et al.* (2013) reported that 64% of the carers were the person's spouse, 31% were their son or daughter, 4% were other relatives, and 1% were their friends. Although their sample was small, these figures are not dissimilar to those of the much larger survey carried out by the Alzheimer's Society in 2011 for the publication 'Support. Stay. Save' (Quince, 2011). Quince (2011) collected 1,388 responses from informal carers of people with dementia; 48 responses from people with dementia, and 989 responses from home care workers. They used a questionnaire referred to in the report as the DEMHOM Questionnaire, which collected both quantitative and qualitative evidence. Quince (2011) reported that 'most family carers (68%) responding to DEMHOM were the spouse of the person with dementia, with just under a quarter of family carers (23%) the

son or daughter of the person with dementia' (Quince, 2011, p. 13). Quince also reported that a higher proportion of people with dementia lived with their carer (79%); however due to the predominance of carers responding to the DEMHOM questionnaire, Miranda-Castillo *et al.*'s (2013) figure is assumed to be more representative.

For the purposes of the TeleDem Simulation a distinction was drawn between 'co-habiting spouse'; 'co-habiting other' (which encompasses sons, daughters, other relatives, and friends); and 'local/non-co-habiting carer'. Based on the figures provided by Miranda-Castillo *et al.* (2013) the following data was input into the model as a probability profile with the following percentages:

- 10% of people arriving into the model are assumed to live alone with no carer
- 57% are assumed to be 'co-habiting spouse'
- 10% are assumed to be 'co-habiting other'
- 23% are assumed to be 'local/non-co-habiting carers'

7.9 Hours of Informal Care Availability

The characteristics of informal carers were outlined in Chapter 2, Section 2.9.1, however what is less well known is the amount of time informal carers spend on caring for individuals with dementia (Moise *et al.*, 2004). Therefore, the model assumes that the spousal carers of people with dementia who are over the age of 65 are also over the age of 65 and are retired, and thus would be available to assist the person with dementia 24 hours a day. The group of carers described as 'co-habiting other', in the absence of data, have been divided into 50% who are available 24 hours a day, 7 days a week, and 50% who are available for only half of the day, due to employment or childcare responsibilities taking them away from the home.

For the 'local/non-cohabiting carers', the number of hours available to provide informal care are based on a simplified interpretation of the data used in Beesley (2006). Beesley presented data from the General Household Survey 2001 on carers of people aged over 65, by number of hours per week spent caring, and living arrangement (2006, p. 4). The data showed that 89% of carers within this group provided informal care for less than 20 hours per week, and 6% of carers provided between 20 to 34 hours (Beesley, 2006). Although this data is looking at a general population of over 65 year olds, rather than specifically people with dementia, in the absence of a suitable alternative, it is assumed to be sufficiently representative.

It is assumed for local carers that, in the case of telecare being offered as a service option, they would be available to respond to infrequent alerts raised because of the early stages of dementia, but that they would not be sufficiently available to provide telecare response in the later stages of dementia.

7.10 Level of Carer Burden

Previous research has shown that as dementia progresses and the person requires increasing support and supervision, the level of burden experienced by informal carers also rises (Razani *et al.*, 2009; Kahle-Wroblewski *et al.*, 2015). As discussed in Chapter 2, Section 2.9.1.1, various studies of interventions that have targeted informal carers have shown positive outcomes in terms of reduced carer burden and delayed admissions to institutional care (Mittelman *et al.*, 2006; Andrén and Elmståhl, 2008; Tremont *et al.*, 2008; Dowd *et al.*, 2018). Tremont *et al.* (2008) explored the impact of an intervention referred to as the Family Intervention: Telephone Tracking-Dementia (FITT-D). FITT-D is a psychosocial intervention for informal carers of people with dementia delivered to caregivers by telephone over the course of a year. The average ZBI score for informal carers at the end of the trial reduced from 32.50 at baseline to 23.81, which represents a reduction of 27%. Although FITT-D is a different type of intervention to telecare; this study does demonstrate that by providing informal carers with the resources to cope with their role, it is possible to modify their level of carer burden and therefore reduce their ZBI score.

The literature has suggested that telecare can have a positive impact by reducing carer burden (Miskelly, 2001; The Audit Commission, 2004; Department of Health, 2005a; Woolham, 2006; Gitlin *et al.*, 2010b). However, there is currently insufficient evidence on the specific impact of telecare; therefore, this was identified as a key element to test and explore using the TeleDem Simulation (see Chapter 8).

Carer burden is represented in the TeleDem Simulation through ZBI scores. ZBI scores are assigned through the Dependency Statechart to represent the likely level burden being experienced by an informal carer at each level of dependency. The ZBI scores within the model are then modified by telecare services, to simulate the impact of telecare on reducing carer burden. The assigned ZBI scores are based on Kahle-Wroblewski *et al.*'s (2015) paper, which is discussed in detail in Chapter 2, Section 2.8.2. The mean ZBI scores for each level of dependency are presented in Table 7.2.

Table 7.2: Mean ZBI Scores by Dependency Level

Dependency Level	ZBI Mean (95% CI)
1	15 (12.4-17.7)
2	22.1 (20.9-23.3)
3	30.6 (29.1-32.1)
4	33.8 (32.6-35.1)
4.5	35.2 (32.2-38.1)
5	40 - 50

Source: Adapted from Kahle-Wroblewski *et al.* (2015) and Author's Work

The ZBI scores within the TeleDem Simulation are modelled as normally distributed with suitably chosen standard deviations to reflect the confidence intervals in Kahle-Wroblewski's (2015) work. It has been assumed that carers of people at dependency level 5 in the general population are likely, on average, to be experiencing higher levels of burden than reflected in the summary statistics of Kahle-Wroblewski *et al.* (see Appendix 6). It is also assumed that at this level of dependency the support provided by telecare is unlikely to continue to provide a modifying effect on the carer's level of burden, due to the significant increase in medical needs at the end stages of dementia. Therefore, ZBI scores are assumed to be in the range 40 to 50 in the newly defined Level 5 (see Section 6.5.1), to reflect a significant increase in dependency and to reflect the strain that is likely to be experienced when caring for someone at this point.

As each person moves through the Dependency Statechart they are assigned new ZBI scores based on their current level of dependency. Hébert *et al.* (2001) classified carer burden based on ZBI scores into three categories, which form the basis of the Carer Burden Statechart. Table 7.3 shows how Hébert *et al.*'s (2001) work informs the statechart structure.

Table 7.3: Carer Burden States and Zarit Burden Scores

Zarit Burden Score	Hébert <i>et al.</i> 's (2011) Categorisation	Carer Burden Statechart
0–17	<i>Low to Moderate burden</i>	Coping Carer
18–32	<i>Severe Burden</i>	Coping with Severe Burden
33–88	<i>Extreme Burden</i>	Coping with Extreme Burden

Source: Derived from Hébert *et al.*'s (2001)

As discussed in Chapter 2, Section 2.9.1.1, Hébert *et al.* (2001) asserted that carer burden is a strong predictor of institutional care admission for people with dementia. Each of these 'Coping' nodes within the statechart represent a stepped increase in carer

burden, and therefore an increased risk of carer collapse and consequently admission to an institutional setting.

7.11 Daily Transition Probabilities for ‘Informal Care Collapse’

Figure 7.4 shows the aspect of the Carer Burden Statechart that this section relates to. At present, no probabilities of carer collapse, based on ZBI scores, have been published. Therefore, the model uses estimated state transition probabilities generated from various sources of information. The transition probabilities are assigned to the label: ‘lbl_TRANSITION_Informal Care Collapse’ through an internal spreadsheet within the TeleDem Simulation. The value is assigned based on an ‘adjusted ZBI score’ that is recalculated to take into account the impact of telecare on carer burden.

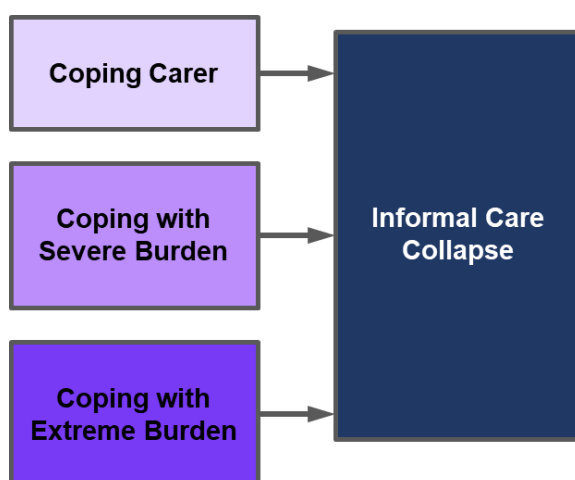


Figure 7.4: Transitions Between ‘Coping’ Nodes and the Informal Care Collapse Node

Spackman *et al.* (2012) and Neumann (2001) both published transitions probabilities to institutional care that increased significantly as the dementia moves from mild to moderate, and then to severe as shown by Table 7.4. In the absence of specific data, these values were used as a starting point for estimating a scale for transitions between ‘Coping’ nodes and the Informal Care Collapse node.

Table 7.4: Annual Transition Probabilities to Institutional Care from Two Publications

	Spackman <i>et al.</i> (2012) Annual Transition Probability to Institutional Care	Neumann <i>et al.</i> (2001) Annual Transition Probability to Institutional Care
Mild (95% CI)	1%	4%
Moderate (95% CI)	3%	11%
Severe (95% CI)	7%	26%

Source: Spackman *et al.* (2012) and Neumann *et al.* (2001)

A series of simple spreadsheet calculations were used to compare the transition probabilities in Spackman *et al.* (2012) and Neumann *et al.* (2001). It was concluded that Neumann *et al.* (2001) more closely met expectations for the transition probabilities based on other data sources (see Appendix 26). Furthermore, Neumann *et al.*'s (2001) work was based on data from the Consortium to Establish a Registry for Alzheimer's Disease (CERAD). CERAD is a longitudinal database of 1,145 dementia patients who were examined annually by clinicians in 22 major medical centers in America between 1986 and 1995 (Fillenbaum *et al.*, 2008). One of the requirements of CERAD is that each person with Alzheimer's disease included in the study must have an informal carer to provide information on their behalf. Therefore, Neumann *et al.*'s transition probabilities can be assumed to incorporate the impact of increased carer burden and consequently were taken as a basic proxy for informal care collapse in the Carer Burden Statechart.

Initial iterations of the TeleDem Simulation assumed a linear relationship between increasing ZBI scores and the transition rate to Informal Care Collapse (institutional care). However, consultation with domain experts suggested that this relationship is more likely to be exponential. The odds ratios published in Hébert *et al.* (2001) appear to confirm this, as shown in Figure 7.5. Therefore, the transition probabilities used in the TeleDem Simulation assume an initial linear relationship over 'coping' and 'severe' categories, and then a rapid increase in probability of transition once the person enters Hébert *et al.*'s (2001) 'extreme' burden category.

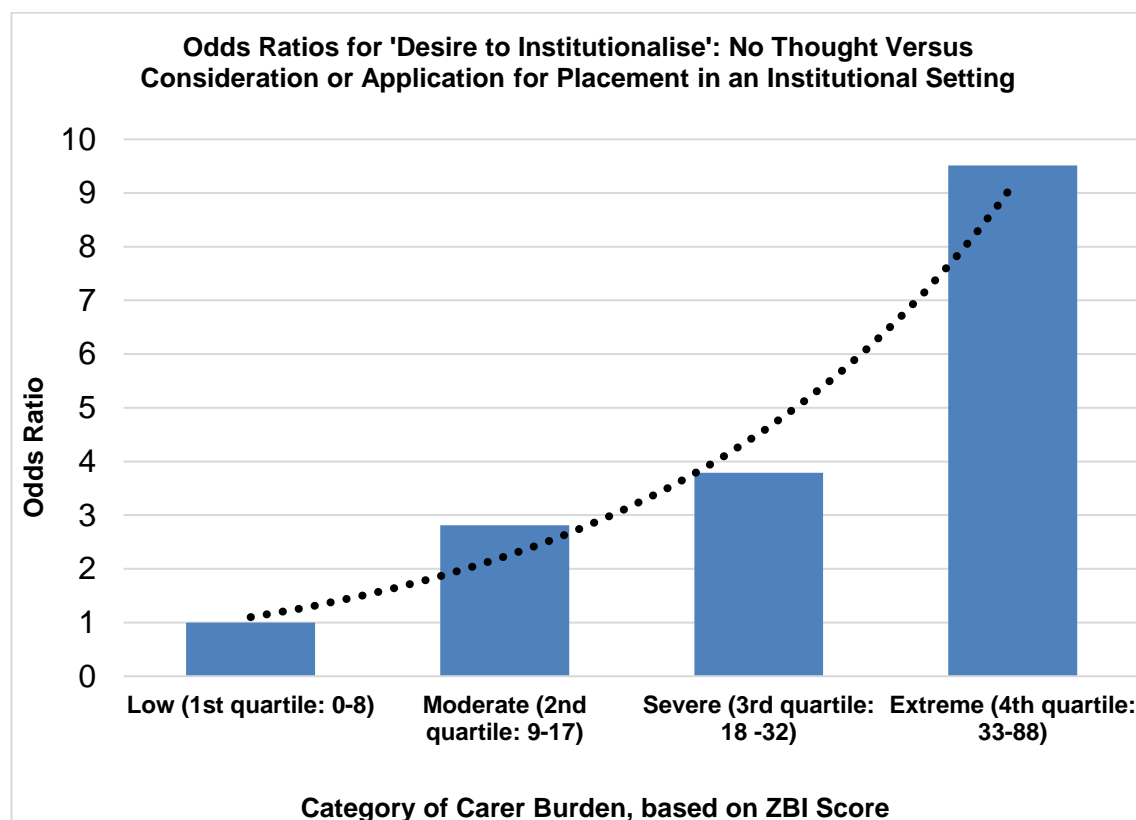


Figure 7.5: Odds Ratio for 'Desire to Institutionalise' (Hébert et al., 2001)

Figure 7.6 shows annual transition probabilities used in the TeleDem simulation. These probabilities were generated by averaging and adjusting the transition probabilities for a linear relationship, until the probabilities for TeleDem's assigned ZBI scores averaged at Neumann *et al.*'s (2001) transition probabilities for mild, moderate, and severe dementia. These annual probabilities were then converted into daily probabilities using the formula given in Section 7.4. This approach was an approximation based on the available data, however the model validation (see Section 7.16) shows that the approach generated realistic values. A full list of the transition probabilities used for Informal Care Collapse are provided in Appendix 27.

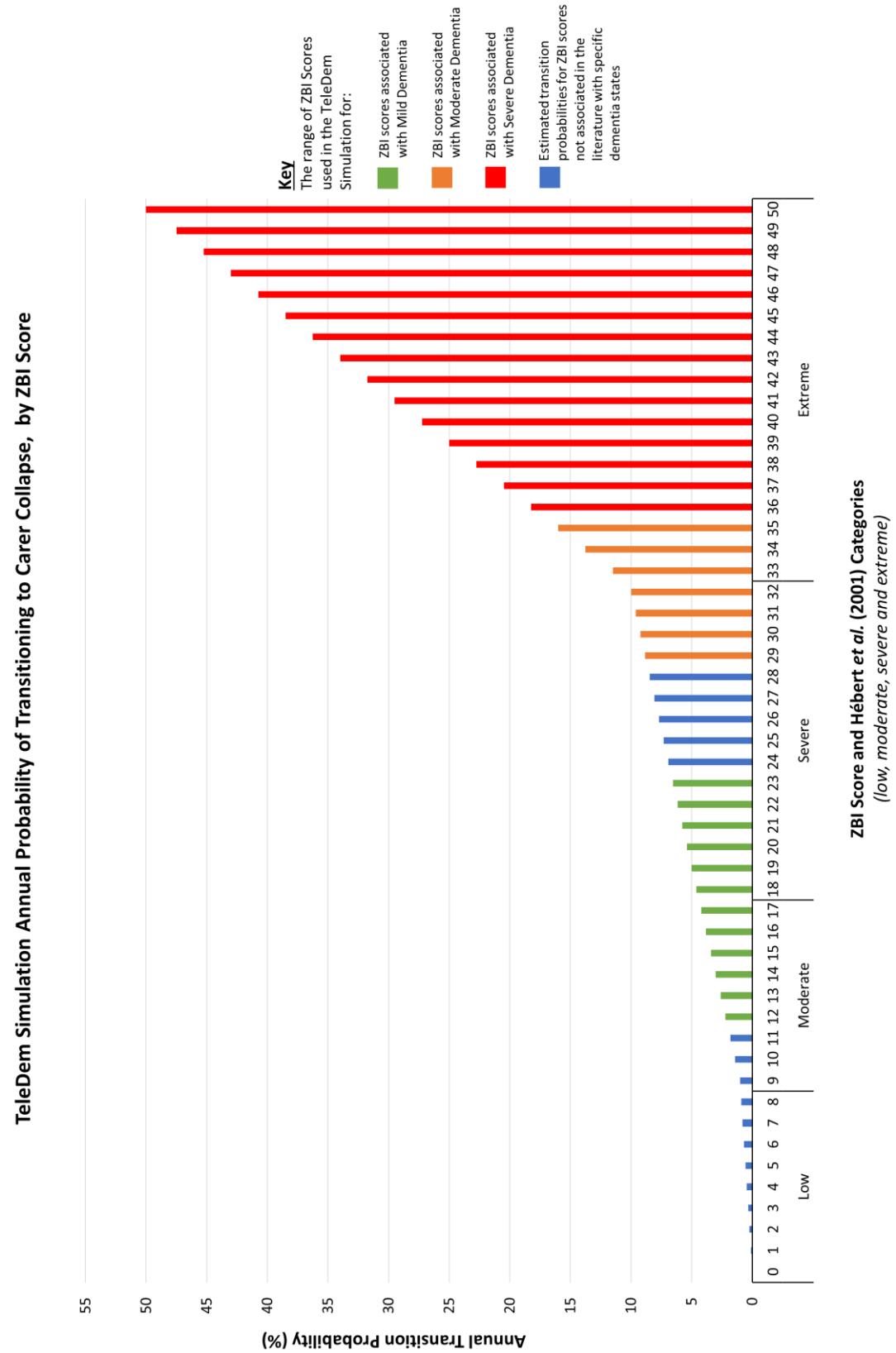


Figure 7.6: TeleDem Simulation Annual Transition Probabilities for Carer Collapse by ZBI Score

7.12 Daily Transition Probabilities for ‘Informal Carer Seeking Extra Support’

The transition probabilities for a person seeking extra support were derived from a study by Scherer *et al.* (2008). The values are only required for people with informal carers. They are used when the person is either being supported at home without any formal care service support, or is in receipt of ‘Basic Telecare (only)’. The values are assigned to a label (lbl_TRANSITION_seeking extra support) that regulates movement in the section of the Carer Burden Statechart shown in Figure 7.7.

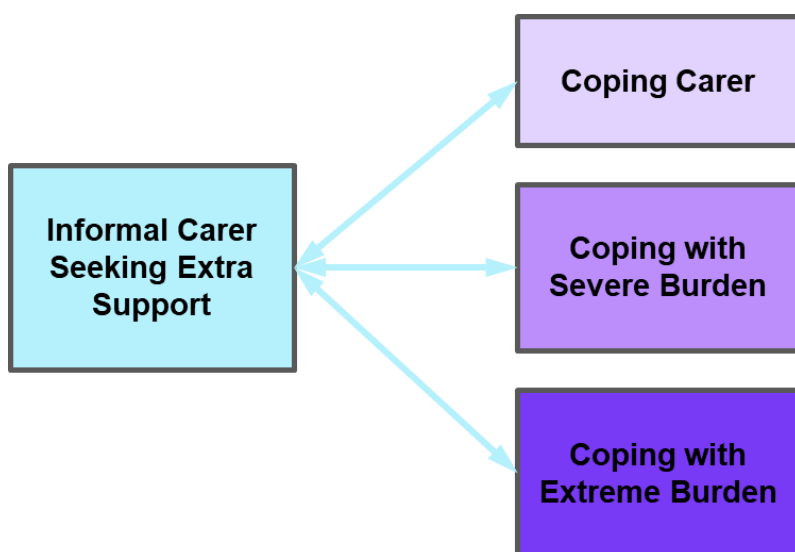


Figure 7.7: The Section of the Carer Burden Statechart that Uses Transition Probabilities for ‘Informal Carer Seeking Extra Support’

Scherer *et al.* (2008) based their work around a sample of patients with probable AD from the Predictors Study, which was a seven year cohort study across three university-based AD centres in the United States. Their final study population consisted of 300 observations from 75 participants and their informal carers. They used Markov modelling to evaluate annual transition probabilities for predicting the use of ‘home health aide’ (HHA) at different dependency levels. HHA was defined in the study as assistance with the ‘custodial and supportive care that AD patients require, including assistance with dressing, toileting, bathing, cooking, and companionship’ (Scherer *et al.*, 2008, p. 1005).

Using Stern *et al.*’s (1994) Dependency Score (DS) they created three ‘total dependence score groups’ corresponding to a total score of 0 to 3, 4 to 6, and 7 to 10. Although the DS has a range of 0-13, there were no participants in their sample who had total scores greater than 10 at any visits used in the analyses. These groups roughly correspond to the severity ranges (mild, moderate, and severe), as shown in Table 7.5.

Table 7.5: Annual Transition Probabilities for Home Health Aide

Stage	Dependence Grouping	Annual Transition Probabilities
Mild	0-3	6%
Moderate	4 to 6	17%
Severe	7 to 10	25%

Source: Scherer et al. (2008)

For the purposes of the TeleDem Simulation, these transition probabilities were broken down further by the person's dependency level and applied to the label (lbl_TRANSITION_seeking extra support) through the Dependency Statechart. For dependency level 1, it was assumed that the informal carer will be able to meet the persons care needs as long as they are available to provide care. Therefore, the transition probabilities were only applied from dependency level 2 and up. At dependency level 2 the 6% annual transition probability is used.

Scherer *et al.* (2008) found the transition probability for moderate dementia (identified as people with dependency scores between 4 and 6) was 17%. However, they also noted that transition probabilities for the presence of an HHA (if one was not present at the previous year's visit) were significantly higher (24%) if the participant needed to be watched or kept company when awake, or if the participant needed to be escorted when outside.

Therefore, for the purposes of the Carer Burden Statechart, an assumption is made that if the person requires more than 12 hours of supervision in the moderate stage of dementia, then they will have an annual transition probability of 24% of moving to seeking extra support. Whereas if they require under 12 hours of supervision, then the transition probability will be 10% (thus providing an average value of 17% overall).

Scherer *et al.* (2008) identified an annual transition probability of 25% for the grouping with dependency scores from 7 to 10, indicating that people in severe dementia have a 25% chance of requiring additional home support each year. Therefore, people with the severe dependency level 4.5 in the Dependency Statechart are assigned a transition probability of 25%. People at dependency level 5 are assumed to have a higher transition probability for this model (30%) in recognition of the fact Scherer *et al.*'s (2008) sample had no participants with the highest levels of dependency. The transition probabilities are summarised in Table 7.6.

Table 7.6: The TeleDem Simulation Transition Probabilities for 'Informal Carer Seeking Extra Support'

	Annual Transition Probability	Daily Transition Probability
Dependence Level 1	0%	0
Dependence Level 2	6%	0.000169507
Dependence Level 3	10%	0.000288617
Dependence Level 4	24%	0.000751599
Dependence Level 4.5	25%	0.00078786
Dependence Level 5	30%	0.000976714

Source: Estimated based on Scherer et al. (2008)

7.13 Need for Support Following Diagnosis

Following diagnosis, people are initially directed to referral if they have over 30 minutes of unmet need. If they have a carer who is available to meet their needs, they are directed by one of three probability profiles, that are based on the information provided by respondents to the DEMHOM survey (Quince, 2011).

Respondents to DEMHOM reported that 61% of people with dementia in their cohort had been assessed and received social services support. The reasons given by the remaining 39%, who did not receive formal support following diagnosis, included:

- Not being eligible to receive care services, either because they did not meet local authority criteria for support, or because they had too much money to be provided formal services for free.
- They were not aware they were eligible for assessment.
- They did not want formal support because they felt their carer could look after them.

Consequently, 61% of the people who enter the TeleDem Simulation and are diagnosed as mild are sent for referral, while 39% return home without support from a formal care service.

Quince (2011) reported that 16% of people who had been living at home with dementia for four to six years were not receiving any services. This is taken as a reasonable proxy for living at home with moderate dementia. Therefore, this value was taken as an indication of the number of people who would not seek further support despite a diagnosis of moderate dementia. Therefore, 84%% of people with moderate dementia who enter the TeleDem Simulation are sent for referral to a care service following diagnosis.

It is assumed that people who enter the model having been diagnosed with severe dementia are highly likely to require referral to a care service. Therefore, 100% of people who enter the simulation with severe dementia are sent for referral to a care service.

7.14 Care Service Referrals

“There is very limited information available from representative population-based studies regarding the use of health and social services by people with dementia, and their informal care. Again, these parameters would be expected to change over time given changes in policy, legislation and level of provision.” (Knapp *et al.*, 2007, p. 21)

Despite a decade passing since Knapp *et al.*'s statement in 2007, the information available on the use of social care services by people with dementia remains limited and disjointed. Consequently, the 'rules for referral' in the TeleDem Simulation were established through consultation with domain experts, the available literature, and through logical assumptions.

In the absence of data describing how and when telecare is referred to as a mainstream care service, this model input was identified as a key variable to examine in Chapter 8. Therefore, referrals to telecare-based services (basic or complex) are controlled within the model by six 'probability profiles' (user-input empirical probability distributions). The referrals have been treated as an alternative to 'traditional' community care and the profiles are used to vary the proportion of community care referrals that should be redirected to a telecare-based service. As people who live alone without the support of informal carers are more likely to be placed in institutional care earlier in their disease progression (Moise *et al.*, 2004; Draper, 2013), 5% of referrals for this group that would otherwise be directed to community care, are referred to residential care. Therefore, depending on the person's stage of dementia and informal care support, the six probability profile distributions refer them to:

- **Community Care** or **Basic Telecare (only)**
- **Community Care** or **Basic Telecare with Community Care**
- **Community Care** or **Complex Telecare with Community Care**
- **Community Care** or **Residential Care** or **Basic Telecare (only)**
- **Community Care** or **Residential Care** or **Basic Telecare with Community Care**
- **Community Care** or **Residential Care** or **Complex Telecare with Community Care**

The rules are implemented within the TeleDem Simulation through Visual Logic applied through If Statements within the Referral activity. The key points to note about the 'rules' are as follows:

- People are sent for referral if:
 - Following diagnosis, they require additional support.
 - Unmet need is detected at diagnosis or review. Unmet need is calculated by looking at the number of hours of care the person requires compared to the number of hours of care their informal carer can provide.
 - The person has an informal carer seeking extra support.
 - The person's informal care 'collapses' and they require referral (and therefore admission) to an institutional setting.
 - The person is living in residential care, but they advance to dependency level 5 and require nursing home support.
- If telecare equipment is unavailable, the person will be referred to community care instead.
- If the person arrives at referral at dependency level 1 or 2 with an 'informal carer seeking extra support' having previously received basic telecare only, the person will be referred to receive community care support alongside their telecare equipment.
- It is assumed that informal carers who are available 24 hours a day, 7 days a week, will be able to continue caring at home, if carer burden is managed. Therefore, only 'carer collapse' will trigger an admission to institutional care, as long as the informal carer is available enough hours to meet the person's care need.
- If informal care collapses the person will be referred to institutional care. The type of institutional setting (residential care or nursing home) will depend on the person's stage of dementia.
- If the person's dependency level is less than or equal to 4 they will be referred to residential care. If their dependency is 4.5 the person has equal probability of being referred to residential care or nursing home support. At dependency level 5 a referral will direct the person straight to the nursing home, as Kahle-Wroblewski *et al.*'s paper explicitly stated that the 'care needs' at this level require placement in a nursing home (Kahle-Wroblewski *et al.*, 2015).
- If a person lives alone without an informal carer and requires less than 1 hour 15 minutes of support a day, they are considered eligible for Basic Telecare Only. If

the person has a greater level of need they are referred to a service with community care.

- In line with Caro *et al.* (2002), requiring more than 12 hours of support is deemed as a 'tipping point' in terms of care needs in the TeleDem Simulation. If the person needs to be supervised for more than 12 hours a day they are considered 'dependent'. Therefore, people who live alone and require greater than 12 hours of support are referred to institutional care. This is in line with Draper (2013), who stated that people who live alone are more likely to be referred to institutional care earlier, as 'often overnight care is the stumbling block' (p. 180). It was therefore assumed that if someone could not be left unsupervised for 12 hours, then it would not be possible to leave them alone overnight. The costs associated with overnight community services are huge; and therefore, beyond what the average person can afford (Draper, 2013).
- If the person lives with an informal carer, but their informal carer is only available 12 hours a day, the number of hours of supervision they require is taken into consideration. It is assumed that the informal carer will be able to provide night time supervision, and therefore the additional support will be required during the day. If the person needs to be supervised for 20 hours a day or more, then it is assumed that formal care services would need to visit too frequently to address their unmet need and therefore they require 24/7 care in an institutional setting.

7.15 Assumptions

Various assumptions have been made during the modelling process, several of which have already been referred to over the course of this chapter. The following points provide a summary of the main assumptions used in the TeleDem Simulation:

- Residential care home spaces, nursing home beds, community care packages, and available telecare resources are assumed to be unlimited.
- The arrival rate into the model remains the same each year.
- Individuals who have the same dependency levels and informal care provision are assumed to have similar needs and therefore utilise the same types of care service.
- Once a person with dementia has entered a form of institutional care they do not return to community living. This assumption is consistent with Neumann *et al.* (2001) and CERAD standard practice.

- The model only considers the use of telecare by people living in the community; it does not consider the potential use of telecare within 'institutional' settings.
- People in the model are assumed to be living in their own home or the home of a family member. Assisted living settings (e.g. sheltered housing, retirement villages, or close care schemes) are not included as they are not as widely available.
- The model works on the assumption that an excellent quality, holistic assessment of the person is carried out prior to installation of the telecare, and therefore that the equipment will only be installed where it is appropriate for the individual. Therefore, the model does not account for people who reject the equipment after installation.
- The model assumes there is a response service available to respond to telecare alerts, therefore enabling people in the initial stages of dementia without any informal care to receive telecare support.
- The model assumes that as people's care needs increase they will require telecare of increasing complexity to meet their additional needs.
- It is assumed that telecare can benefit informal carers by reducing their carer burden (reflected in the TeleDem Simulation as a reduction in the person's associated ZBI score). Once the ZBI 'reduction factor' is applied and the carer's burden has been recalculated to give an 'adjusted ZBI score', the impact is assumed to remain constant throughout the time the person is receiving the telecare-based service.
- Any benefit experienced due to reduced carer burden while using telecare will be lost or recalculated on referral to a new care service.
- It is assumed that at dependency level 5, telecare can no longer reduce carer burden, as the person's medical care needs at this stage will become the primary focus, and the strain of end of life care is assumed to be greater.
- Informal carer health status and mortality are not taken into consideration; the model assumes that aside from carer burden, there are no other limiting factors that could impact the provision of informal care.
- Dementia is assumed to be the primary motivation for seeking support from care services; other co-morbidities are not taken into consideration.
- The model does not take into consideration the potential role of telecare for reducing hospital admissions.
- The model assumes that people only require nursing home support when they advance to dependency level 5; in reality people at all stages of dementia may

require nursing home support due to other existing co-morbidities. Therefore, the model will naturally underestimate nursing home usage.

7.16 Model Validation

Chilcott *et al.* (2010) emphasise the importance of model checking as one of the key elements of the model development process. Model checking is concerned with both model verification, 'is the model correct?', and model validation 'is it the correct model?' (Squires and Tappenden, 2011). Validation is primarily concerned with checking that both the modeller and the relevant stakeholders are satisfied that the logic and assumptions used in the design of the simulation reflect how the real system functions (Anderson *et al.*, 2003). Pidd (2004) asserts that complete validation is not possible, because 'most simulation models are used to investigate things that are not understood' (p. 37).

Chapter 5, Section 5.5, explained how the conceptual structure of the model was validated through consultation with domain experts involved in the development and delivery of telecare. Chapter 6, Section 6.7 detailed how the TeleDem Simulation was verified. The following subsections outline how the computer implementation of the TeleDem Simulation was validated.

7.16.1 Checking Survival Times

To validate Spackman *et al.*'s (2012) death transition probabilities, a mini trial was carried out with five runs, each lasting 30 years with a fixed arrival rate of one person every five days. On average 1,676 people entered and then died within each run. Everyone entered the model with a mild diagnosis to simulate onset. Over the course of the five runs, data was collected to check life spans for 8,378 modelled individuals.

The mean lifespan for the TeleDem Simulation output data was 6 years, and the median value was 5.4 years. This met the expectation set by Ganguli *et al.*, (2005). Ganguli *et al.* (2005) examined mortality in Alzheimer's disease for a cohort of 1,670 adults aged 65 years and found the 'main duration of survival' with Alzheimer's disease was 5.9 years.

Life expectancy with Alzheimer's disease can vary significantly depending on the age of onset (Ganguli *et al.*, 2005; Xie *et al.*, 2008). Xie *et al.* (2008) provided median estimates of survival after onset of dementia by age and sex; based on the analysis of data for 356 individuals from the UK based Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS). The TeleDem Simulation life spans were then compared to those published in Xie *et al.* (2008). Table 7.7 shows the median life spans by age band

produced by the TeleDem Simulation, and the median life spans by the same age bands in Xie *et al.* (2008).

Table 7.7: Life Spans of the TeleDem Simulation Population Compared to Observed UK Based Data

Age	Xie <i>et al.</i> , 2008 Median Survival Times and IQR		TeleDem Simulation Median Survival Times	
	Women	Men	Women	Men
65-69	7.5 (4.8 - N/A)	N/A (9.1- N/A)	7.3	7.4
70-79	5.8 (3.6 - 8.3)	4.6 (3.0 - 8.6)	6.5	5.7
80-89	4.4 (2.8 - 7.0)	3.7 (2.5 - 6.3)	5.5	5.1
>90	3.9 (2.4 - 5.2)	3.4 (1.5 - 5.5)	4.2	4.1

Source: Xie *et al.* (2008) and the TeleDem Simulation

The transition to death probabilities derived from Spackman *et al.*'s (2012) model generate sensible life spans within the TeleDem Simulation that follow expected patterns set out in the literature. Lifespan reduces with age of onset, and the simulated males have shorter lifespans than the females, as is reflected in Xie *et al.*'s (2008) data. The simulated survival times from onset produced by the TeleDem Simulation also sit comfortably within the interquartile ranges of Xie *et al.*'s (2008) output data.

7.16.2 Checking Model Population Distribution Between Stages of Dementia

In addition to checking the simulated lifespans, the distribution of the model population in different stages of dementia was also checked. The model was run for 25 years with a fixed arrival rate of one person per day. All referrals were directed to mild, to simulate the whole model population from dementia onset. At the end of the run there were 2,026 people 'alive' within the model. The proportions of the population at each stage of dementia were examined. Prince *et al.* (2014) reported the proportions of dementia severity among people with late-onset dementia in the UK as follows:

- 55.4% have mild dementia,
- 32.1% have moderate dementia,
- 12.5% have severe dementia.

The TeleDem Simulation consistently produced similar proportions. For instance, at the end of the 25-year run described above:

- 51% of the simulated population were mild,
- 34% were moderate,
- 15% were severe.

7.16.3 Checking Proportion of the Model Population that Live in Institutional Care

The simulated patterns of referral were sense checked with domain experts. The model was run repeatedly with different arrival rates over different time frames. Data was recorded using onscreen nodes which counted the number of people living in the community and the number of people living in institutional care for each stage of dementia to confirm that they correlated with distributions printed in the literature.

In the following example the model was run for 25 years with a fixed arrival rate of one person per day, and all referrals were simulated from mild to represent the whole model population from dementia onset. At the end of the run, 64% of the model population were living in the community and 36% were living in institutional settings. This is consistent with the estimates produced by Prince *et al.* (2014), who suggested that in 2014, out of the 805,369 people with dementia in the UK, 61% were community dwelling, while 39% lived in institutional care (either residential care homes or nursing homes).

7.16.4 Checking the Proportion of the Model Population Living in the Community Versus Institutional Care, by Stage of Dementia

To check how patterns of community versus institutional residence varied by stage of dementia, data presented in Prince *et al.* (2014) and Hancock *et al.* (2006) were used to estimate the proportion of people at each stage of dementia living in each setting. Table 7.8 shows how the population's severity of dementia is distributed by residential status in the TeleDem Simulation compared to the literature:

Table 7.8: Proportion of People at Each Stage of Dementia in Each Residential Setting within the TeleDem Simulation

Stage	Estimates based on the literature		TeleDem Simulation Outputs	
	Institutional	Community	Institutional	Community
Mild	32%	69%	22%	67%
Moderate	42%	27%	50%	25%
Severe	26%	5%	28%	8%

Source: Prince *et al.* (2014), Hancock *et al.* (2006) and the TeleDem Simulation

Prince *et al.* (2014) estimated that 5% of people living in the community have severe dementia. The TeleDem Simulation consistently produced very similar results to those estimated from the literature; with 8% of the community dwelling population, in the example below, having a diagnosis of severe dementia.

The model results were also used to check where people were living at each stage of dementia, as show in Table 7.9.

Table 7.9: Where People Live at Each Stage of Dementia:

	<i>Estimates Based on the Literature</i>		<i>TeleDem Simulation Outputs</i>	
	Institutional	Community	Institutional	Community
Mild	21%	79%	15%	85%
Moderate	48%	52%	53%	47%
Severe	75%	25%	67%	33%

Source: Prince et al. (2014) and the TeleDem Simulation

Although there are slight discrepancies between the estimates derived from the literature and the TeleDem Simulation outputs, they appeared to be sufficiently consistent and suitably representative of reality to provide an environment in which to test the modelling scenarios.

7.17 In Summary

This chapter has described the data sources and inputs that were used to parameterise the TeleDem Simulation. These are summarised in a table in Appendix 24. This chapter concluded by outlining the model validation process. The following chapter explores the scenarios that the TeleDem Simulation was used to test and their results.

Chapter 8: Results

8.1 Chapter Overview

This chapter presents results from the experiments completed using the TeleDem Simulation; addressing the eighth step of the modelling framework, shown below in Figure 8.1.

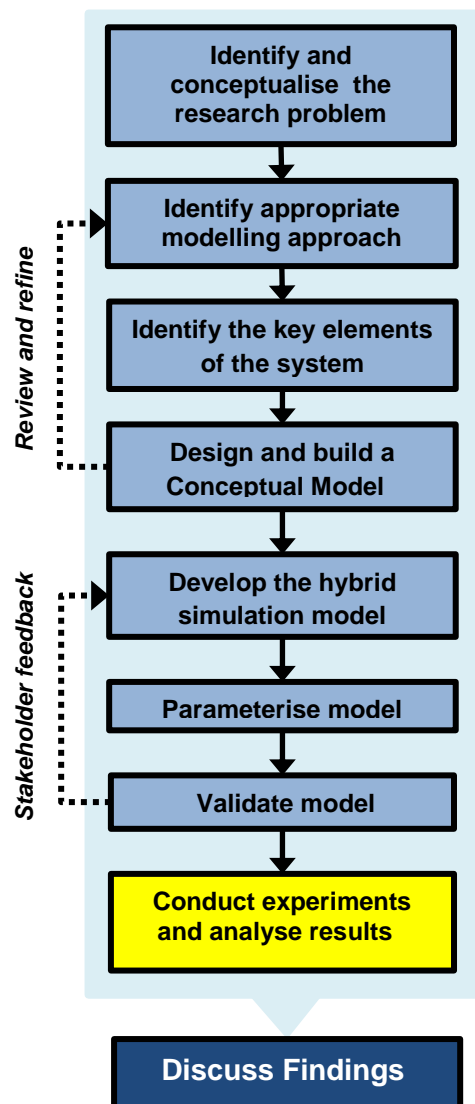


Figure 8.1: Addressing Part Eight of the Modelling Framework

The TeleDem Simulation could be used to test an extensive range of scenarios as there are numerous possibilities for varying the model inputs and parameters. However, for the purposes of this thesis, this chapter focuses on answering one specific research question (research question 3; see Chapter 1, Section 1.3):

➤ *What can simulation modelling show us regarding the impact of telecare on institutional care admissions for people with dementia?*

To answer this question, it is important to understand how telecare fits within the current care pathway for people with dementia. The stakeholder engagement in Chapter 5 and the background research in Chapter 2 highlighted that the care needs of people with dementia change as the disease progresses. In recognition of this, the conceptual model, and the final simulation (both outlined in Chapter 6) distinguish between basic and complex telecare, as defined in Figure 8.2.

Basic Telecare – For this package of telecare a person would receive a base unit, pendant alarm and up to four additional sensors or devices. For example, a fall detector, linked carbon monoxide detector, medication dispenser, or GPS device. These devices facilitate independent living, by minimising risk.

Complex Telecare – This care service represents a step up in both care need and equipment complexity. In this category, patients would normally be provided with a full suite of telecare sensors and devices alongside a base unit. Passive activity monitors will be central to this package of care. For instance, in addition to equipment included under basic, people would be offered property exit sensors, lifestyle monitoring equipment, bed and chair occupancy sensors, property exit alerts, and enuresis sensors. The emphasis in this package of telecare is supervision.

Figure 8.2: The Definitions for Basic and Complex Telecare

Therefore, the TeleDem simulation was used to test the impact of varying the availability of basic versus complex telecare on the number of institutional care admissions for people with dementia. These policy options were tested against a baseline scenario where no telecare was available.

Finally, two additional experiments were conducted to examine how changes to the core assumptions within the model would influence the output of the model. The second experiment involved running the model for a series of simplified trials to explore the effect of varying the proportion of referrals to telecare services. The third experiment examined the impact of varying the ability of telecare to reduce carer burden.

8.2 Baseline Scenario

Baseline results were collected from the model using a scenario where no telecare was available. This meant the resources of basic telecare and complex telecare were set to zero, whereas community care, residential care, and nursing home resources were all set to a very large number (10,000: essentially, unconstrained). In this scenario the arrival rate into the model was set to reflect the diagnosis rate for Southampton. Age Concern Hampshire (2017) reported that approximately 1,500 people in Southampton are

diagnosed with dementia every year; which equates to roughly four people per day. Therefore, on average four new patients per day entered the model, using the Poisson distribution to represent random, independent arrivals.

Each single run of the model was 40 years long in total. All results relating to the population (for example: day counts, number of institutional care admissions, and lifespans) were collected over the full 40 year duration. However, results relating to resource utilisation (average and maximum use of care service resources) were collected over the final 30 years of each run to allow for a warm up period of 10 years. Each trial consisted of 35 runs and took between six and 73 hours depending on the specification of the computer used. The results from the baseline trial are shown in Table 8.1.

Table 8.1: TeleDem Simulation Results for the Baseline Scenario

(95% Confidence Interval)		Simple Telecare Equipment	Community Care Package	Complex Telecare Equipment	Residential Care Home Space	Nursing Home Bed
Baseline Scenario: No Telecare	Average Use	0	3934 (3927-3940)	0	2143 (2137-2150)	766 (764-769)
	Maximum Use	0	4061 (4053-4070)	0	2281 (2271-2291)	846 (842-850)

Source: TeleDem Simulation

Table 8.1 demonstrates the reliability of the average, as the 95% confidence intervals are quite narrow. The baseline results also show a logical pattern. The probability of transitioning to death increases as dementia progresses, so it would be expected that demand for more intensive care services, such as residential care, would be lower than community-based services. Furthermore, it would be expected that nursing home beds would be the least utilised, as this level of care requires survival to advanced stages of dementia.

8.2.1 Description of the Baseline Scenario

The baseline scenario showed that for each 40 year run of the model approximately 58,400 people with dementia entered the TeleDem Simulation. During each run approximately 50,099 people died within the simulation and exited the model. Consequently, over the course of 35 runs in the trial, data for 1,753,456 simulated people was generated for inclusion in this analysis. For each 40 year run:

- On average, there were 23,280 residential care admissions, and 16,457 nursing home admissions.

- The mean number of days spent in institutional care was 1,174 days (3.2 years); with an average stay of 1,027 days (2.8 years) spent in residential care, and 551 days (1.5 years) spent in nursing homes.
- 30.2% of the residents living in institutional care had died by 462 days, whereas 40.2% lived in institutional care for more than three years. The longest ‘stayer’ remained in institutional care for 31 years.

On average during the final 30 years of run time 2,143 residential care spaces were occupied on any given day, whereas the daily average number of nursing home beds in use was 766. On average, 3,934 packages of community care were in use daily.

8.3 Main Experiment - Basic versus Complex Telecare

For the main experiment, the configuration of the model matched the baseline scenario to emulate a city the size of Southampton, with arrivals into the model set to an average of four per day, model run time lasting 40 years, and number of runs per trial set to 35. The impact of telecare on ZBI scores was set to a normal distribution to incorporate variability between individuals. For this hypothetical exercise, it was assumed that telecare could reduce carer burden by a quarter, in line with the findings of a previous carer-focused intervention published by Tremont *et al.* (2008). Therefore, the mean value of the distribution associated with telecare ‘impact’ on ZBI was set to 25%, with a standard deviation arbitrarily set to a plausible value of 2.5 to reflect individual variability.

This main experiment focused on varying the availability of basic versus complex telecare. The proportion of people referred to the telecare-based services was varied through the six probability profiles described in Chapter 7, Section 7.14. For this experiment the TeleDem Simulation trials were run under three policy options and compared to the baseline scenario where no telecare was available; these are summarised in Table 8.2.

Table 8.2: Values Used within the TeleDem Simulation to Denote Resource Availability

	Basic Telecare Equipment	Community Care Package	Complex Telecare Equipment	Residential Care Home Space	Nursing Home Bed
Baseline Scenario: No Telecare	0	10000	0	10000	10000
Policy Option One: Unlimited Basic, No Complex Telecare	10000	10000	0	10000	10000
Policy Option Two: Unlimited Complex, No Basic Telecare	0	10000	10000	10000	10000
Policy Option Three: Unlimited Telecare	10000	10000	10000	10000	10000

Source: TeleDem Simulation

With no evidence base to indicate how many referrals might be eligible for support from telecare, policy options one to three were repeated twice. Firstly, under an optimistic scenario, where 90% of all referrals to community care would both benefit from and be suitable for telecare. Secondly, under a conservative scenario, where only 10% of all referrals to community care would be suitable for telecare.

For the optimistic scenario, the value of 90% was used rather than 100%, in recognition of the fact that, as stated in Chapter 3, Section 3.11, there are a number of reasons why telecare might not be suitable for some people with dementia. One domain expert asserted that with careful and thorough holistic assessment, telecare could be of benefit to everybody; however, other experts who were consulted disagreed, suggesting that there will always be certain instances where people reject the equipment. Without a consensus on what proportion of people who would accept or reject telecare, the two extreme values of 10% and 90% were selected to see if similar patterns were noted. Table 8.3 summarises the conditions applied to the TeleDem Simulation for this experiment.

Table 8.3: The Six Policy Options Tested to Examine the Impact of Varying the Availability of Basic Versus Complex Telecare

Scenario	Policy Option	% of Referrals to Telecare	Impact of Telecare on the Person's ZBI Score	Telecare Resource Availability	
				Basic Telecare	Complex Telecare
<i>Baseline</i>	Baseline	0%	/	0	0
<i>Optimistic</i>	Option 1	90%	25% mean reduction	10000	0
	Option 2	90%	25% mean reduction	0	10000
	Option 3	90%	25% mean reduction	10000	10000
<i>Conservative</i>	Option 1	10%	25% mean reduction	10000	0
	Option 2	10%	25% mean reduction	0	10000
	Option 3	10%	25% mean reduction	10000	10000

Source: TeleDem Simulation

A summary of the results from these scenarios and policy options are shown in Table 8.4. Section 8.3.1 provides an overview briefly describing what the results indicate. The results are then explored in more detail over the following subsections (Section 8.3.2 to Section 8.3.6).

Chapter 8: Results

Table 8.4: Summary of Results from the Main Experiment - Basic Versus Complex Telecare

No.	Result	Conservative Scenario (95% Confidence Intervals)				Optimistic Scenario (95% Confidence Intervals)		
		BASELINE	Option 1	Option 2	Option 3	Option 1	Option 2	Option 3
1a	Average utilisation of basic telecare equipment	0	285 (282-288)	0	284 (281-287)	2379 (2373-2385)	0	2378 (2371-2384)
1b	Maximum utilisation of basic telecare equipment	0	321 (317-325)	0	321 (316-325)	2491 (2481-2501)	0	2489 (2480-2498)
2a	Average utilisation of complex telecare equipment	0	0	159 (157-160)	160 (158-162)	0	1430 (1425-1434)	1483 (1478-1487)
2b	Maximum utilisation of complex telecare equipment	0	0	188 (185-190)	191 (188-194)	0	1527 (1519-1535)	1581 (1573-1590)
3a	Average utilisation of packages of community care	3934 (3928-3941)	3761 (3751-3770)	4936 (3927-3945)	3771 (3761 -3780)	2424 (2418-2431)	4054 (4046-4062)	2560 (2554-2565)
3b	Maximum utilisation of packages of community care	4062 (4053-4070)	3901 (3887-3915)	4088 (4074-4103)	3911 (3899-3922)	2552 (2541-2563)	4201 (4188-4214)	2696 (2684-2707)
4a	Average utilisation of residential care home space	2143 (2137-2150)	2124 (2116-2132)	2132 (2125-2140)	2113 (2105-2121)	1987 (1980-1993)	2050 (2044-2057)	1892 (1885-1899)
4b	Maximum utilisation of residential care home space	2281 (2271-2291)	2268 (2257-2280)	2272 (2261-2283)	2252 (2242-2263)	2121 (2112-2131)	2186 (2177-2195)	2024 (2015-2034)
5a	Average utilisation of nursing home beds	766 (764-769)	762 (759-765)	758 (755-761)	756 (753-759)	757 (754-760)	728 (725-732)	722 (719-725)
5b	Maximum utilisation of nursing home beds	846 (842-850)	842 (836-847)	843 (837-848)	836 (831-842)	837 (831-843)	810 (804-817)	801 (794-808)
6	Average number of residential care home admissions	23280	23190	23105	23052	22655	21906	21215
7	Average number of nursing home admissions	16457	16423	16330	16329	16275	15588	15524
8	Average number institutional care admissions (total across residential and nursing homes)	39737	39613	39435	39381	38930	37494	36739
9	Average number of days spent in residential care	1027	1021	1029	1023	985	1041	999
10	Average number of days spent in nursing home	551	551	549	549	551	549	551
11	Average number of days spent in institutional care (total across residential and nursing homes)	1174	1168	1174	1168	1136	1180	1142

Source: TeleDem Simulation

8.3.1 Overview of the Results from the Main Experiment

8.3.1.1 Average and Maximum Utilisation of Basic and Complex Telecare Resources (results numbered 1a, 1b, 2a and 2b)

These results show that the average number of basic telecare resources used on a day to day basis under policy option 1 and policy option 3 are very similar. This indicates that the uptake of basic telecare is relatively unaffected by the addition of complex telecare under policy option 3. In contrast complex telecare uptake rises under policy option 3 when compared to policy option 2 where only complex telecare is available. This rise is barely detectable under the conservative scenario, but under the optimistic scenario the average day to day utilisation of complex telecare rises by 50 when basic telecare is also offered (1,430 packages of complex telecare in use under option 3, compared to 1,483 packages in use under option 2). This is likely to be due to basic telecare reducing the number of people entering institutional care early on in their disease progression. This has a knock-on effect of creating a larger pool of people living in the community and therefore available for referral onto complex telecare services as their disease progresses.

8.3.1.2 Average and Maximum Utilisation of Packages of Community Care (results numbered 3a and 3b)

The results show that policy options that include basic telecare reduce the average number of packages of community care that are utilised on a day to day basis compared to the baseline scenario. This is because basic telecare offers a direct alternative to community care for supporting people with dementia and their carers during the earliest stages of dementia. In contrast, the policy option where only complex telecare is offered (option 2), results in an increase in the uptake of packages of community care compared to the baseline. All packages of complex telecare are offered in combination with community care; this is in recognition of the need for additional human support in order to meet more complex care needs in the later stages of dementia. Therefore, as complex telecare increases the number of people supported at home compared to baseline, more community care is required.

Policy option 1 (basic telecare only), under both scenarios, shows the lowest utilisation of community care compared to baseline. The results relating to community care usage are shown graphically in Section 8.3.6.

8.3.1.3 Average and Maximum Utilisation of Residential Care Home Spaces and Nursing Home Beds (results numbered 4a, 4b, 5a, and 5b)

All policy options reduce the average occupancy (utilisation) of residential care home spaces and nursing home beds (from a baseline of 2,143 spaces and 766 beds respectively), indicating that both categories of telecare reduce the utilisation of institutional care. Unsurprisingly, the impact of telecare is magnified under the optimistic scenario, where more people are referred to telecare based services. Under both scenarios policy option 3, where both types of telecare are offered, has the greatest impact on reducing average occupancy across institutional settings.

However, basic telecare, if offered in isolation (option 1), has a greater impact on the average occupancy of residential care spaces, when compared to complex telecare offered in isolation (option 2). Whereas the results indicate that complex telecare has a greater impact on the average occupancy of nursing home beds, when compared to policy option 1.

The results relating to the utilisation of residential care are discussed in more detail in Section 8.3.2; while results relating to the average utilisation of nursing home beds are discussed in more detail in Section 8.3.3.

8.3.1.4 Average Number of Admissions to Institutional Care Settings (results numbered 6, 7 and 8)

All policy options resulted in a reduction in the number of admissions to residential care and nursing home beds compared to the baseline where there was 23,280 residential care admissions and 16,457 nursing home admissions.

Basic and complex telecare offered in combination (policy option 3) had the greatest impact on reducing institutional care admissions. Under the optimistic scenario residential care admissions dropped to 21,215, and nursing home admission dropped to 15,524. On the other hand, policy option 1 (basic telecare only) resulted in the smallest reduction in the number of both types of institutional care admissions. These results are discussed in more detail in Section 8.3.5.

8.3.1.5 Average Number of Days Spent in Institutional Care Settings (results numbered 9, 10 and 11)

The introduction of either complex or basic telecare has very little impact on average length of stay in nursing homes. This is likely to be a consequence of the assumptions made in the model design relating to the need for nursing home support during the end of life stages of dementia; when it is assumed that the role of telecare will diminish.

In contrast, introducing telecare does have an observable impact on the number of days spent in residential care. Policy options including basic telecare (option 1 and 3) reduced length of stay compared to baseline. By contrast the length of stay in residential care increases when only complex telecare is offered, this is due to the reduction in the number of short stayers when complex telecare is offered. This is discussed in more detail in Section 8.3.4.

8.3.2 Impact of Telecare on Utilisation of Residential Care Home Space

As mentioned in Section 8.3.1.3, the impact of telecare on the average day to day utilisation of residential care home space is small under the conservative scenario compared to the optimistic scenario (as shown in Figure 8.3). Under both scenarios, providing basic and complex telecare in combination has the greatest impact on the average occupancy of residential care spaces.

If only complex telecare is made available, then average day to day use of residential care space is reduced by 0.51%. This equates to an average of 11 fewer occupied residential care home spaces when compared to the baseline scenario. Although 11 fewer residential care home spaces is a relatively small number in relation to a baseline of 2,143 spaces without telecare, the financial implications of this reduction are not trivial.

In the South East of England, where Southampton is located, the daily cost of a residential care home place for the financial year: 2016-17, was £100 (Laing, 2017). Therefore, using an average of 11 fewer residential care home spaces in Southampton equates to an average daily saving of £1,100.

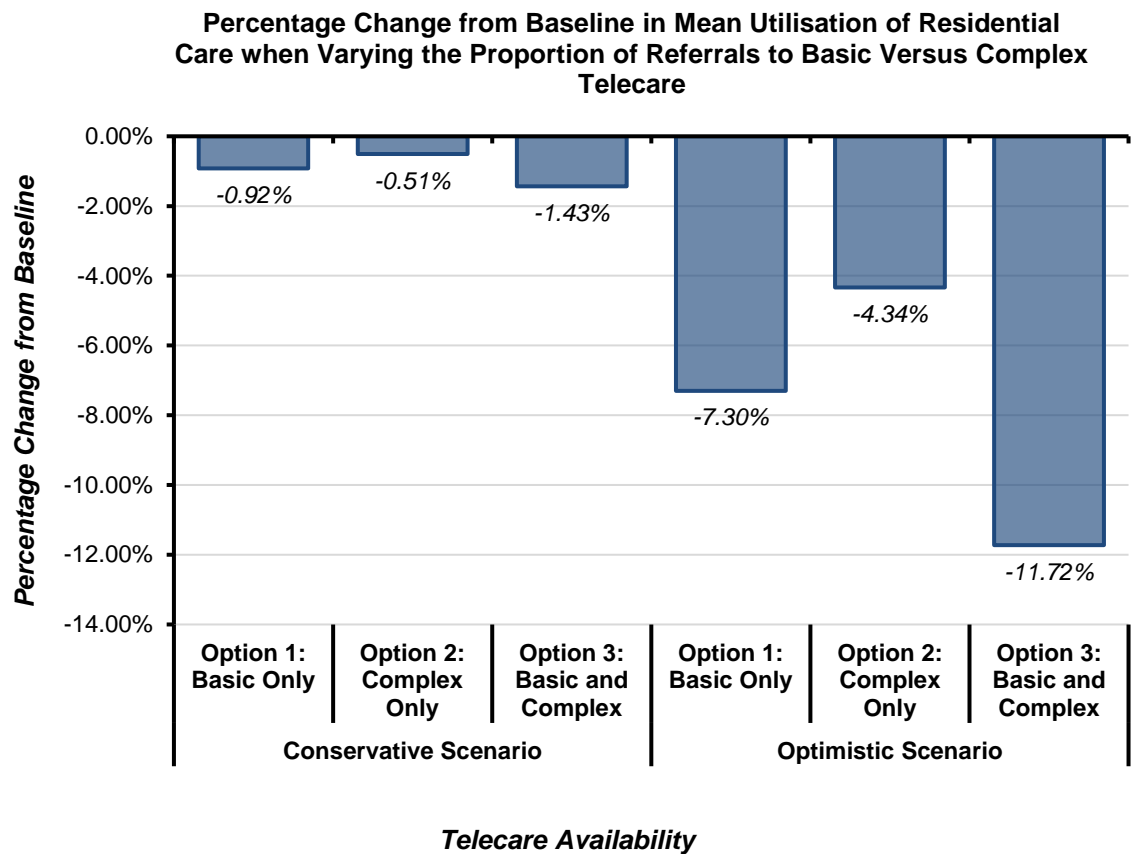


Figure 8.3: The Impact of Varying the Availability of Basic Versus Complex Telecare on the Mean Utilisation of Residential Care Home Space

Only offering basic telecare provides an average reduction in daily utilisation of 0.92% (20 residential care spaces). Whereas providing both basic and complex telecare reduces daily utilisation by 1.43% (31 fewer residential care home spaces on average).

The impact of telecare on daily residential care home space utilisation is greatly increased under the optimistic scenario. Offering only basic telecare under the optimistic scenario reduces average daily residential care utilisation by 7.30% (156 residential care home spaces). Making only complex telecare available reduces average daily residential care utilisation by 4.34% (93 residential care home spaces). Whereas providing both complex and basic telecare reduces average daily residential care utilisation by 11.72%, which equates to 251 fewer spaces being used on average. This would equate to a saving of £25,100 a day in Southampton.

8.3.3 Impact of Telecare on Utilisation of Nursing Home Beds

As seen with the results for residential care, the results for nursing home beds also show that under both scenarios, providing basic and complex telecare in combination has the greatest impact on the average occupancy. However, complex telecare provided in

isolation (option 2) has a greater impact on the average daily occupancy of nursing home beds, compared to basic telecare only (option 1), as illustrated by Figure 8.4.

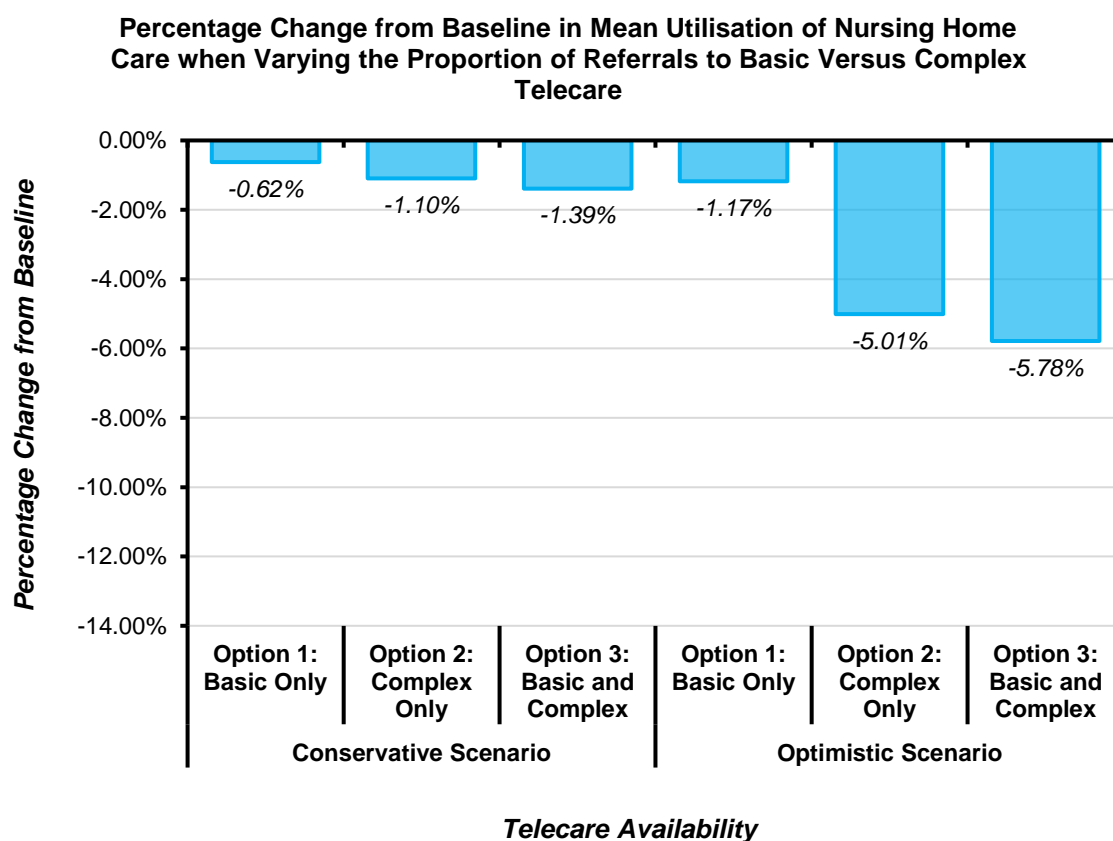


Figure 8.4: The Impact of Varying the Availability of Basic Versus Complex Telecare on the Mean Utilisation of Nursing Home Beds

Under the conservative scenario, basic telecare reduces average daily nursing home bed occupancy by 0.62%, which equates to five fewer nursing home beds required per day, compared with the baseline scenario. In the South East of England, the daily cost of a nursing home bed for the financial year: 2016-17, was £149 (Laing, 2017). Therefore, a day to day reduction in the utilisation of five beds equates to a daily cost saving of £745 in Southampton. Complex telecare reduces utilisation by 1.10% (eight beds), and providing both complex and basic telecare offers a reduction of 1.39% (11 beds).

Under the optimistic scenario, even with 90% of referrals being supported with basic telecare (option 1), the impact remains less than if both types of telecare (option 3) are offered under the conservative scenario (option 3). The results indicate that 10% of referrals being supported with complex telecare (option 2) has a similar influence over nursing home bed utilisation (1.10% reduction) than if 90% of referrals are supported with basic telecare (1.17% reduction).

When 90% of referrals are supported with complex telecare, without provision for basic telecare, the daily average utilisation of nursing home beds is reduced by 5.0% (an average of 38 fewer beds in use per day). If both complex and basic telecare are offered under this scenario, that equates to a reduction of 5.8% daily utilisation of nursing home beds (44 fewer beds in use). Based on Laing's (2017) figures for the South East of England this would equate to a saving of £6,556 a day in a city the size of Southampton.

8.3.4 Impact of Telecare on the Number of Days Spent in Institutional Care

Figure 8.5 shows that in both the conservative and optimistic scenarios, providing basic telecare in isolation, as is the case in option 1, has the greatest impact on reducing length of stay in residential care when compared to policy options 2 and 3.

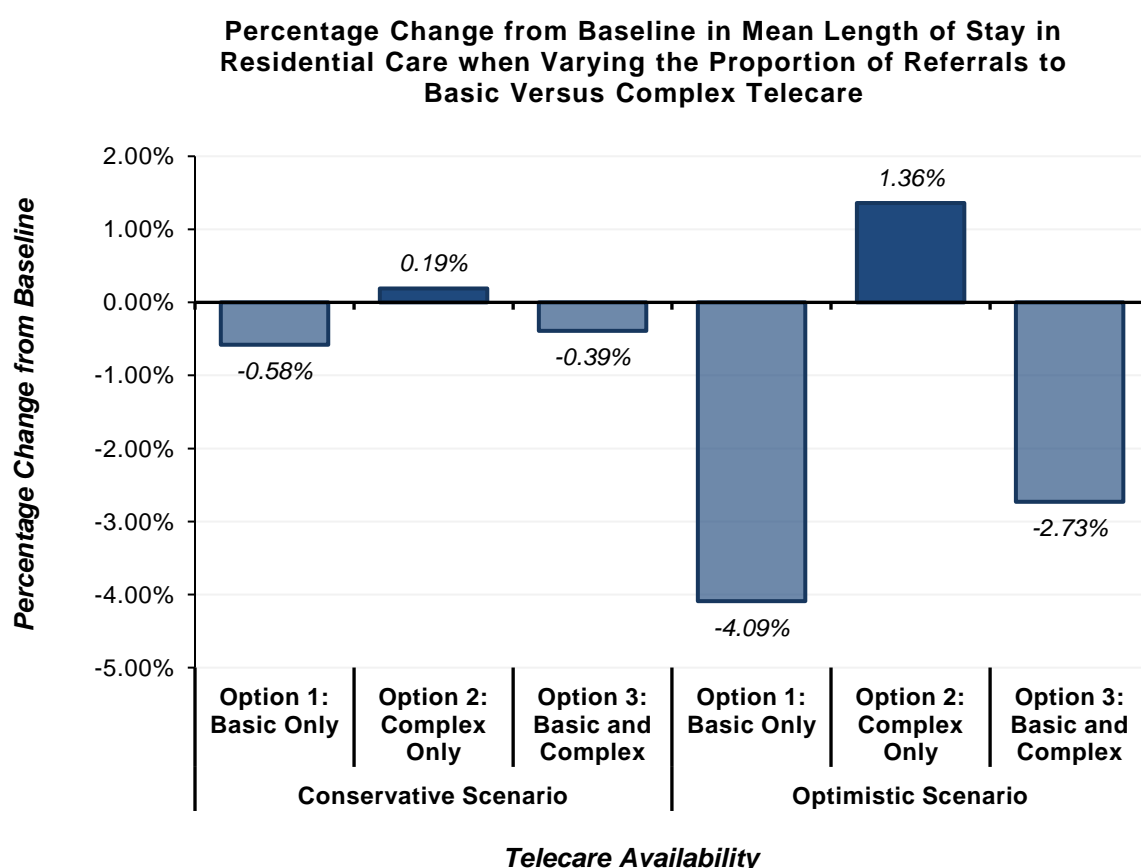


Figure 8.5: The Impact of Varying the Availability of Basic Versus Complex Telecare on the Mean Number of Days Spent in Residential Care

The impact of basic telecare on length of stay relates to the timing of the intervention in relation to disease progression and mortality rate. Reducing the number of people entering institutional care early on in the progression of their dementia when the mortality rate is lower (see Spackman *et al.*'s (2012) transition probabilities between dementia

severity levels and death in Table 7.1, Section 7.4), consequently reduces the number of long stayers in institutional care settings.

Length of stay in residential care is 0.2% higher in the conservative scenario and 1.4% higher in the optimistic scenario than it was at baseline when complex telecare is provided in isolation (option 2). This is because the mean length of stay at baseline includes more 'short-stayers'. Reducing the number of institutional care admissions in the later stages of dementia, by offering complex telecare, reduces the number of short 'end of life' stays. Therefore, without so many short stays the average length of stay increases and consequently the average is higher than at baseline.

In contrast, the mean length of stay in nursing homes was comparatively unaffected by the introduction of telecare as illustrated by Figure 8.6.

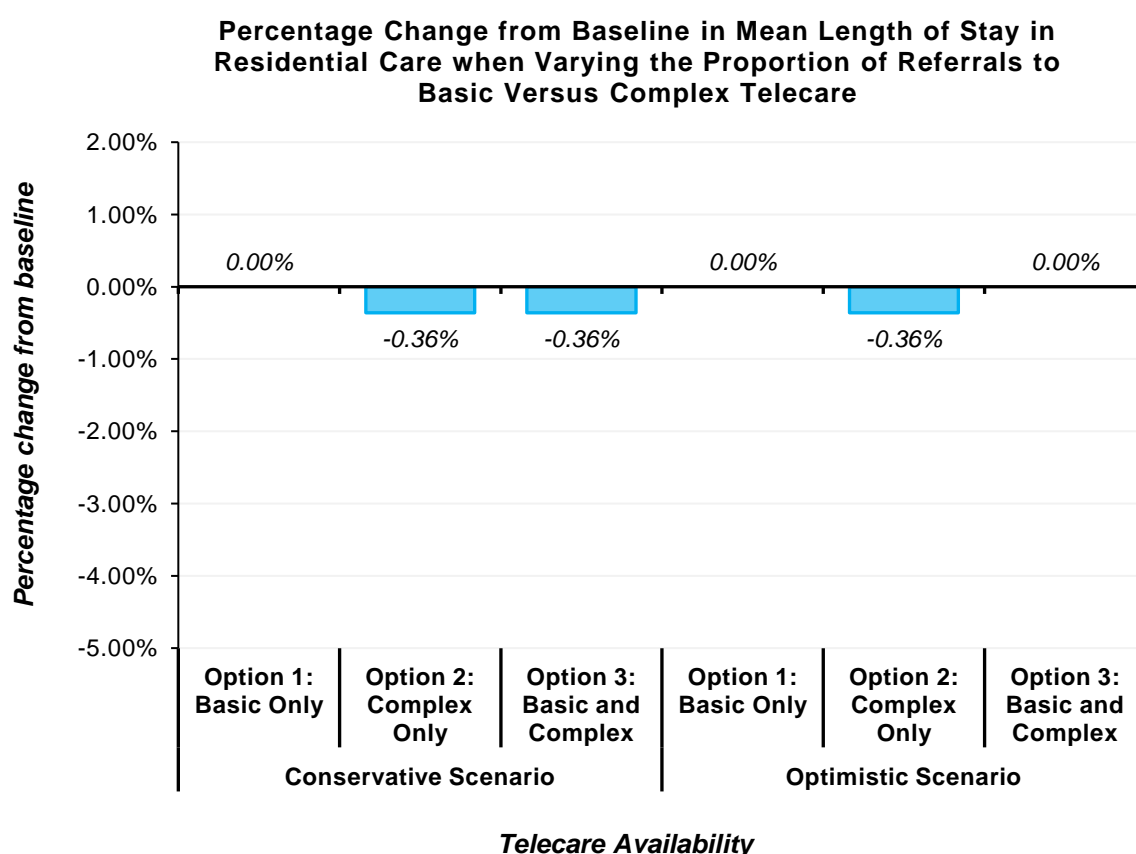


Figure 8.6: The Impact of Varying the Availability of Basic Versus Complex Telecare on the Mean Number of Days Spent in Nursing Home Care

The variation from baseline (mean length of stay: 551 days) in options 2 and 3 under the conservative scenario, and option 2 under the optimistic scenario is less than 0.4%.

Although option 2 (offering complex telecare only) shows a consistent reduction across scenarios, option 3 does not. Furthermore, the reduction under the optimistic scenario is

the same as under the conservative scenario and does not demonstrate any additional reduction, despite the increase in referrals to complex telecare. Therefore, it can be assumed that the small amount of variation shown is insignificant and may be due to the natural variability within the model. Increasing the number of runs of the TeleDem Simulation per trial may remove this variation.

As mentioned in Section 8.3.1.5, telecare may not have an impact on the length of stay in nursing homes as a consequence of the assumptions made in the model design. Whereby it is assumed that once a person reaches dependency level 5, telecare can no longer reduce carer burden, as the person's medical care needs at this stage will become the primary focus, and the strain of end of life care is assumed to be greater. Therefore, the need for nursing support will exist with or without the provision of telecare and consequently the time spent in nursing homes will be unaffected by the policy changes described in this exercise. See Chapter 7, Section 7.15 for the modelling assumptions.

8.3.5 Impact of Telecare on the Number of Institutional Care Admissions

As demonstrated by result number 8 in Table 8.4, Section 8.3 earlier in this chapter, introducing telecare reduces the number of admissions to institutional care over the 40 year model run time across all policy options, when compared to baseline.

Providing both types of telecare together for option 3 offers the greatest reduction in institutional care admissions for both the optimistic and conservative scenarios. Option 2 (complex telecare only) results in the second largest reduction in admissions, and option 1 (basic telecare only) has the smallest impact on admissions out of the three options. Under the optimistic scenario, institutional care admissions reduce by 7.54% under option 3, which represents a reduction of 2,998 admissions from a baseline of 39,737; 5.64% under option 2 (2,243 fewer admissions compared to baseline) and 2.03% under option 1 (807 fewer admissions compared to baseline).

The introduction of telecare under the conservative scenario only has a minimal impact on the number of admissions to institutional care ($\leq 1\%$ reduction in admissions), when compared to the optimistic scenario. Figure 8.7 distinguishes between the two types of institutional care (residential care and nursing home) and considers the impact of the different telecare policy options on admissions.

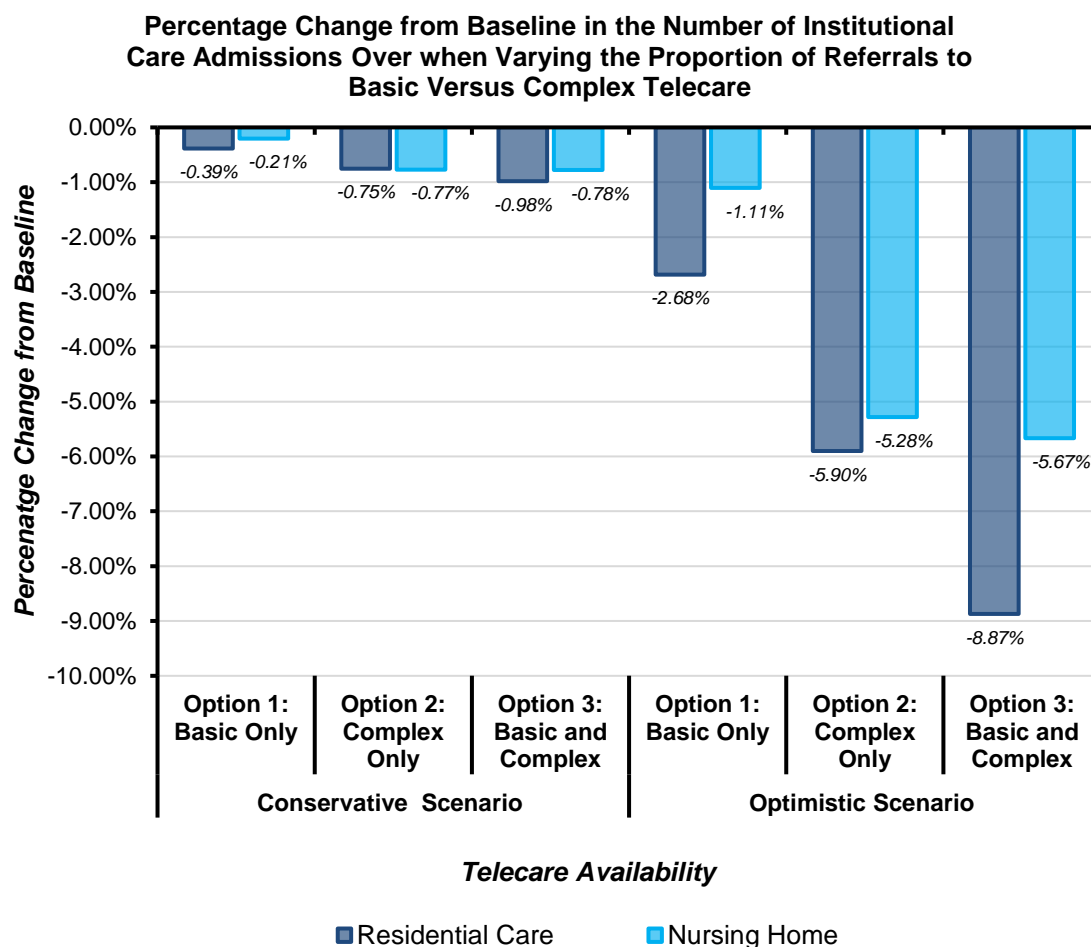


Figure 8.7: The Impact of Varying the Availability of Basic Versus Complex Telecare on the Number of Institutional Care Admissions Over the 40 Year Run Period

Figure 8.7 highlights the importance of the presence of complex telecare for reducing the number of admissions to institutional care settings.

Under the optimistic scenario, in option 2, when only complex telecare was available, residential care admissions reduced by 5.90% over the 40 year time frame compared to the baseline scenario (21,906 admissions over 40 years compared to 23,280 admissions). By comparison, admissions to residential care only reduced by 2.68% under option 1 when only basic telecare was available (22,655 admissions compared to the baseline of 23,280). Admissions reduced by 8.87%, compared to the baseline (no telecare) when under option 3, where both forms of telecare were available (21,215 admissions compared to the baseline of 23,280).

Basic telecare (option 1) in the optimistic scenario only reduces nursing home admissions by 1.11%. Options 2 and 3 both have a similar impact on the number of admissions to nursing homes, reducing them by 5.28% and 5.67% respectively.

8.3.6 Impact of Telecare on Utilisation of Packages of Community Care

Figure 8.8 shows the impact of each policy option on the utilisation of packages of community care.

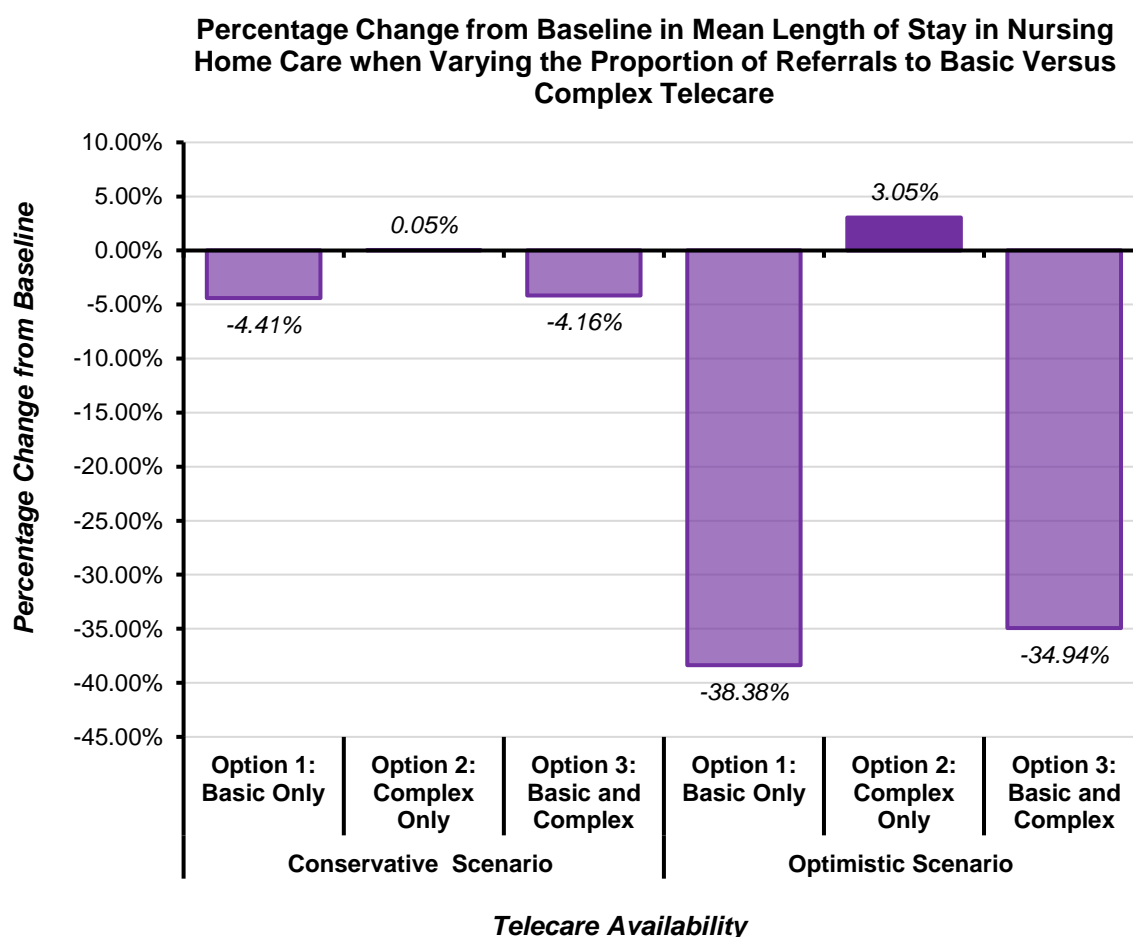


Figure 8.8: The Impact of Varying the Availability of Basic Versus Complex Telecare on the Mean Utilisation of Packages of Community Care

At baseline an average of 3,934 community care packages were in use on any given day, as shown in Figure 8.8. Offering basic telecare only (policy option 1), under both scenarios, resulted in the greatest reduction in uptake of community care packages; whereas offering complex telecare in isolation (option 2) lead to an increased uptake of community care packages. These changes were most notable under the optimistic scenario, where the introduction of basic telecare reduced the number of packages of community care in use to 2,424. This change represented a reduction of 38.38% from baseline. Offering complex telecare only (policy option 2) resulted in an increase in the average daily use of community care packages of 0.05% (to 3,936 packages) under the conservative scenario and 3.05% (to 4,054 packages) under the optimistic scenario. As stated earlier in the chapter, this increase in use of packages of community care under

policy option 2 directly relates to the role of community care for supporting the delivery of complex telecare. Therefore, because complex telecare is able to support more people at home compared to baseline, more packages of community care are required.

8.3.7 Cost Implications

To illustrate the possible economic implications of introducing telecare to the dementia care pathway for a city the size of Southampton, this section of the thesis provides a simplified cost analysis, applied retrospectively to the TeleDem Simulation results. This analysis considers the overall social care costs of delivering telecare, independent of whether the local authority pays for care, or the person covers the cost themselves. The literature indicates that telecare may also have cost saving implications with regard to the use of healthcare services (see Chapter 3, Section 3.9); however, the impact of telecare on healthcare utilisation is beyond the scope of this research, and therefore is not considered within this analysis.

This section begins by looking at introducing basic telecare under policy option 1; it then considers the impact of expanding this simple analysis across all policy options. Table 8.5 summarises the average number of each resource in use each day (rounded to the nearest whole number) for policy option 1 from the main results in Table 8.4. The costs used to calculate the estimated values for the average resource usage are summarised in Table 8.6.

Table 8.5: Resource Usage for Policy Option One Under Each Scenario Compared to Baseline

Care Resource	Average Daily Utilisation		
	<i>Baseline</i>	<i>Conservative</i>	<i>Optimistic</i>
Basic Telecare Equipment	0	285	2379
Package of Community Care	3934	3761	2424
Residential Care Space	2143	2124	1987
Nursing Home Bed	766	762	757

Source: TeleDem Simulation

Table 8.6: Costs used for Care Service Resources

Care Resource	Cost*	Source of Cost
Basic Telecare Equipment	£2.16	The mean annual costs identified by Henderson <i>et al.</i> (2013b) for the WSD programme were assumed to offer a suitable estimate of cost for basic telecare (see Chapter 3, Section 3.6 for further information). $£792 / 365 \text{ days} = £2.16 \text{ per day}$
Package of Community Care	£22.33	Information obtained by BBC News from Local Councils using Freedom of Information requests showed that in 2014-15 Southampton City Council paid £17.30 per hour of community care ($£17.30 / 60 \text{ minutes} = 29p \text{ per minute}$). It also showed that on average the council provide 9 hours of community care per week (77 minutes per day) (BBC News, 2016). Therefore: $29p \times 77 \text{ minutes} = £22.33$
Residential Care Space	£100	A UK market report published by LaingBuisson, entitled 'Care of Older People' provided average costs for residential care and nursing home placements during the 2016 -17 financial year for the South East of England (Laing, 2017).
Nursing Home Bed	£149	

*Costs are per person, per day

Sources: Various (see text for specific references)

Table 8.7 shows the daily average resource usage multiplied by the cost per person per day as reported in Table 8.6. This shows the overall cost for resourcing the care service under policy option one compared to baseline for both the conservative and optimistic scenario.

Table 8.7: Estimated Daily Costs Based on Average Daily Resource Use

Care Resource	Baseline	Conservative Scenario	Optimistic Scenario
Basic Telecare Equipment	£0.00	£615.60	£5,138.64
Package of Community Care	£87,852.54	£83,974.96	£54,138.33
Residential Care Space	£214,300.00	£212,400.00	£198,700.00
Nursing Home Bed	£114,134.00	£113,538.00	£112,793.00
TOTAL:	£416,286.54	£410,528.56	£370,769.97

Sources: Author's Work

The results indicate that offering basic telecare can reduce the overall expenditure on care resources. Firstly, by reducing admissions to institutional care settings and secondly, by providing an economical alternative to community care for some people in the earliest stages of dementia, therefore reducing demand for community care services. Under the conservative scenario the daily cost of resourcing the care service was reduced by 1.38%, which equates to a daily saving of £5,757.98. Over the course of a year, this would add up

to a saving of £2,101,661.37. Under the optimistic scenario spending reduced by 10.93% or £45,516.57, which equates to £16,613,547.90 over the course of the year.

The method applied for policy option 1 was then repeated and applied across all policy options. In the absence of specific equipment costs, it was assumed that complex telecare equipment would cost double that of basic telecare, therefore £1,584 per annum, per person, or £4.32 per day, per person. The results were then used to calculate the annual costs for resourcing the care service. At baseline the annual cost was £151,944,585 for providing community care packages, residential care and nursing home beds.

Figure 8.9 shows the percentage change from baseline for each of the three telecare policy options under both the conservative and optimistic scenarios.

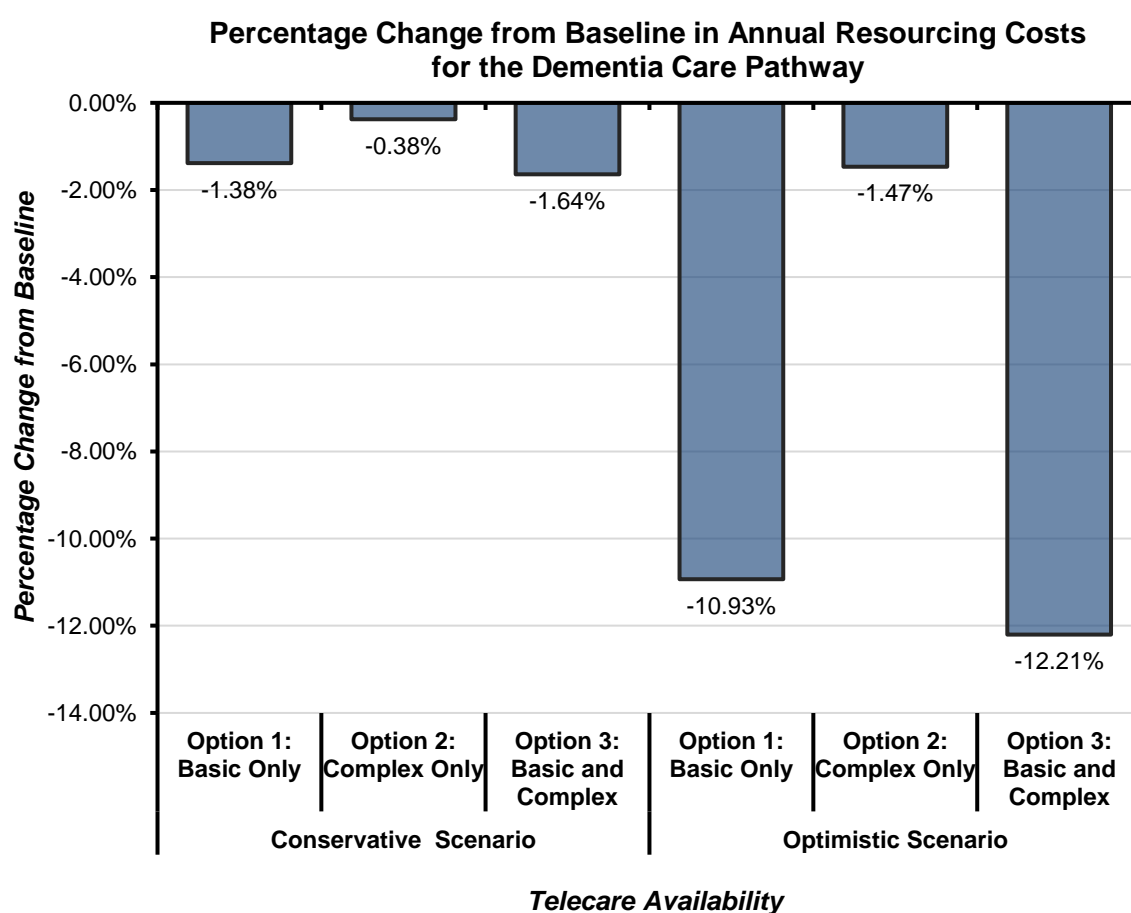


Figure 8.9: The Percentage Change from Baseline in Annual Resourcing Costs for Each Policy Option

The results show that policy option 3 incurs the greatest savings, where both types of telecare equipment are offered together. However, the savings associated with offering basic telecare only, under policy option 1, are close behind. Offering both complex and basic telecare together reduced annual spending on care resources for the dementia care

pathway by 1.64% under policy option 3 compared to baseline in the conservative scenario. This equates to an annual saving of £2,496,606. The reduction of 12.21% under the optimistic scenario, represents an annual savings of £18,545,667.

The introduction of basic telecare (policy option 1), results in annual savings of £2,101,661 (1.38% reduction compared to baseline) under the conservative scenario and a reduction of £16,613,548 (10.93% reduction compared to baseline) under the optimistic scenario.

By comparison, complex telecare when delivered alone (option 2) has the smallest impact on spending. Under the conservative scenario policy option 2 spending represented a reduction of 0.38% (£2,101,661 saving) and 1.47% (£2,228,695 saving) under the optimistic scenario, when compared to baseline. Although complex telecare reduces the spending associated with institutional care occupancy, the overall cost saving is partially negated by the increased cost of supporting more people in the community with a combination of two care resources (both complex telecare and community care).

This section demonstrates that telecare has the potential to provide significant cost savings. However, it is important to caveat these results, therefore the limitations of this simplified cost analysis are included in Chapter 9, Section 9.4.

8.4 Experiments Two and Three

The final two experiments presented in this chapter are simplified trials that were used to test the main two assumptions used in the TeleDem Simulation; consequently:

- **Experiment two** – explores the impact of varying the proportion of referrals to telecare services on the number of institutional care admissions for people with dementia;
- **Experiment three** – explores the impact of varying the ability of telecare to reduce carer burden on the number of institutional care admissions for people with dementia;

For both experiments the arrival rate of the model was fixed at one person every five days to reduce model run time. This allowed for multiple trials to be completed in quick succession (with an average runtime of approximately 20 minutes per trial). As in the main experiment, each trial consisted of 35 runs, with each run lasting 40 years in total; consisting of a warm up period of 10 years, and a data collection period of 30 years. The

availability for the care service resources (basic telecare, complex telecare, community care, residential care space, and nursing home beds) were all set to 10,000 to denote unlimited availability.

In experiment two, the impact of telecare equipment on ZBI scores was set to 25% to mirror the main experiment. This meant every modelled person who received telecare as a care service had their ZBI score (representing carer burden) reduced by 25%. The TeleDem Simulation was run eleven times with the proportion of people referred to telecare services incremented at 10% intervals (0% to 100% of referrals) for each trial.

Experiment three focused on varying the impact of telecare on ZBI scores. Experiment two was repeated a further five times with the impact on ZBI scores adjusted by intervals of 5% for each trial. This meant that results could be compared for six scenarios (when including the results from experiment one), which ranged from a 5% to a 30% reduction in ZBI.

8.4.1 Experiment Two Results

The results for experiment two were compared against a baseline scenario where no telecare was available. For this configuration of the model 2,920 simulated people with dementia entered the TeleDem Simulation. Approximately 2,502 people died during each simulation run and exited the model. Consequently, over the course of the 35 runs in the trial, data for 87,570 simulated people was generated for inclusion in this analysis.

At baseline, for each 40 year run without telecare, there were on average 1,160 residential care admissions, and 833 nursing home admissions. The mean number of days spent in institutional care was 1,180 days (3.2 years); with an average stay of 1,033 days (2.8 years) spent in residential care, and 551 days (1.5 years) spent in nursing homes.

Increasing referrals to telecare at 10% increments from baseline (no telecare) showed a slight, but steady reduction in admissions to both forms of institutional care (as shown by Figure 8.10).

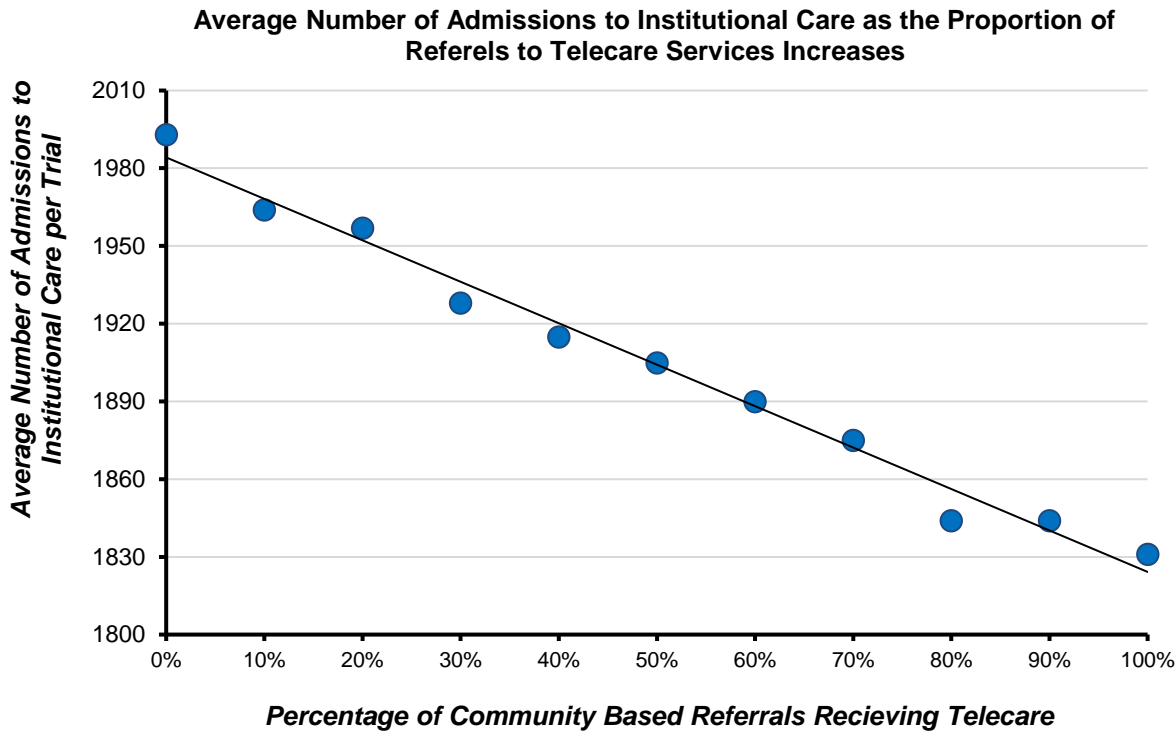


Figure 8.10: Average Number of Institutional Care Admissions as Referrals to Telecare Services Increase

Over the 40 year modelled period, the average number of institutional care admissions reduced by 8.13% (1,831 from 1,993) when 100% of referrals to community care were supported with telecare.

Results relating to length of stay in institutional care and the utilisation of institutional care places showed similar downward trends, demonstrating that the impact on institutional care is greater as telecare provision increases. For instance, the average daily occupancy of residential care home spaces dropped from 107 at baseline, when there were no referrals to telecare, to 93, when 100% of community care referrals were supported with telecare equipment. This change represents a 13.08% reduction in the average use of residential care home space when everyone living in the community is supported with telecare.

8.4.2 Experiment Three Results

Results from experiment three demonstrate that the greater the impact of telecare on reducing carer burden, the greater the reduction in number of institutional care admissions (as shown by Figure 8.11).

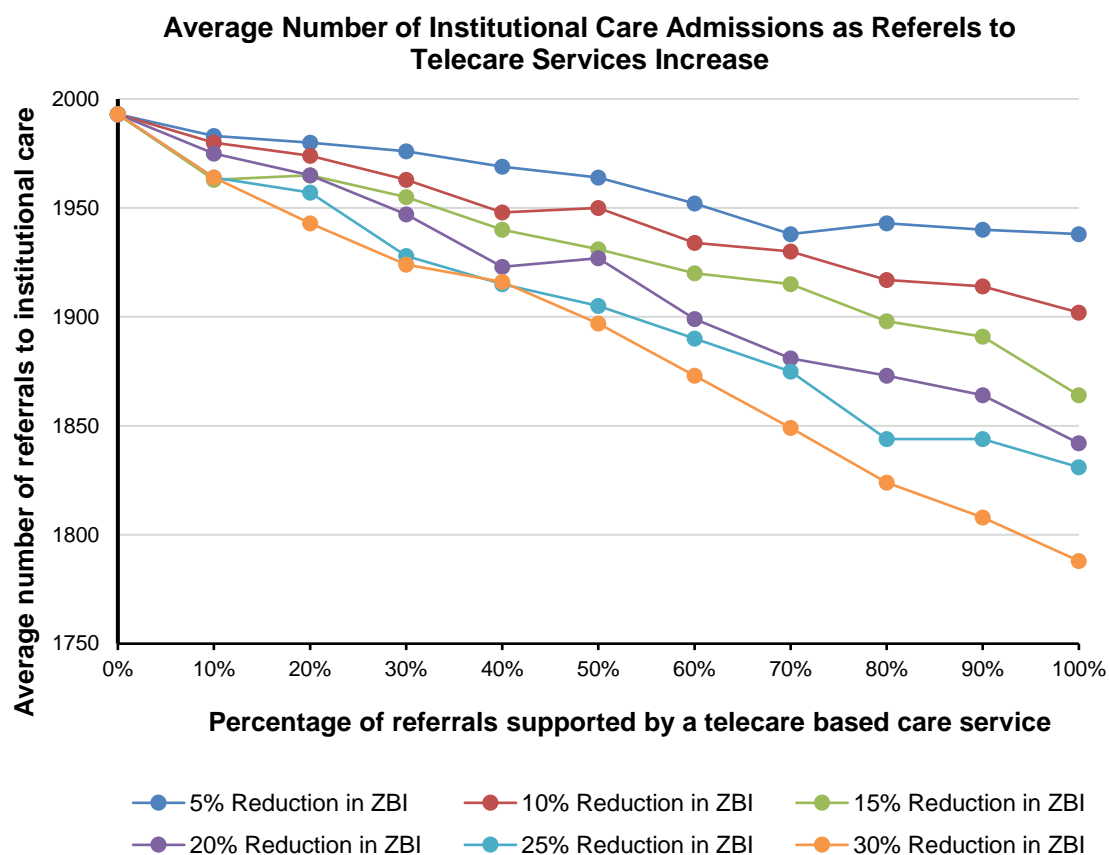


Figure 8.11: The Impact of Varying the Ability of Telecare to Reduce Carer Burden on Number of Institutional Care Admissions

Although the relationship between increasing referrals to telecare and the number institutional care admissions shows a clear downward trend, the relationship is not entirely linear, there is unexpected variation within the results. For instance, when 10% of referrals are supported with telecare a reduction in ZBI of 15% has a greater impact on institutional care admissions than a reduction in ZBI of 20%. This fluctuation may be due to the natural variability captured by the model, increasing the number of runs may smooth the trendlines. However, the number of runs chosen reflects the trade-off between smoothing out variation and model run time. As the proportion of referrals to telecare increases, the difference between the impact of telecare on ZBI scores becomes more apparent.

The relationship between the impact of telecare on reducing carer burden and the length of stay in institutional care shows more variability compared to Figure 8.11. However, as the impact of telecare increases (from 5% to 30%), the data begins to smooth (as shown by Figure 8.12).

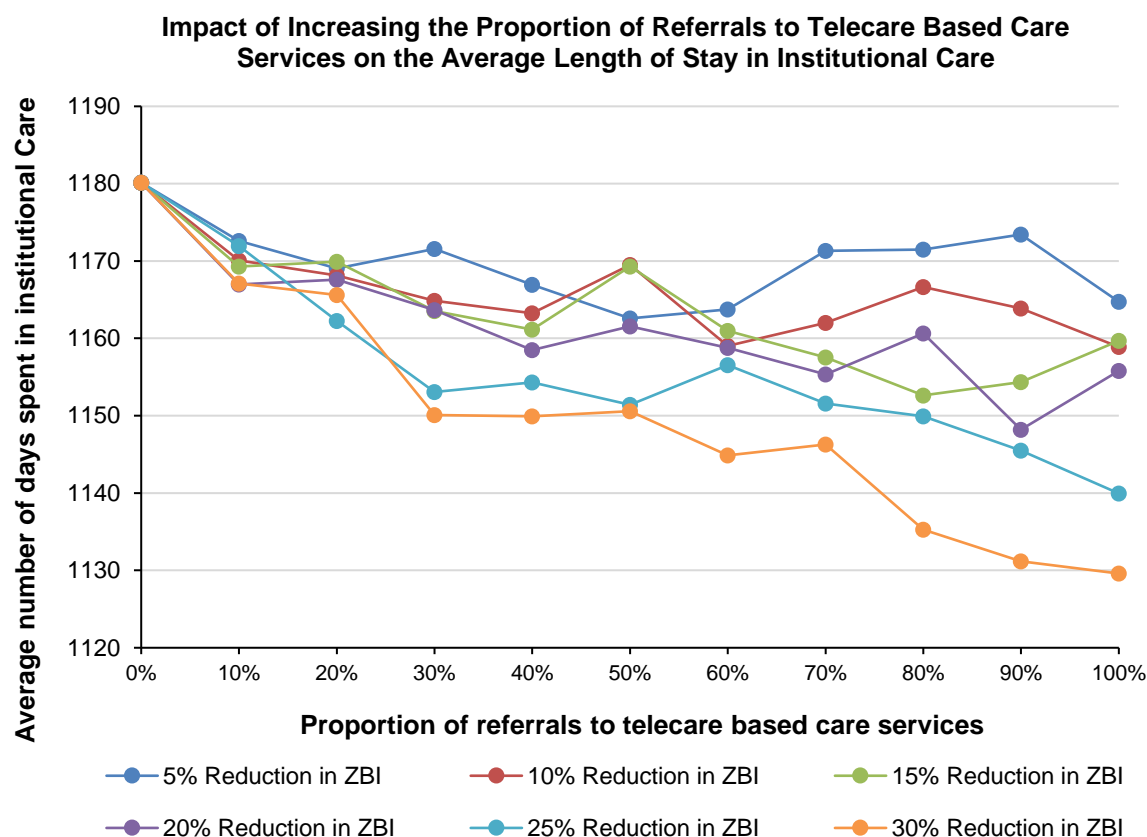


Figure 8.12: The Impact of Varying the Ability of Telecare to Reduce Carer Burden on Length of Stay in Institutional Care

Further experiments could be run to extend this analysis and look at the impact of reducing ZBI even further (35%, 40%, 45%, 50%...100% ZBI reduction, for instance), however for the purposes of this research testing these six intervals was deemed sufficient to examine the relationship between increasing reductions in ZBI and institutional care use. It seems logical to assume that telecare will never be able to completely remove carer burden, and therefore until more is understood about the relationship between telecare and ZBI scores, these findings offer some insight.

8.5 In Summary

This chapter has demonstrated how the TeleDem Simulation can be used to answer research question 3, which was set out in Chapter 1, Section 1.3 of this thesis. It has provided an example of a hypothetical scenario, as described by the main experiment (Section 8.3), to illustrate the potential impact of telecare on admissions to institutional care for people with dementia. Two further experiments were carried out to test the main assumptions used within the model. The results from all three experiments will be discussed in the following chapter.

Chapter 9: Discussion and Conclusion

9.1 Chapter Overview

This chapter draws together the key findings from the previous eight chapters. It begins by revisiting the objective for this research, which was set out in Chapter 1; it then summarises how this body of work has addressed each of the four research questions. The chapter considers the contributions of this work, the limitations of the adopted approach, and the possibilities for future avenues of research. This chapter concludes the modelling process and therefore addresses the last step in the modelling framework, as shown by Figure 9.1.

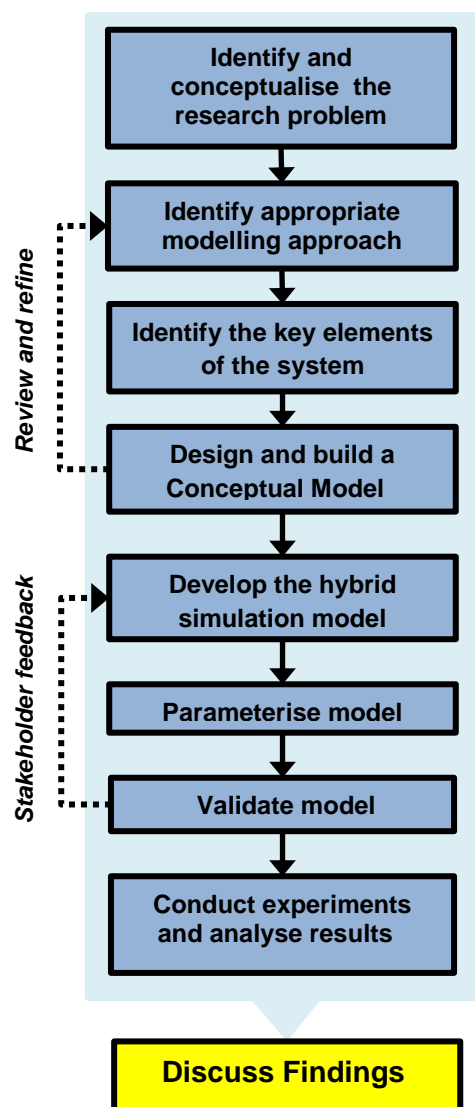


Figure 9.1: Addressing the Final Part of the Modelling Framework

9.2 Meeting the Research Objective

The aim of this research was to explore the impact of telecare services for people with dementia living at home through the application of OR modelling techniques.

The core objective was to design and build a hybrid simulation model combining DES with statecharts to examine the impact of telecare on a) the numbers of people with dementia able to remain living within their own homes rather than entering institutional care, and b) the ability of these patients' carers to cope.

This research has achieved its objective through the design and implementation of the TeleDem Simulation, as described in detail in Chapters 5 and 6. The results from the model examining the impact of telecare on people with dementia entering institutional care, and the implications for varying the impact that telecare has on carer burden, were presented in Chapter 8. The following subsections will discuss the key findings and conclusions from this thesis in relation to the four research questions set out in Chapter 1.

9.2.1 Addressing Research Question 1

- *How can the use of statecharts enhance the capability of Discrete Event Simulation to effectively take into account the variability associated with the progression of dementia, and also the variation in the ability of carers to cope?*

The background research (Chapters 2 and 3) and stakeholder engagement activities (Chapter 5) highlighted the importance of individual level variability within this problem situation. Firstly, in terms of the rate at which dementia progresses. Secondly, variability between individuals regarding each person's level of care need, and finally, the variability in the capacity of carers to cope. Consequently, the TeleDem Simulation used DES to model the care system for people with dementia combined with statecharts to represent each of these variable characteristics. How statecharts enhance the capability of DES to capture this variability was explored in Chapter 6, Section 6.2 through the justification of the modelling methodology. Therefore, this research question has already been addressed within this thesis. Consequently, this chapter will focus on the broader question posed by research question two, as discussed below.

9.2.2 Addressing Research Question 2

- *What are the advantages and disadvantages of using statecharts in addition to 'standard' DES for modelling patient care pathways?*

Answering this research question brings together the experience of building the TeleDem Simulation and findings from the existing OR literature described in Chapter 4. As highlighted in the literature review, combining multiple modelling techniques is advantageous to overcome the limitations of individual approaches. DES has been proven to be a highly effective methodology for modelling complex stochastic systems from an operational or tactical perspective (Bailey, 1952; McGuire, 1994; Harper and Shahani, 2002; Miller *et al.*, 2004; Katsaliaki and Brailsford, 2007; Pilgrim and Chilcott, 2008; Lebcir *et al.*, 2017). However, it can be challenging to capture individual level variability, such as disease progression within a 'standard' DES.

By contrast, ABS, with which statecharts are most commonly associated, naturally accommodates these variations. ABS is particularly well suited for providing insights into the health of large populations over time (Marshall *et al.*, 2015). For instance, Chapter 4 presented the example of an ABM by Macal *et al.* (2014), which used statecharts to model the transmission of MRSA in Chicago. Statecharts are powerful, expressive, and capable of capturing complex behaviour with relatively few elements (Vickland and Brodaty, 2008). Yet ABM struggles to get the same level of uptake by modelers as traditional OR approaches such as SD and DES, as it requires an understanding of computer languages and programming skills. Furthermore, ABMs can be slow to build and harder to communicate to stakeholders. However, while the source code used in an ABM may be challenging to explain, statecharts in themselves, are visually expressive and can provide a general talking point for feedback and refinement. Therefore, combining statecharts with DES for the TeleDem Simulation allowed individual level realism to be combined with the structural robustness of traditional DES, in a format that was easy to communicate to stakeholders.

Although dementia progression could be modelled empirically with Markov models, as shown by the work of Dowd *et al.* (2018), statecharts have the advantage of being straight forward to implement. Furthermore, Markov states lack 'memory' to record the person's previous states; which is important when the person exists with multiple interacting characteristics. Statecharts lend themselves to situations where patients are simultaneously characterised by more than one state. In the case of the TeleDem Simulation: stage of dementia, dependency level, and carer capacity to cope.

As discussed in Chapter 6, Section 6.2, combining statecharts with DES to model patient care pathways enables the model to describe what is happening to the patient in a more realistic way. A person's progression through a statechart is independent of that person's position within the DES, however movement around the DES can be triggered by changes in state. For instance, standard DES is not able to model a change in status, such as death, as effectively. When a person dies within the TeleDem Simulation, they are immediately removed from the DES component, which reduces the risk of the model overestimating resource usage.

Statecharts are simple to parameterise; within SIMUL8, data is input through a series of simple drop-down menus. Transition rates can be applied using the labels that assign attributes within the DES; these can then be linked to spreadsheets. Although simple implementation is an advantage, the ability to plug existing study data into the model, increases the risk of extrapolating errors that may exist within the original studies. Traditional empirical approaches used for parameterising DES models (such as Markov modelling) allows the modeler greater control over the quality of the final inputs.

Previously, one of the main disadvantages of building a hybrid model was the need for coding expertise. However, the inclusion of statecharts within the SIMUL8 modelling platform, facilitated implementation of this methodology, as it allowed the TeleDem Simulation to be constructed within a single package of software. The introduction of multi-paradigm elements within a 'drag and drop' environment has enhanced the modelling experience. It enabled hybrid modelling without the need for the expertise in Java coding that is required for using multiparadigm packages such as AnyLogic.

One of the surprising consequences of increasing the functionality of SIMUL8 in this way, was a significant increase in model runtime. Consultation with the SIMUL8 team established that duplicating the modelled person multiple times, so they could coexist within each component of the model, greatly increased processing time. A limitation in the design of the software is the inability to adjust time constructs within each model element. If the DES runs in days (the maximum time unit), the statecharts check and update the transition rates for every modelled person on each day. Consequently, the TeleDem Simulation runtime rose to 73 hours when the arrival rate into the model was set to four people per day. Therefore, it could be argued that while the inclusion of statecharts enhances the modelling capability of traditional DES, it appears to also reduce the ability to run 'quick and dirty models' which Siebers *et al.* (2010) argues benefited the advancement of simulation. An approach that slows down the modelling process could be

seen as a disadvantage and therefore a step backwards compared to using the more established methods, such as 'standard' DES. Consequently, further development of this element of SIMUL8 may be beneficial.

Nonetheless, the ability to combine statecharts with DES gives modellers the capacity to choose the 'best tools' for representing specific components of a patient's care pathway. This removes the limitations of confining a modeller within the boundaries of a single paradigm specific approach. As OR increasingly seeks to represent complex human centric systems the ability to combine paradigms only serves to enhance simulation's potential.

9.2.3 Addressing Research Question 3

➤ *What can simulation modelling show us regarding the impact of telecare on institutional care admissions for people with dementia?*

The results of the TeleDem Simulation, as describe in Chapter 8, demonstrated that telecare can reduce the number of admissions for people with dementia to institutional care. The model was used to test a hypothetical scenario where, in the absence of data, it was assumed that telecare can reduce carer burden by 25%. The model was then run, firstly under an optimistic scenario, where 90% of all referrals to community care were supported by telecare. Secondly, the model was run under a conservative scenario, where only 10% of all referrals to community care were supported by telecare. The results of the TeleDem Simulation suggested that:

- Providing both complex and basic telecare together has a greater impact on reducing the average day to day occupancy of institutional care when compared to either type of telecare offered in isolation.
- Policy options which included complex telecare (policy options 2 and 3) had a greater impact on the average daily occupancy of nursing home beds, compared to policy option 1, which only included basic telecare.
- Policy option 2 (complex telecare only), provided the largest reduction in institutional care admissions over the 40 year modelled timeframe.
- As reported in Chapter 8, average length of stay in residential care was 0.19% higher than at baseline in the conservative scenario, and 1.39% higher in the optimistic scenario if complex telecare was provided in isolation. This is because

reducing the number of admissions to institutional settings in the later stages of dementia reduces the number of short 'end of life' stays, which distort the average length of stay. Therefore, without these shorter stays reducing the mean length of stay, the average is higher than at baseline.

- The number of people supported by packages of community care increased with the introduction of complex telecare, when compared to the baseline scenario where no telecare was offered. This finding was not unexpected. The reduction in numbers of people entering institutional care caused by the introduction of telecare naturally increases the number of people requiring community care support. This is due to the inclusion of community care alongside every referral to complex telecare in recognition of the need for support with ADLs in the later stages of dementia. Domain experts asserted the importance of recognising that telecare equipment alone would be insufficient to meet the person's needs in the later stages of the disease, and therefore the equipment would need to be provided alongside some degree of human support.
- While the increased use of complex telecare had the greatest impact on the number of institutional care admissions, basic telecare, when provided in isolation, had the greater impact on average occupancy of residential care. It also reduced the average length of stay in institutional care.

These results suggest that complex telecare can eliminate the need for institutional care for some people by providing additional support for carers, so that the person with dementia can continue to be cared for at home until the end of their life. However, basic telecare, if offered in isolation, can delay institutional care placement, rather than eliminating the need for it all together.

To further test the model and to understand the impact of assumptions on which the model was based, the TeleDem Simulation was used to test two additional simplified experiments. These experiments examined the impact of varying the proportion of referrals that are supported with telecare, and also the impact of varying the extent to which telecare can modify carer burden. The results of these additional trials showed that increasing the number of referrals supported with telecare reduced the number of admissions to institutional care. Furthermore, the larger the impact the equipment has on reducing carer burden, the greater its potential to reduce the number of admissions to residential care and nursing homes. However, it was also noted that the smaller the mediating effect telecare had on carer burden, the less stable the relationship was

between increased number of referrals to telecare and reductions in institutional care admissions. These results highlight the importance of further research to gain a clearer understanding on the impact of telecare on carer burden.

Nonetheless, the TeleDem Simulation has demonstrated the potential of using simulation modeling to explore the impact of telecare for people with dementia. Over the last few decades telecare has gained increasing attention from academics and policy makers alike. As discussed in Chapter 3, telecare has many potential benefits for people with dementia, including supporting independence and reducing carer burden. However, despite the growing interest in the potential of the equipment, much of the existing evidence is based upon anecdotes and short-term trials, which has been insufficient to encourage nationwide implementation. In situations, such as this, simulation offers an alternative to empirical research by providing a safe and cost-effective environment to test different courses of action (Squires and Tappenden, 2011; Pidd, 2004; and Royston, 1999).

Consequently, the TeleDem Simulation provides a platform to investigate the impact of telecare. It has shown that introducing telecare to the care pathway has the potential to postpone and even eliminate the need for institutional care. These results are in line with the findings from telecare pilot studies, which found that telecare for people with dementia reduced the need for residential care, in particular through delayed admissions (Clark, 2008).

Delaying or even eliminating the need for institutional care has both social and financial implications for people with dementia. As described in Chapter 2, Section 2.9.4, people with dementia who are supported at home experience slower cognitive decline (Wilson *et al.*, 2007), a better quality of life (Jing *et al.*, 2016), and lower mortality (Aneshensel *et al.*, 2000). As touched upon in Chapter 8, there are also significant financial implications for reducing the utilisation of institutional care. These implications need to be carefully weighed up against the cost of providing the required level of support within the community. The cost implications of the TeleDem Simulation results are discussed in Section 9.2.4.2.

9.2.4 Addressing Research Question 4

- *Can OR modelling approaches help local authorities improve the way they plan services for people with dementia? And if so, how?*

The benefit for local authorities of the OR modelling process is twofold. Firstly, through the process of conceptual model building, and secondly, through the ability to explore and test a simulated system.

9.2.4.1 Conceptual Model Building

Working with Dorset County Council and building the conceptual model for the TeleDem Simulation with input from domain experts facilitated conversations between key stakeholders. This helped to broaden perspectives regarding the problem situation. Providing a clearer understanding of the bigger picture improved planning and implementation of services. For instance, the key recommendations to come from this exercise, regarding the planning of services, were as follows:

- **Recommendation one** – for a telecare service to be successful, staff need to be fully trained and confident in the equipment. A lack of staff confidence can be a significant barrier to a successful service.
- **Recommendation two** – the needs of people with dementia are far too complex and variable to see telecare as an isolated solution. Telecare services can provide support, but cannot replace human care, particularly when an increasing amount of help is required with ADLs. Services need to plan for telecare provision as part of community care packages, rather than as a sole alternative.
- **Recommendation three** – a thorough holistic assessment of the individual is crucial to avoid inappropriate telecare installations. Understanding a person's home environment, their support network, and their routines, is essential. A one size fits all approach to telecare is inappropriate. If people lose faith in the equipment, the service will suffer.
- **Recommendation four** – telecare equipment needs to be maintained and reviewed regularly to ensure it continues to meet the person's needs. Service planning needs to look at the service as a whole, beyond the initial purchase of equipment.
- **Recommendation five** – awareness of telecare needs to be raised, both among health and social care staff, and the wider community.

These findings, along with the recommendations made in Chapter 3, Section 3.12: 'Overcoming Barriers', will assist local authorities to avoid the mistakes of the past, and plan future services more effectively.

9.2.4.2 The Simulation

Running the TeleDem Simulation demonstrated that telecare can have a significant impact on the number of admissions to institutional care. The results indicate that for local authorities to maximise the impact of telecare services, they need to invest in both types of equipment. Basic telecare helps to delay the need for institutional care and avoid premature admissions. Whereas complex telecare helps to support people at home in the later stages of dementia, reducing the overall number of admissions to institutional care.

The retrospective cost analysis carried out in Chapter 8, Section 8.3.7 showed that offering both complex and basic telecare together reduced annual spending on care resources for the dementia care pathway. The hypothetical equipment showed that annual spending reduced by 1.64% under the conservative scenario, representing a saving of £2,496,606 and 12.21% under the optimistic scenario, representing a saving of £18,545,667.

The results also demonstrate that if the local authority were looking to focus their attention on offering only one category of equipment (either basic or complex), then their priority should be basic equipment, as the cost savings for basic telecare are greater than if offering complex telecare only. The annual savings attributed to policy option 1 (a 1.64% reduction under the conservative scenario, and a 10.93% reduction under the optimistic scenario) are not far behind the savings associated with policy option 3.

The TeleDem Simulation provides a platform to test different scenarios and policy options, which would enable decision makers to understand the impact of changes on the wider system and also the cost implications of those decisions. While the value of RCTs are recognised in Chapter 3, Section 3.13, for providing evidence for telecare, previous studies have been limited by their design (see Chapter 3, Section 3.4 and Section 3.10). A key limitation of the WSD programme was its restrictive time frame (Newman et al., 2014). The TeleDem Simulation allows the exploration of policy options over extended time frames, which provides the opportunity to investigate the longer-term implications of the interventions, such as the impact on institutional care admissions, which can be missed during short term RCTs.

The TeleDem Simulation could be adapted to represent a specific locality, and used to review the impact of telecare within a constrained system. Local costs could be applied and built into the model so that cost-effectiveness could be more realistically measured by capturing the individual level variability associated with resource use. The results produced by the simulation could then be used to help local authorities plan the number of telecare resources to provide.

By running the model and testing the different policy options, local authorities are able to provide evidence for any proposed improvements to the system. In addition, the visual nature of TeleDem Simulation would facilitate communication with stakeholders and therefore potentially improve their engagement when implementing proposed changes.

9.3 Scientific Contribution

The contributions of this research are: a novel application of hybrid modelling, the creation of a simulation to explore the impact of telecare on admissions to institutional care for people with dementia, and finally, it is the first model of its kind to explore the impact of varying the complexity of telecare.

9.3.1 Modelling the Impact of Telecare for People with Dementia

Having examined the telecare and OR literature, it is possible to conclude that this thesis addresses a unique gap in both fields of research. As stated in the closing remarks of Chapter 3, there is an ongoing lack of robust evidence to support the mainstreaming of telecare, particularly for individuals with dementia, who have very specific care needs, as outlined in Chapter 2. OR modelling has previously been utilised, in the absence of robust empirical data, to provide insight into a range of complex health and social care systems.

Bayer *et al.* (2007) examined the impact of telecare using SD; however, they did not specifically examine its role for people with dementia. People with dementia have their own unique set of care needs, and therefore pose their own set of challenges to policy makers. The variability in care needs between individuals with dementia is one of the key challenges when considering the suitability of care interventions for this group.

9.3.2 Combining Statecharts with DES

Careful consideration of the modelling paradigms explored in Chapter 4 indicated that a hybrid model combining statecharts and DES would provide the 'best tools for the job',

and a suitable framework to achieve the research objective of this thesis. No previous examples have been identified of DES being used to explore the impact of telecare on institutional care admissions for people with dementia. The use of DES in combination with statecharts makes the approach even more novel.

The concept of combining different simulation paradigms to capture different components of a larger system is not entirely new (Viana, 2014), although it is still relatively novel; hybrid modelling, as shown in Chapter 4, Section 4.3.4, has been applied to a range of situations. The benefits of combining DES with statecharts have been demonstrated previously, for example by Siebers and Aickelin (2011). However, there were no examples identified within the literature of DES being combined with statecharts for a social care application. The statecharts are used within the TeleDem Simulation to capture individual level variability and therefore enhance the realism of the modelled system depicted by the DES.

9.3.3 Exploring the Impact that Varying the Complexity of Telecare has on the Care System

The TeleDem Simulation provided the opportunity to explore the impact of varying complex versus basic telecare. This was a unique addition built into the research following feedback from domain experts during the stakeholder engagement.

9.4 Limitations and Future Work

The inputs used for the model and the assumptions made (as listed in Chapter 7, Section 7.15), were formulated based on the evidence available at the time of model building. Each assumption has the potential to impact the reliability of the TeleDem Simulation and therefore provide an area for future exploration, as discussed below:

- Certain assumptions were made within the model to maintain the simplicity of the test environment. For instance, the availability of residential care home spaces, nursing home beds, and community care packages within the TeleDem Simulation, are assumed to be unlimited. This limits the realism of the model, as unlimited availability of resources does not reflect the reality of the care system, however it did provide suitable conditions to examine the impact of telecare under a hypothetical scenario. The model could be customised to look at a specific locality and could be adapted to consider the resource restraints within that area. For example, the number of residential care home beds available. Furthermore, to

ensure conditions remained consistent, the arrival rate into the model was set to remain the same each year. However, the model could be used to examine the impact of telecare under different population projections, to examine the impact of the ageing population, by varying the arrival rate into the model for each year the model runs.

- The model works on the assumption that an excellent quality, holistic assessment of the person is carried out prior to installation of the telecare, and therefore that the equipment will only be installed where it is appropriate for the individual. Therefore, the model does not account for people who reject the equipment after installation. A further avenue of research that came to light through consultation with one of the domain experts was the possibility of exploring the proportion of referrals to telecare that fail, in order to test the impact of staff training initiatives on telecare success rate.
- The positive impact of telecare on carers has been consistently recognised within the literature (Sixsmith, 2000; Reeves, 2005; Alasewski and Capello, 2006; Beale 2009; Dunk and Schuette, 2009; Jarrold and Yeandle, 2009; Yeandle, 2009; Koivunen, 2014); with multiple studies explicitly stating that telecare can reduce carer burden (Dunk and Doughty, 2006; Clark, 2008; Barlow and Hendy, 2011; Craig *et al.*, 2013). However, this impact is challenging to quantify (Beale *et al.*, 2009). Therefore, an assumption within the model had to be made as to what the influence of telecare on carer burden would look like. Firstly, it was implemented as a percentage reduction in each person's associated ZBI score. The impact was assumed to remain constant throughout the time the person was receiving the telecare-based service. Secondly, it is assumed that at dependency level 5, telecare can no longer reduce carer burden, as the person's medical care needs at this stage become the primary focus of care. The impact of these two assumptions may cause the model to overestimate and underestimate respectively, the impact of the equipment on burden. Further research to better understand the relationship between telecare and burden would be beneficial. The results from the ATTILA project described in Appendix 13, is seeking to quantify the impact of telecare on ZBI; however, at the time of writing the results from this RCT have not yet been published.
- To reduce complexity within the model, people are assumed to either have informal care or not, and the amount of time their carer is available is assumed to remain static. Informal carer health status and mortality are not taken into consideration; the model assumes that aside from carer burden, there are no other

limiting factors that could impact the provision of informal care. Therefore, the model may overestimate the potential for people to continue to be cared for at home. The model could benefit from considering the loss of informal care through mortality. Furthermore, Eska *et al.* (2013) found the age of non-spousal carers, unlike spousal carers, could be a significant predictor of admission to institutional care. If further research supports Eska *et al.*'s findings, then the model could also be developed to factor in non-spousal carer age.

- Dementia is assumed to be the primary motivation for seeking support from care services; other co-morbidities are not taken into consideration. The model also assumes that people only require nursing home support when they advance to dependency level 5, based on the work of Kahle-Wroblewski *et al.* (2015). However, people at all stages of dementia may require nursing home support due to other existing co-morbidities. Therefore, the model will naturally underestimate nursing home usage. Nonetheless, as the focus of this thesis was on the impact of admissions across all institutional settings, this caveat does not undermine the validity of the results. It does however present an area that could benefit from further exploration. The TeleDem Simulation could be developed further to explore how other co-morbidities impact the person's care pathway.
- Further research could be carried out to explore the point at which people with dementia require complex telecare over basic telecare. This model assumes, based on consultation with domain experts, that as people reach moderate dementia their needs are such that the complexity of telecare must increase to meet those needs. However, the validity of this assumption could be tested with additional stakeholder engagement activities.
- Cost analysis was carried out retrospectively using the TeleDem Simulation results to offer another perspective on the findings and to highlight possible areas for further investigation. There are a number of limitations that relate specifically to the TeleDem Simulation results when considering the cost implications:
 - The values used in Chapter 8, Table 8.6 are average costs, whereas individual circumstances vary considerably. As reported in Chapter 2, Section 2.9.2, the requirement for home care support increases as dementia progresses and dependency increases (Scherer *et al.*, 2008). For instance, the hours of community care and therefore the cost of the community care will depend on individual circumstances. Someone who lives with an informal carer may need considerably less formal support than someone who lives alone; furthermore, someone with mild dementia may

only need 30 minutes of support per day, whereas someone with severe dementia may need many hours, depending on the availability of informal care. Further exploration of the impact of community care costs is necessary.

- In addition, there is likely to be variation between individuals in the level of sophistication of the telecare systems installed. For instance, one person may only require a simple pendant alarm, while another may require a far more complex set of peripheral devices and passive sensors (Barlow et al., 2005a).
- Also, as mentioned in Chapter 3, Table 3.3, social care means testing alters how much telecare costs for different individuals. Means testing is not reflected in the cost estimates presented in Chapter 8. This individual level variation will impact the evaluation of costs and would need further exploration if the model was to be used for policy decisions in practice.
- The resources in the TeleDem Simulation are unlimited. Therefore, they do not represent the constrained resources or the real social care system. Constraining the resource would also impact on the costs incurred.
- Furthermore, as highlighted by Barlow and Hendy (2009), the costs and benefits of telecare may sit with different stakeholders and the boundaries between 'health' and 'social' care may be blurred. Evidence has suggested that telecare can reduce the number of hospital admissions for people with dementia, this in turn has significant cost implications (O'Sullivan, 2011). Developing the TeleDem Simulation to examine the impact of telecare on admissions to hospital is another avenue for future research regarding cost-effectiveness.

The TeleDem Simulation could be expanded to explore numerous avenues of further research. For instance, the TeleDem Simulation only examines the use of telecare by people living in the community. However, there are other ways in which technology could enhance care delivery that are not considered within this research. Telecare can also play a role in supporting people with dementia after they enter institutional care. There are also potential avenues for improving the provision of dementia care through the introduction of telehealth care, which focuses on the monitoring of the person's health state. Additionally, the rise in availability of smartphones has brought with it numerous applications designed at supporting the delivery care.

The purpose of the TeleDem Simulation was to provide a platform to run experiments and generate understanding to address the research questions of this thesis. As previously stated, any model is a simplification and therefore has inherent limitations; nonetheless the process of researching, designing, and building this hybrid model, has highlighted the potential of OR for providing insight in this complex area of research. It has offered an avenue for exploring the wider impact of telecare on institutional care admissions for people with dementia in a way that is unachievable through small scale pilot studies. As further evidence for telecare for people with dementia becomes available, the TeleDem Simulation can be developed and expanded. Until that time, the model serves as an example of an exciting direction for OR modelling within multidisciplinary research, where simulation can easily combine multi-paradigm elements within a single package software.

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Appendix 1: University Ethics and Research Governance Online Forms



ERGO application form – Ethics form

All mandatory fields are marked (M*). Applications without mandatory fields completed are likely to be rejected by reviewers. Other fields are marked “if applicable”. Help text is provided, where appropriate, in italics after each question.

1. APPLICANT DETAILS

1.1 (M*) Applicant name:	Katherine. E. E. Penny
1.2 Supervisor (if applicable):	Professor Sally Brailsford Professor Maria Evandrou
1.3 Other researchers/collaborators (if applicable): <i>Name, address, email, telephone</i>	

2. STUDY DETAILS

2.1 (M*) Title of study:	The Use of Telecare for People with Dementia
2.2 (M*) Type of study (<i>e.g. Undergraduate, Doctorate, Masters, Staff</i>):	Doctorate
2.3 i) (M*) Proposed start date:	01/08/2012
2.3 ii) (M*) Proposed end date:	31/10/2014

2.4 (M*) What are the aims and objectives of this study?
1. Examine the future prevalence of Dementia in the context of an ageing society 2. Explore telecare as a care service option for people with dementia, both in terms of published literature and real life applications. 3. Explore the role of telecare for supporting unpaid carers in caring for someone with dementia.

4. Build a Discrete Event Simulation Model, factoring in the facilitators and hurdles influencing telecare uptake, to explore how telecare could help meet the increasing social care demand from an ageing population.

5. Carry out cost benefit analysis of telecare compared to traditional care services

2.5 (M*) Background to study (*a brief rationale for conducting the study*):

This study forms part of the Care Life Cycle Project (CLC). The CLC is a multidisciplinary research project at the University of Southampton, which brings together social scientists, complexity scientists and management scientists under the 'Complexity Science in the Real World' initiative, to examine meeting the health and social care needs of an ageing population. The Care Life Cycle project's ultimate aim is to develop a suite of innovative modelling tools for informing the development of social policy.

The research carried out within this PhD will look specifically at using telecare to meet the social care needs of people with dementia within this ageing population. The project will use modelling techniques to explore the potential role of telecare in supporting care delivery, enabling people to remain within their own homes for longer and out of long term institutional care. Ultimately this project will lead to the development of a discrete event simulation model which will be used to examine the facilitating or obstructive factors that influence telecare uptake and its success for people with dementia.

2.6 (M*) Key research question (*Specify hypothesis if applicable*):

- What is going to be the increase in the prevalence of dementia within the ageing population and what impact will this have on the demand for care services?
- What are the socio-economic/demographic characteristics of people with dementia?
- What levels of cognitive deterioration are associated with each stage of dementia?
- What is the associated level of care required for each stage of dementia?
- What services are currently provided for people with dementia/the carers of people with dementia?
- What role can telecare play in delaying or eliminating the need for institutional care?
- What role can telecare play in helping carers of individuals with dementia return to work?
- What is the cost benefit of utilising telecare over traditional care services?

2.7 (M*) Study design (*Give a brief outline of basic study design*)

Outline what approach is being used, why certain methods have been chosen.

Ultimately this project will lead to the development of a discrete event simulation (DES) model which will be used to examine the facilitating or obstructive factors that influence telecare uptake and its success for people with dementia. A DES model represents a system as a sequence of events consisting of "separate entities which occupy discrete states that will change over time" (Pidd, 1996). In this instance, the 'separate entities' are the individuals with dementia, and the 'discrete states' will represent the uptake of telecare.

The model will require historical data in order to establish distributions for the duration that the entities remain within each state and to ensure the model represents the real life processes that take place. The quantitative data will be obtained from both the literature and publically available studies, such as the English Longitudinal Study of Ageing, which is available through the Economic and Social Science Data Service. Ageing related data will also be obtained from the Office of National Statistics and other such datasets that can be used to determine the likelihood of developing dementia.

The DES will allow individuals to be followed throughout the system, simulating the potential experiences of hundreds or even thousands of different hypothetical patients, based on a combination of data from the literature and empirical data. The empirical data will be gathered by interviewing 'key informants' (professionals involved in the development or delivery of telecare); interviewing potential and current service users; interviewing carers of people with dementia (paid and unpaid) and by holding focus groups with 'healthy' older people.

The interviews with 'key informants' will involve a range of people whose professional roles give them particular insights into the development or delivery of telecare. These professionals will include policymakers, clinicians, technology developers, representatives from telecare manufacturers, Local Authority service managers and researchers.

The interviews with unpaid carers will help me understand the role they feel telecare plays in supporting them and the impact it has on their quality of life. I will also speak to carers without any experience of using telecare to see what they think of the equipment.

Interviews with current and potential service users will involve speaking to individuals who have experienced or are experiencing periods of cognitive confusion as a consequence of dementia. They will be interviewed in order to gain a better understanding of their experience of dementia and how it affects their day to day quality of life. A significant proportion of the literature focuses on the importance of ensuring people with dementia maintain their voice and are involved in the decisions relating to their care, therefore excluding them from the research would be counterproductive when the focus is to help people stay as independent functioning members of society for as long as possible. In the case of current service users, these are the people who are actually living with the telecare equipment on a day to day basis, so their opinion is central to understanding what facilitates and hinders its uptake. Due to the vulnerability of the individuals involved, extra care will be taken with the interview process (this is covered further in the remainder of the form and on the risk assessment).

The interviews will be semi-structured, as this allows a greater degree of freedom than a questionnaire or a structured interview. It provides flexibility as to how and when the questions are asked, enabling the interviewer to probe and explore new paths that were not previously considered.

The purpose of the focus groups with healthy older people will be to gauge their current awareness of telecare and its role. The groups will hopefully offer insights into people's perceptions of using technology to support care. It will allow me to test hypothetical scenarios and establish whether they see telecare as something they would use if they needed support in the future.

Focus groups have been chosen as they will allow a concentrated amount of data to be obtained on a precise topic area and provide the opportunity to gain greater insights into participants' opinions and experiences through group interaction.

*Amendment 2:

Additional focus groups will be held with carers and potential/current service users with dementia to supplement the one to one interviews. In some instances the focus groups may be a more appropriate form of data collection if they reduce inconvenience to the participants and can take place in comfortable, familiar surroundings, such as a regular meeting venue or day centre. For example, I am looking to conduct a focus group with the help of Age Concern Hampshire, through their Day Services with a small group of their clients (and their carers

where appropriate) to discuss their experiences of dementia and their thoughts on the telecare equipment.

Furthermore, there is an opportunity for collaboration with Katie Cheeseman (Project manager – Assistive Technology) at Portsmouth City Council, who through the council's Tele Advisory Group would like to assist me in organising Focus Groups with healthy older people, carers and people experiencing dementia in order to obtain feedback on telecare services.*

In addition to focus groups and interviews, valuable data will be provided through collaboration with Dorset County Council. In exchange for evaluating the first 12-18 months of a lifestyle monitoring pilot the council are running from September 2012, they will provide anonymised data on telecare uptake across the county.

The pilot, which is being run by Dorset County Council (DCC), will focus on the use of Lifestyle Monitoring Equipment to aid the hospital discharge of people with dementia. Lifestyle monitoring is a form of telecare which, through the installation of a series of sensors in different rooms throughout their home, allows an individual to be assessed within their familiar environment. This assessment will be carried out by DCC care staff over a period of 3- 6 weeks following a patient's discharge from hospital. It is hoped that using the equipment to aid assessment will reduce the number of unnecessary admissions into long term institutional care.

In order to carry out the evaluation I will have access to anonymised versions of all the case notes collected by DCC during the assessments of the participants in the DCC pilot study. I will also have access to the raw outputs from the Life Style Monitoring equipment.

Further to this, I will be interviewing members of DCC care staff to gain their perspective on the equipment and in a few instances I will be shadowing the care workers through the assessment process in order to build up case studies to support my research.

To summarise, I will use the following methods:

- i. Quantitative data analysis of national datasets, such as ELSA
- ii. Approximately 5 focus groups with a total of 30 older persons who do not suffer from dementia.

*Amendment 2:

- iii. Semi-structured qualitative interviews *or focus groups* with approximately 40 informal carers of persons with dementia; including carers with experience of telecare and those without.

- iv. Semi- structured qualitative interviews with 10 -15 'key informants'.

*Amendment 2:

- v. Semi- structured qualitative interviews *or focus groups* with 20 potential and current telecare service users (individuals with dementia).

- vi. The DCC's pilot evaluation data, both raw and analysed by DCC, including semi-structured qualitative interviews with approximately 10 paid care staff.

- vii. Observational data will be collected by shadowing members of DCC staff through the assessment process in order to build up case studies/examples of good practice, which will be anonymised. I will aim to shadow between 3 - 5 members of staff.

3. SAMPLE AND SETTING

3.1 (M*) How are participants to be approached? Give details of what you will do if recruitment is insufficient. If participants will be accessed through a third party (e.g. children accessed via a school) state if you have permission to contact them and upload any letters of agreement to your submission in ERGO.

Participants will be contacted by post or e-mail. The required contact details will be obtained as follows:

Focus Groups:

'Healthy' older people will be recruited for focus groups through charities and local forums, for example: Southampton Pensioners Forum <http://www.sotonpensforum.hampshire.org.uk/>.

Caroline Hadley, Trustee for Age Concern Hampshire has offered her assistance in contacting older people and my second supervisor Professor Maria Evandrou has contacts in local Aging related charities. Dorset County Council has also said they are happy to provide contacts. If initial recruitment is insufficient I will approach more forums, societies and charities nationally.

*Amendment 2:

Through collaboration with Katie Cheeseman at Portsmouth City Council, I will hopefully be able to hold focus groups with a range of different key groups in Portsmouth, including: 'healthy' older people, carers and people with the early stages of dementia. These groups will focus on the subject areas proposed for the one to one interviews. These groups will be contacted through the Portsmouth Tele Advisory Group, subject to ethical approval.

In addition, Kym Devine (Age Concern Hampshire, Health and Wellbeing Services Manager - South East) has said Age Concern, Hampshire would be happy to help me arrange a focus group through their Day Services. They would invite a small group of their clients (and carers if applicable) to join my group.

If the work with Age Concern Hampshire is successful, I will seek to make similar contact with other Age Concern groups, such as Age Concern Dorset and see if they are also able to assist me in arranging a similar focus group.*

Interviews:

- 'Key informants' will be looked up online and contacted directly by e-mail. In some instances they may be introduced to me through telecare or dementia events or through existing contacts, in which case once recruited they will be e-mailed/posted further information.

- Carers will be identified through local care groups, such as the Carers UK local groups network: eg Help and Care Dorset, Swanage Carers Group and Blandford Carers Group. Carers will also be contacted through local authorities, such as Dorset County Council. Once identified, they will be sent a letter through the post or e-mailed.

- Potential and current service users will be contacted through carers groups, carer interviews or local authorities. In the instances where service users may be present at the interviews with carers, questions can be directed to both parties during the interview; therefore the "interview" will become more of an informal conversation, which will hopefully put the participants at ease. Furthermore, Dorset County Council has agreed to help facilitate interviews with services users by asking a Memory Advisor from their Memory Clinics to introduce me to participants and to 'sit in' for interviews. In addition, I recently gave a presentation on my research at a Wessex HIEC Telehealth/care event after which I was approached by a lady with Posterior cortical atrophy (PCA), an atypical variant of Alzheimer's disease. The lady (who for the sake of anonymity, shall be referred to as Mrs B hereafter) asked if she could be involved in my research to share her experiences of what living with dementia is really like.

The DCC Pilot:

- Dorset County Council will be running the lifestyle monitoring pilot; therefore they will be responsible for the selection of participants.
- DCC will facilitate the interviews and shadowing with the care workers; they will contact them on my behalf and recruit them as part of the evaluation process.

3.2 (M*) Who are the proposed sample and where are they from (e.g. fellow students, club members)? List inclusion/exclusion criteria if applicable. NB The University does not condone the use of 'blanket emails' for contacting potential participants (i.e. fellow staff and/or students).

It is usually advised to ensure groups of students/staff have given prior permission to be contacted in this way, or to use of a third party to pass on these requests. This is because there is a potential to take advantage of the access to 'group emails' and the relationship with colleagues and subordinates; we therefore generally do not support this method of approach.

If this is the only way to access a chosen cohort, a reasonable compromise is to obtain explicit approval from the Faculty Ethics Committee (FEC) and also from a senior member of the Faculty in case of complaint.

The sample for the 'healthy* older people' focus groups will include approximately 30 individuals aged 60 years and over who have not been diagnosed with dementia and are free from cognitive impairment. *In this setting, the term "healthy" means free from any form of dementia or cognitive condition that could impact their capacity to consent to participating in this study.

The sample of 40 informal carers will consist of anyone willing to participate who provides care for someone with dementia. They will be contacted either through the DCC pilot or through local carer forums. It is hoped that the majority of these participants will have experience of using telecare to assist them in their caring role.

Both the 'carers' and the 'healthy older people' will be people living in Dorset and Hampshire. Unless recruitment is insufficient, in which case the 'net will be cast further'.

*Amendment 2:

Individuals contacted for interviews or focus groups who have been identified as having cognitive issues as a consequence of dementia, will mostly be from within local authorities, including Dorset County Council, Hampshire County Council and Portsmouth City Council. They will be contacted via a third party, for example a memory advisor, a member of DCC staff, someone from Age Concern Hampshire, or someone recommended by the Tele Advisory Group in Portsmouth. In a few instances they will be individuals with a dementia diagnosis who I have met through interactions at Dementia events or carers groups and have expressed a willingness to participate in my research. Any additional participants will be recruited through third parties, such as charities or support organisations.*

The 10-15 'key informants' will be a range of people whose professional roles give them particular insights into the development or delivery of telecare. These professionals will include policymakers, clinicians, technology developers, representatives from telecare manufacturers, Local Authority service managers and researchers. No blanket e-mails will be sent, these individuals will be specifically selected and contacted individually.

The 10 members of care staff, who will be interviewed, will be those working with participants in the DCC pilot study, they will be contacted via DCC. This will be done on a rolling basis. The members of staff to be shadowed will be recruited on a similar basis.

3.3 (M*) Describe the relationship between researcher and sample (*Describe any relationship e.g. teacher, friend, boss, clinician, etc.*)

There is no previous relationship between researcher and sample.

3.4 (M*) Describe how you will ensure that fully informed consent is being given: (*include how long participants have to decide whether to take part*)

Participants in the majority of cases will be approached through a third party, either a local authority or a charity, they will be given at least a month to decide whether they are willing to participate.

Every participant will be given an information sheet explaining the purpose of the research and how the data will be used. They will also be given a consent form to initial and sign, in order to confirm they are happy to participate and understand what is involved. In addition to this, a briefing will be given at the start of every focus group and interview; it will be made clear that anyone wishing to withdraw from the study, can do so at any point.

Both the consent form and the information sheet have been submitted in an attached document.

In the instance of the observational studies, I will ask the members of DCC staff to sign a consent form and then I will request that they seek verbal consent from the Pilot participant before I shadow the assessment.

Participants who have dementia will still be asked to sign a consent form and although it is recognised that the condition causes periods of confusion every effort will be made to ensure that the participant fully understands what the study involves. Only individuals with a diagnosis of the very early stages of dementia will be interviewed on their own; for example Mrs B who approached me at the event would like to speak to me on her own, and to contradict this and ask her to bring a carer, would undermine her independence. However, individuals experiencing greater levels of confusion will only be approached via their carer or a memory advisor. Therefore one or other will be present at the interview and able to act in the individual's best interests in line with the mental capacity act. They will also be able to reassure the individual and support them, so no distress is caused by the interview. I will be guided by the charity, local authority staff or the local carers' forum as to what stage of dementia the individual is experiencing.

Furthermore, when seeking informed consent every effort will be made to take into consideration the individual's particular needs. For example, in Mrs B's case, her dementia has had a direct impact on her vision, therefore it would be unrealistic to expect her to read the information sheet or the consent form. Therefore I will discuss the purpose of the study with her and read out the consent form in order to record her verbal consent on an audio recorder.

4. RESEARCH PROCEDURES, INTERVENTIONS AND MEASUREMENTS

4.1 (M*) Give a brief account of the procedure as experienced by the participant

(Make clear who does what, how many times and in what order. Make clear the role of all assistants and collaborators. Make clear total demands made on participants, including time and travel). Upload any copies of questionnaires and interview schedules to your submission in ERGO.

Each participant will be contacted a month prior to the focus group or interview and provided with information, explaining what it entails and how it will contribute to the overall research. Where appropriate this will also include an overview of the telecare equipment and what it is designed to do. In the case of current or potential service users with dementia, in certain instances they will be contacted via their carer or memory advisor, in which case initial consent to participate will be obtained via the third party. The invitation letters have been included in an attached document.

A venue will be selected for the convenience of the participants; as the researcher I have access to a car, so I am happy to travel. Travel times for participants will be kept to a minimum and where possible I will go to existing meeting places for participants contacted through charities or older persons groups. If there is not already an existing meeting place, then I will make arrangements to hold the focus groups in the local community centres.

The focus groups/ interviews will last between 1 - 2 hours and they will be recorded using an audio-recorder, which is mentioned on the consent forms.

Each session will begin with a brief introduction to the research. As part of the introduction I will ensure I have collected signed consent forms from all participants and check to make sure everyone is happy to continue and whether they have any questions before we begin. I will also seek all participants permission to use an audi-recorder, which will be switched on at the start of the interview/focus group.

The focus group/interview will then be based around a series of questions regarding the use of telecare to support independent living. The groups and one-to-one sessions will be semi-structured allowing additional questions to be included if they arise through the natural flow of conversation. At the end of the meeting I will debrief the participants and thank them for coming.

The interviews with DCC care staff will also follow a semi-structured format. They will be contacted by DCC directly and asked whether they would be willing to participate in either the interview or the observational work, or both, as part of the evaluation process for the pilot study. If they agree, a time, date and location will be arranged at their convenience and I will travel to meet them. The same briefing and debriefing procedure will be followed as with the focus groups. The questions will relate to the individual's perspective on telecare and whether they feel that the equipment is a useful tool for them and what they consider to be its main problems/benefits.

For the observational work I will follow the member of staff as they carry out their assessment of the individual, although I will be friendly and polite to the participant I will not seek to 'collect data' from them directly; my main goal will be to shadow the member of staff and build anonymous case studies of a few individuals taking part in the pilot.

5. STUDY MANAGEMENT

5.1 (M*) State any potential for psychological or physical discomfort and/or distress?

This study will not put participants through any physical discomfort and/or distress, nor is the study likely to cause psychological distress. However, I do recognise that asking questions regarding dementia or the care of someone with dementia can be distressing.

I also understand that some individuals may be unhappy about me shadowing members of DCC staff during their assessment. So I will ask the care worker to obtain the participants permission before we begin and I will remain mindful of this throughout.

5.2 (M*) Explain how you intend to alleviate any psychological or physical discomfort and/or distress that may arise? (if applicable)

If the discussion causes a participant emotional distress, I will either redirect the conversation or offer to end the session. However, I will endeavour to be as considerate and empathetic as possible, in order to avoid causing upset in the first instant.

If my presence during observational work causes distress I will look to the member of DCC staff for direction, but ultimately I will remove myself from the situation.

5.3 Explain how you will care for any participants in 'special groups' (*i.e. those in a dependent relationship, vulnerable or lacking in mental capacity*) (if applicable)?

*Amendment 2:

Interviews *or focus groups* with individuals who have dementia (potential or current service users), where appropriate, will be carried out in the presence of their carer, a member of care staff or a memory advisor. This will hopefully ensure they feel at ease and encourage conversation; therefore minimising the risk of distress. This will also mean, that if they lack the capacity to consent due to their state of confusion, they will have someone present to act in their best interests in line with the Mental Capacity Act (2005).

In addition, I will be using my experience of volunteering at a local care home to help me work with these particular participants.

5.4 Please give details of any payments or incentives being used to recruit participants (if applicable)?

Where possible I will try to ensure there are tea and coffee making facilities and some biscuits, to help people feel comfortable.

5.5 i) How will participant anonymity and/or data anonymity be maintained (if applicable)?

Two definitions of anonymity exist:

i) Unlinked anonymity - Complete anonymity can only be promised if questionnaires or other requests for information are not targeted to, or received from, individuals using their name or address or any other identifiable characteristics. For example if questionnaires are sent out with no possible identifiers when returned, or if they are picked up by respondents in a public

place, then anonymity can be claimed. Research methods using interviews cannot usually claim anonymity – unless using telephone interviews when participants dial in.

ii) Linked anonymity - Using this method, complete anonymity cannot be promised because participants can be identified; their data may be coded so that participants are not identified by researchers, but the information provided to participants should indicate that they could be linked to their data.

All the data that I record in the focus groups, interviews and observations will be coded and no identifiable data will be used in the shared work. On the whole the data I will be capturing will be opinion and will not be traceable back to one specific individual.

The data provided by DCC will be anonymised prior to handover, as will any data obtained from existing databases. This will be stored securely and "processed" prior to disclosure.

5.5 ii) How will participant confidentiality be maintained (if applicable)?

Confidentiality is defined as the non-disclosure of research information except to another authorised person. Confidential information can be shared with those who are already party to it, and may also be disclosed where the person providing the information provides explicit consent.

All participants in the study will be asked to complete a consent form, consenting to the disclosure of the research information for the purposes of this study.

5.6 (M*) How will personal data and study results be stored securely during and after the study? *Researchers should be aware of, and compliant with, the Data Protection policy of the University. You must be able to demonstrate this in respect of handling, storage and retention of data.*

The data will be stored on a secured, password protected PC in a small office. I will be the only one with access to the PC and at present only 2 other people share the office space, which is always kept locked when unattended.

5.7 (M*) Who will have access to these data?

I will be the only person with direct access to the raw data. My two supervisors Professor Sally Brailsford and Professor Maria Evandrou, will have access the anonymised data if required.

N.B. – Before you upload this document to your ERGO submission remember to:

1. Complete ALL mandatory sections in this form
2. Upload any letters of agreement referred to in question 3.1 to your ERGO submission
3. Upload any interview schedules and copies of questionnaires referred to in question 4.1

Appendix 2: University Ethics Approval

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The Use of Telecare for People with Dementia

Submission ID 2028

Submission Overview

IRGA Form

Attachments

History

Adverse Incident

Approved by the Ethics Committee in 12 days) on 26/09/2012

Date	Activity	Comments	Attached Documents
21/02/2014 8:53 am	Note added	Extension request approved providing there are no other changes to the protocol that may have ethical impact.	
15/10/2012 9:09 am	Note added	Please find attached the university insurance certificate.	Note attachment
26/09/2012 9:19 am	Reviewed and approved by the ethics committee		
17/09/2012 2:07 pm	Approved by supervisor and sent to ethics committee		
27/08/2012 11:39 pm	Submitted to supervisor Sally Braistford (scb)		
7/08/2012 4:40 pm	Revision requested by the ethics committee		
7/08/2012 4:40 pm	Possible problems were found by 1 member of the committee	Your risk form refers to physical observation/factory visits. I can't see to which of the data collection methods this refers. Could you please clarify on both the ethics and risk forms?	
3/08/2012 4:22 pm	Approved by supervisor and sent to ethics committee	No comments	
4/07/2012 6:36 pm	Submitted to supervisor Sally Braistford (scb)		
8/05/2012 1:52 pm	Research submission created		

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Appendix 3: Primary Symptoms and Causes of Different Dementia Subtypes

Primary Symptoms		Causes
Alzheimer's disease <i>First described in 1902 by a German doctor called Alois Alzheimer.</i>	Impaired memory, disorientation in terms of time, place and own person. Difficulties in communication and understanding, as well as possible visio-spatial deficits and personality change. The person may also become anxious, irritable or depressed. They may experience distress over their failure to manage everyday tasks.	Brain cells are attacked by abnormal protein deposits called 'amyloid plaques' and 'tau tangles'. Essential chemicals become reduced impacting the effectiveness of brain nerves and transmitters.
Vascular dementia	The symptoms of vascular dementia vary depending on which parts of the brain become damaged, they may overlap with those of Alzheimer's disease. They commonly include: Poor concentration and communication; along with physical symptoms such as paralysis or weakness in limbs; apathy, mood swings, anxiety, and depression.	Problems with circulation of blood to the brain resulting in oxygen deprivation. If oxygen supply fails, brain cells die. Associated with stroke, high blood pressure, diabetes and heart problems.
Dementia with Lewy Bodies <i>First discovered in 1912 by Frederick Lewy, a colleague of Alois Alzheimer.</i>	Hallucinations, spatial disorientation, impaired recent memory and fluctuations in mental performance. The person may also experience repeated falls, sleep disturbances and find they experience increased problems with handling daily tasks. At least two thirds of people with Lewy Bodies dementia develop movement problems at some point.	The gradual build-up of protein structures, referred to as Lewy Bodies, in the nerve cells located in the mid brain.

<p>Frontotemporal dementia</p>	<p><i>Behavioural variant Frontotemporal Dementia (also known as Pick's):</i></p> <p>Changes in personality and behaviour. Emotional dysfunction. Individuals begin to behave differently, some become withdrawn, some lose their inhibitions and others can become aggressive.</p> <p><i>Primary progressive aphasia:</i></p> <p>Language difficulties; speech; grammar problems; reduced comprehension; loss of understanding of familiar words; difficulty recognising people or objects.</p> <p>During the early stages of frontotemporal dementia, memory of recent events may be unaffected.</p>	<p>Damage to the brain in the frontal and temporal lobes. The deterioration is linked to abnormally forming proteins that interfere with communication between brain cells; causing nerve cells in the brain die and the nerve pathways to break down. The precise location of the initial damage influences the early symptoms.</p>
<p>Parkinson's disease dementia</p> <p><i>Around one third of people diagnosed with Parkinson's disease ultimately develop Parkinson's disease dementia.</i></p>	<p>Shares the same symptoms as dementia with Lewy Bodies; with symptoms becoming increasingly similar as the condition progresses.</p>	<p>Parkinson's disease causes damage in the brain in a region that plays a key role in movement. This damage is caused by the build-up of deposits called Lewy Bodies. As the disease gradually spreads, the changes in the brain begin to affect mental functions.</p>
<p>Other dementias include:</p>	<p><i>There are many other diseases that can lead to dementia. Including: Korsakoff's Syndrome; Posterior Cortical Atrophy; HIV-associated dementia; corticobasal degeneration, progressive supranuclear palsy, Niemann-Pick disease type C, Gaucher's disease, Tay Sach's disease and Creutzfeldt-Jakob disease (CJD). These are rare and tend to be more prevalent among younger people with dementia (under the age of 65).</i></p>	

Source: Adapted from Stephan and Brayne (2010) and Alzheimer's Society (2016d)

Appendix 4: Risk Factors for Developing Dementia

Risk factor	Reason/Rationale
Age	The chances of developing dementia rises significantly as we get older; 45% of those over the age of 95 have dementia (Brayne <i>et al.</i> , 2006)
Gender	<p>Dementia is more prevalent among women, even when taking into account the higher longevity of women versus men. The reasons for this remain unclear (Alzheimer's Society, 2017b). It has been suggested that men who survive to advanced ages may be more resistant against dementia (Fratiglioni <i>et al.</i>, 1997). Potential links have been made between traditional gender roles and a greater cognitive reserve amongst men; with men traditionally being more likely to work and reach higher levels of education than women. Lower educational level has been cited as a possible risk factor for Alzheimer's disease (Cummings <i>et al.</i>, 1998; Hall <i>et al.</i>, 2007; Meng and D'Arcy, 2012). The concept of 'cognitive reserve' is discussed in more detail later in this section.</p> <p>The higher prevalence amongst women has also been linked to a drop in the level of the hormone oestrogen following the menopause. Older men have been found to have slightly higher levels of the hormone than older women, which could act as a protective factor (Hamblin <i>et al.</i>, 2013).</p> <p>Furthermore, Stanford University School of Medicine reported in 2014 that there may also be genetic factors influencing the prevalence of dementia amongst women (Altmann <i>et al.</i>, 2014). They suggested that women who carry the APOE-E4 gene are significantly more likely to develop the disease than men who have the same gene (Altmann <i>et al.</i>, 2014).</p> <p>In contrast, men are at a slightly higher risk than women for developing vascular dementia; this is because men are more prone to stroke and heart disease, which can lead to vascular and mixed dementia (Alzheimer's Society, 2017b). For most other dementias, men and women have much the same risk (Alzheimer's Society, 2017b).</p>
Lower levels of education in women, and smoking in men	Launer <i>et al.</i> (1999) conducted a pooled analysis in Europe of four population-based prospective studies of 'individuals 65 years and older, with 528 incident dementia patients and 28,768 person-years of follow-up' (P. 78). In addition to age and female gender, they also found that current smoking (particularly in men), and lower levels of education (particularly in women), significantly increased the risk of developing Alzheimer's disease (Launer <i>et al.</i> , 1999).
Moderate to severe head injuries in young men	Plassman <i>et al.</i> (2000) suggested that moderate and severe head injuries in young men may also be associated with an increased risk of developing dementia in later life. However, the strength of this

	association remains unproven (Hamblin <i>et al.</i> , 2013), with other papers producing findings to the contrary (Launer <i>et al.</i> , 1999).
Conditions that cause damage to the heart, arteries, or blood circulation	<p>There is growing recognition in the literature, that conditions that cause damage to the heart, arteries or blood circulation can increase the risk of a person developing not only vascular dementia, but also Alzheimer's disease (Lis and Gaviria, 1997) . These cardiovascular factors include hypertension, diabetes mellitus, smoking and heart disease (Van der Flier and Scheltens, 2005). In turn, these risk factors are linked to lifestyle choices.</p> <p>Any activities that promote better cardiovascular health will therefore reduce the risk of developing dementia. For example: physical exercise; not smoking; only drinking alcohol in moderation; and maintaining a healthy diet and weight (Alzheimer's Society, 2017b).</p>
Reserve capability	<p>Keeping mentally active builds up cognitive reserve and is thought to have a buffering effect against cognitive decline (Hamblin <i>et al.</i>, 2013). Cognitive reserve or 'active reserve', refers to a person's ability to make more efficient use of their pre-existing brain networks as a means of compensating in order to maintain normal function (Stern, 2009). Xu <i>et al.</i> (2015) describe the five primary sub categories of cognitive reserve including:</p> <ul style="list-style-type: none"> • Educational background • Occupational experience • General intelligence • Leisure activity • Environmental enrichment
Passive/brain reserve	<p>Passive/brain reserve relates to brain size or neuronal count (Stern, 2009). The degree of damage to the brain does not always directly correspond to the severity of the manifestation (Stern, 2009). For instance, someone with a larger than average brain may be able to sustain a greater amount of brain deterioration before reaching the critical threshold that results in observable symptoms (Stern, 2009). In 1989, Katzman <i>et al.</i> reported 10 cases of older people with normal cognitive performance, who were found to have advanced Alzheimer Disease (AD) pathology in their brains at death (Katzman <i>et al.</i>, 1989).</p>

Sources: Various (see text for specific references)

Appendix 5: Alzheimer's Disease Cooperative Study Activities of Daily Living Inventory (ADCS-ADL) Assessment Questionnaire

Alzheimer's Disease Cooperative Study Activities of Daily Living Inventory (ADCS-ADL) Questions:

1. Regarding eating: Which best describes subjects usual performance during the past 4 weeks?

- Ate without physical help
- Used a fork or spoon, but not a knife to eat
- Used fingers to eat
- Usually or always was fed by someone else

2. Regarding walking (or getting around in a wheelchair), in the past 4 weeks, which best describes his/her optimal performance:

- Mobile outside of home without physical help
- Mobile across a room without physical help
- Transferred from bed to chair without help
- Required physical help to walk or transfer

3. Regarding bowel and bladder function at the toilet, which best describes his/her usual performance in the past 4 weeks:

- Did everything necessary without supervision or help
- Needed supervision, but no physical help, and was usually continent
- Needed physical help, and was usually continent
- Needed physical help, and was usually incontinent

4. Regarding bathing, in the past 4 weeks, which best describes his/her usual performance:

- Bathed without reminding or physical help
- No physical help, but needed supervision/reminders to bathe completely
- Needed minor physical help (e.g., with washing hair) to bathe completely
- Needed to be bathed completely

5. Regarding grooming, in the past 4 weeks, which best describes his/her optimal performance:

- Cleaned and cut fingernails, without physical help
- Brushed or combed hair without physical help
- Kept face and hands clean without physical help
- Needed help for grooming of hair, face, hands, and fingernails

6a. Regarding dressing, in the past 4 weeks: Did subject select his/her first set of clothes for the day?

Yes / No / don't know

If Yes, which best describes his/her usual performance:

- Without supervision or help
- With supervision
- With physical help

6b. Regarding physically getting dressed, which best describes his/her usual performance in the past 4 weeks: (check one)

- Dressed completely without supervision or physical help
- Dressed completely with supervision, but without help
- Needed physical help only for buttons, clasps, or shoelaces
- Dressed without help if clothes needed no fastening or buttoning
- Always needed help, regardless of type of clothing
- Don't know

7. In the past 4 weeks, did subject use a telephone

Yes / No / don't know

If Yes, which best describes his/her highest level of performance:

- Made calls after looking up numbers in white or yellow pages, or by dialing directory assistance
- Made calls only to well-known numbers without referring to a directory, list, or preprogrammed numbers
- Made calls only to well-known numbers by using a directory or list
- Answered the phone; did not make calls
- Did not answer the phone, but spoke when put on the line

8. In the past 4 weeks, did subject watch television?

Yes / No / don't know

If Yes, ask each of the following:

- Did subject usually select or ask for different programs or his/her favourite show?
Yes / No
- Did subject usually talk about the content of a program while watching it? **Yes / No**
- Did subject talk about the content of a program within a day (24 hours) after watching it? **Yes / No**

9. In the past 4 weeks, did subject ever appear to pay attention to conversation or small talk for at least 5 minutes? (note subject did not need to initiate the conversation)

Yes / No / don't know

If Yes, which best describes his/her usual degree of participation:

- Usually said things what were related to the topic
- Usually said things that were not related to the topic
- Rarely or never spoke

10. Did subject clear the dishes from the table after a meal or snack?

Yes / No / don't know

If Yes, which best describes how he/she usually performed:

- Without supervision or help
- With supervision
- With physical help

11. In the past 4 weeks, did subject usually manage to find his/her personal belongings at home?

Yes / No / don't know

If Yes, which best describes how he/she usually performed:

- Without supervision or help
- With supervision
- With physical help

12. In the past 4 weeks, did subject obtain a hot or cold beverage for him/herself?

Yes / No / don't know

If Yes, which best describes his/her highest level of performance:

- Made a hot beverage, usually without physical help
- Made a hot beverage, usually if someone else heated the water
- Obtained a cold beverage, usually without physical help

13. In the past 4 weeks, did subject make him/herself a meal or snack at home?

Yes / No / don't know

If Yes, which best describes his/her highest level of performance:

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- Cooked or microwaved food, with little or no help
- Cooked or microwaved food, with extensive help
- Mixed or combined food items for a meal or snack, without cooking or microwaving (e.g., made a sandwich)

14. In the past 4 weeks, did subject dispose of garbage or litter in an appropriate place or container at home?

Yes / No / don't know

If Yes, which best describes how he/she usually performed:

- Without supervision or help
- With supervision
- With physical help

15. In the past 4 weeks, did subject get around (or travel) outside of his/her home?

Yes / No / don't know

If Yes, which best describes his/her optimal performance:

- Alone, went at least 1 mile away from home
- Alone, but remained within 1 mile of home
- Only when accompanied and supervised, regardless of the trip
- Only with physical help, regardless of the trip

16. In the past 4 weeks, did subject ever go shopping?

Yes / No / don't know

If yes, ask A and B

A) Which one best describes how subject usually selects items?

- Without supervision or physical help
- With some supervision or physical help
- Not at all, or selected mainly random or inappropriate items

B) Did subject usually pay for items without supervision or physical help?

- Yes
- No

17. In the past 4 weeks, did subject keep appointments, meetings with other people, such as relatives, a doctor, the hairdresser, etc.?

- Usually remembered, may have needed written reminders, e.g., notes, a diary, or calendar

- Only remembered the appointment after verbal reminders on the day
- Usually did not remember, in spite of verbal reminders on the day

18. In the past 4 weeks, was subject ever left on his/her own?

Yes / No / don't know

If yes, ask all questions:

Was subject left:

- away from home for 15 minutes or longer, during the day? **Yes / No**
- at home for an hour or longer, during the day **Yes / No**
- at home, for less than 1 hour during the day **Yes / No**

19. In the past 4 weeks, did subject talk about current events? (This means events or incidents that occurred during the past month.)

Yes / No / don't know

If yes, ask all questions:

Did subject talk about events that...

- he/she heard or read about or saw on TV but did not take part in? **Yes / No**
- he/she took part in outside home involving family, friends, or neighbors? **Yes / No**
- events that occurred at home that he/she took part in or watched **Yes / No**

20. In the past 4 weeks, did subject read a magazine, newspaper or book for more than 5 minutes at a time?

Yes / No / don't know

If yes, ask all questions:

Did subject usually:

- talk about details of what he/she read while or shortly (less than 1 hour) after reading?
Yes / No
- talk about what he/she read 1 hour or longer after reading? **Yes / No**

21. In the past 4 weeks, did subject ever write things down?

Yes / No / don't know

Note: if subject wrote things only after encouragement or with help, the response should still be 'Yes'.

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If yes, which best describes the most complicated things that he/she wrote:

- Letters or long notes that other people understood
- Short notes or messages that other people understood
- His/her signature or name

22. In the past 4 weeks, did subject perform a pastime, hobby, or game?

Yes / No / don't know

If yes, how did subject usually perform his/her most common pastimes:

- Without supervision or help
- With supervision
- With help
- If subject performs hobbies/pastimes only at day care, check here

23. In the past 4 weeks, did subject use a household appliance to do chores?

Examples include washer, dryer, vacuum, dishwasher, toaster, toaster oven, range, microwave, food processor

Yes / No / don't know

If yes, for the most commonly used appliances, which best describes how subject usually used them:

- Without help, operating more than on-off controls if needed
- Without help, but operated only on-off controls
- With supervision, but no physical help
- With physical help

TOTAL ADCS-ADL:

(ADCS-ADL maximum score = 30)

- **24 - 30** normal, depending on age, education, complaints
- **20 - 23** mild
- **10 - 19** moderate
- **1 - 9** severe
- **0** profound

Appendix 6: Kahle-Wroblewski *et al.*'s (2015) Summary Statistics by Level of Dependence

Level	Number of Patients (% Total Sample)	MMSE Mean (95% CI)	ZBI Mean (95% CI)	NPI Mean (95% CI)	EQ-5D (Proxy-Reported) Mean (95% CI)	Caregiver Time/Month (hr) Mean (95% CI)	Patient Medical Costs (Monthly) (€) (mean) (95% CI)	Total Societal Costs (Monthly) (€) (Mean) (95% CI)
0	10 (0.7%)	23.3 (21.8 - 24.8)	12 (8.4- 15.6)	4.1 (-0.1 - 8.3)	0.8 (0.62 - 0.98)	8.6 (-2.5 - 19.7)	1179 (-1038 - 3395)	1437 (-1036 - 3910)
1	35 (2%)	23.2 (22.2- 24.2)	15 (12.4- 17.7)	3.7 (2.7 - 4.8)	0.8 (0.76 - 0.84)	37.5 (19.5 - 55.6)	295 (96 - 493)	881 (559 - 1204)
2	443 (30%)	20.8 (20.5- 21.2)	22.1 (20.9- 23.3)	9.2 (8.3 - 10.1)	0.75 (0.73 - 0.77)	74.2 (64.2 - 84.2)	311 (227 - 395)	1091 (969 - 1212)
3	382 (26%)	18.3 (17.8- 18.8)	30.6 (29.1- 32.1)	14.5 (13.2 - 15.9)	0.67 (0.64 - 0.69)	177.5 (159.7 - 195.3)	353 (267 - 439)	1762 (1577 - 1946)
4	516 (34%)	14.8 (14.2- 15.3)	33.8 (32.6- 35.1)	19 (17.6 - 20.4)	0.53 (0.50 - 0.56)	276 (259.1 - 292.8)	412 (307 - 516)	2685 (2455 - 2915)
5	111 (7%)	10.1 (8.6- 11.5)	35.2 (32.2- 38.1)	27.6 (23.3 - 32.0)	0.35 (0.28 - 0.42)	349 (310.4 - 388.4)	616 (241 - 992)	3725 (3065 - 4386)
	<i>p value:</i>	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001

Source: Kahle-Wroblewski *et al.* (2015)

Appendix 7: Types of Telecare Equipment

The list of telecare equipment presented below provides a summary of the current available equipment deemed to be of benefit for someone with dementia.

Overview of the Types of Telecare Equipment Widely Available to Local Authorities in 2017

Device	Description
Home unit	Central to the entire system, the home unit connects all the other telecare sensors to the monitoring centre. It usually connects to a landline and a power supply; although a growing number of telecare services operate on mobile phones.
Personal alarm	Allows the service user to summon help by pushing a portable button (usually supplied as a pendant, belt clip or on a wrist strap) or pulling a ceiling mounted cord.
Activity monitors also referred to as lifestyle monitoring equipment	Sensors are positioned around the home enabling the remote assessment of daily activities. For example, a sensor in the kitchen will provide insight into whether a person is preparing meals regularly; whereas a sensor near the front door will detect if the person is leaving the house at night. They also detect changes in movement patterns indicating that assistance may be required. For instance, if no movement is detected for a long period an alert will be sent to the monitoring centre and assistance will be called for in case the person has fallen or is unwell. The sensors do not take images or use video, they are passive infra-red detectors (PIR) which can only pick up movement.
Fall detectors	A device is worn by the service user and automatically initiates an emergency alert if the individual experiences a fall. Lying on a cold floor for any length of time can lead to a deterioration in a person's health. This can lead to the development of serious health conditions and consequently admission to hospital.
Flood detectors	Raises an alert if water is detected above a certain level on the floor, indicating that perhaps a bath has overflowed or pipe has burst.
Gas detectors	Sounds an audible local alarm and sends an alert to the monitoring centre if dangerous levels of gas are detected. A gas leak can cause headaches, sickness and dizziness but it can also be fatal. Someone with dementia, may not know how to respond to the local alarm, which is why the alert sent to the monitoring centre is crucial. The monitoring centre staff can then decide the appropriate response.
Carbon Monoxide detector	As above, but for detecting Carbon Monoxide.
Smoke detector	As above, but for detecting smoke.

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Gas shut-off valves	The risk of forgetting to light a gas ring or a gas fire increases when people experience cognitive impairment. Gas shut-off valves physically cut off the gas supply when triggered by a gas detector sensor connected to a telecare control box. A key operated switch on the control box is used to switch the gas supply back on when the reason for the leak has been investigated. These shut off valves would be fitted only by registered Corgi fitters.
Extreme temperature detectors	Detects extreme changes in temperature. A rapid rise in temperature may indicate a fire, whereas a drop in temperature could pose the risk of hypothermia to the individual.
Medication reminders and dispensers	Provides an audible and visual alert to remind the user to take their medication. As the telecare system only dispenses the tablets at the correct pre-set time, the risk of repeating a dose in error is greatly reduced. If the tablets are not accessed an alert is sent to the monitoring centre or carer so that action can be taken to ensure the medication programme is maintained.
Enuresis sensors	Placed between bedding and the mattress it provides an early warning for service users who are prone to incontinence whilst sleeping.
Property exit sensors	Alerts the monitoring centre and/or carer when an individual leaves their property or if the front door is left open. These sensors can be helpful if the person is disorientated or confused when they leave home, or if they sometimes go out at inappropriate times during the day or night. The exit sensors can be set to work at certain time of day, during night time hours for example.
Bed occupancy sensors	A pressure sensitive mat is placed under the mattress. If the service user gets out of bed during the night and fails to return after a predefined time, an alarm is raised. An occupancy sensor can also be programmed to switch lights on and off which can be a very important aid when getting in and out of bed.
Chair occupancy sensors	Operates like the bed sensor, alerting a carer that the user has got out of their chair and therefore may be at risk.
Bogus caller devices	Elderly and vulnerable people living alone can often be targets of crime and a bogus caller button may help to reduce anxiety for both the service user and the carer. Sometimes referred to as a panic button, it is designed to be located by the front door and enables the monitoring centre to reassure the service user and allows them to monitor the conversation between the resident and the visitor to ensure the user's safety. Police services may issue these buttons for people who they consider to be at risk.
Safe walking technology	Devices that are able to locate the service user, usually through GPS functionality, helping carers to find the user quickly if they become lost due to wandering behaviour.

Source: Disabled Living Foundation Website (2017) and Telecare Service Association Website (2013)

Appendix 8: The Whole Systems Demonstrator Programme

The Whole Systems Demonstrator (WSD) Programme launched in May 2008. It was established as a large scale randomised control trial (RCT), which included 6191 patients and 238 GP practices across three sites: the London Borough of Newham; Kent; and Cornwall. Participants for the telecare component of the trial were selected using the Fair Access to Care Services criteria; a total of 2,600 people were recruited from 217 general practices across the three pilot study locations. Individuals with either diabetes, heart failure or COPD were selected for the telehealth trial. It was hailed as being the largest RCT of telecare and telehealth in the world (Bower *et al.*, 2011). It was described by Charles Lowe, Contributing Editor at Telehealth & Telecare Aware, as being ‘pioneering’ and ‘visionary’ at its outset (Lowe, 2013).

Each of the three pilot study sites were free to design and implement their own telecare systems; however, all participants were provided with a Tunstall Lifeline Connect or Connect+ base unit together with a pendant alarm, and up to 27 peripheral devices, assigned by local teams. The devices could be divided into four broad categories: ‘personal health and well-being sensors’, such as fall detectors, medication dispensers, bed/chair occupancy sensors, and enuresis sensors; ‘safety and security aids’, such as property exit sensors, and bogus called buttons; ‘environmental monitoring sensors’, including gas, heat and smoke detectors; and finally, what the programme described as ‘sensory impairment aids’, which included stand-alone devices, such as key safes, memo minders and big button phones (Bower *et al.*, 2011).

The telecare service was then compared with ‘usual care’; which was the term used to describe the existing range of health and social care services available in the three areas. The participants were followed up for 12 months, and analysis of outcomes focused on the proportion of people admitted to hospital within that timeframe (Newman *et al.*, 2014). Secondary outcomes that were considered included: rates of secondary care use; contact with general practitioners and practice nurses; proportion of people admitted to permanent residential or nursing care; and weeks in domiciliary social care. Calculations of associated costs were also made (Steventon *et al.*, 2012).

Initial headline findings from the programme, released in December 2011 (Department of Health, 2011b) showed positive results:

“The early indications show that if used correctly telehealth can deliver a 15% reduction in A&E visits, a 20% reduction in emergency admissions, a 14% reduction

in elective admissions, a 14% reduction in bed days and an 8% reduction in tariff costs. More strikingly they also demonstrate a 45% reduction in mortality rates.”

(Department of Health, 2011b, p. 3)

These findings led to the Department of Health launching the ‘3millionlives’ Campaign, in collaboration with partners from industry, the NHS, social care, and other professional bodies; with the view that at least three million people with long term conditions and/or social care needs could benefit from using telehealth and telecare (Department of Health, 2011b).

However, there was little mention of telecare in this preliminary report and when results were eventually released in later peer reviewed publications, they were heavily caveated. Steventon *et al.*’s (2013) paper, ‘Effect of telecare on use of health and social care services: findings from the Whole Systems Demonstrator cluster randomised trial’, stated that, ‘telecare did not significantly alter the rates of health or social care service use or mortality among the participant population, over the 12-month trial period’ (Steventon *et al.*, 2013, p. 506). While Henderson *et al.* (2013a) concluded that second-generation telecare did not appear to be a cost-effective addition to ‘usual care’.

Newman *et al.* (2014) suggested that the telecare deployed in the programme did not result in a statistically significant impact on carer burden or an improvement in quality of life, nor did the study design allow for sufficient evidence to be collected to identify changes in self-care behaviour. Nonetheless, the results did indicate that telecare has a role to play in limiting decline for both the service users and their carers (Hirani *et al.*, 2014).

The main implication from the publications that followed was that evaluating telecare had been far more challenging than expected. The programme had tried to address the shortcomings of previous research that had relied on small pilot studies and anecdotal evidence by utilising robust evaluation standards on a large scale. However, instead, the programme ended up highlighting the complexities of this area of research, and put further emphasis on the need for greater exploration and organisational change in order for telecare to become a mainstream service.

Appendix 9: Key Policy Statements and Initiatives for Telecare 1998 - 2006

Initiative	Objective
An Information Strategy for the Modern NHS 1998 - 2005 (Burns, 1998)	Offered a broad evaluation of the role of Information and Communication Technologies (ICTs) in a modern health service. Also stated: <i>“Telecare technology will be used to provide a reliable but unobtrusive supervision of vulnerable people who want to sustain an independent life in their own home”.</i> (NHS Executive, 1998. P. 15)
Royal Commission on Long Term Care (Sutherland, 1999)	Considered options for long-term care of elderly people, both in their homes and other settings. Highlighted the domestic potential of AT and telecare.
National Service Framework for Older People (Department of Health, 2001)	Sets new national standards and service models of care across health and social services for all older people. It recommended that community based services should include telecare and environmental technologies.
Assistive Technology - Independence and Wellbeing Report (Audit Commission, 2004)	Examines AT and in particular telecare in its policy context; describes the current evidence to demonstrate how the technology can support independence; analyses obstacles to progress and explains how changes can be introduced. Noted the British Department of Health's target of increasing the presence of telecare in people's homes by 2010.
Building Telecare in England (Department of Health, 2005a)	Provides local authorities and their partners with guidance on developing telecare services for their communities. It sets out the purpose of the Preventative Technology Grant and expectations for the use of the grant.
Wanless Social Care Review - Securing Good Care for Older People (Wanless <i>et al.</i> , 2006)	Sir Derek Wanless was commissioned in 2005 to conduct a yearlong review examining the long-term trends that would affect the demand for social care services for older people and to consider the resources required to provide comprehensive, high-quality care. Chapter 9 of the review examined the role of telecare and concluded that: <i>“Enough lessons have been learned from pilot studies that the emphasis should now shift to moving telecare into the mainstream.”</i> (P. 153)
Telecare and Older People (Poole, 2006) <i>Background paper released as part of the Wanless Social Care Review</i>	Provides further background information for Chapter 9 of 'Securing Good Care for Older People' (Wanless <i>et al.</i> , 2006). It discusses the purpose of telecare; the evidence base; it considers the acceptability of telecare for older people; and also looks at modelling the impact of telecare as a care service.

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Everybody's business: integrated mental health services for older adults: a service development guide (Care Services Improvement Partnership, 2005)	This guide aimed to build on the service models outlined in the National Service Framework for Older People (2001) and included reference to the role of telecare.
Dementia: Supporting people with dementia and their carers in health and social care (National Institute for Clinical Excellence and Social Care Institute for Excellence, 2006)	Guidelines covering preventing, diagnosing, assessing, and managing dementia in health and social care, and includes recommendations on Alzheimer's disease. It recommends that this document should be used alongside the Department of Health's publication ' <i>Everybody's business. Integrated mental health services for older adults: a service development guide</i> ' (Care Services Improvement Partnership, 2005) as a framework for the implementation of assistive technology and telecare.

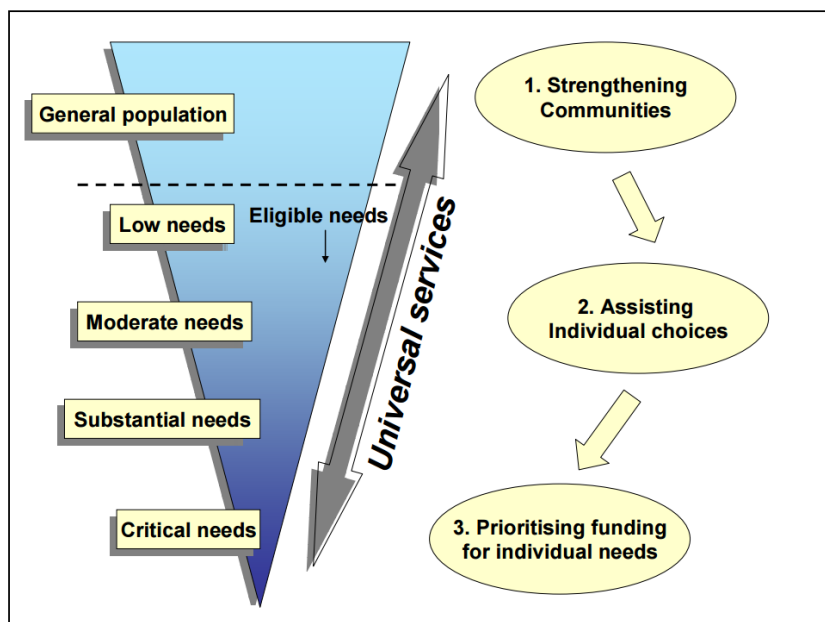
Source: Barlow et al. (2007) and Roulstone et al., (2013b)

Appendix 10: Guidance on Eligibility Criteria for Adult Social Care

Adapted from the Department of Health's 2010 Best Practice document entitled:

'Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care Guidance on Eligibility Criteria for Adult Social Care, England 2010'.

In general, councils may provide community care services to individual adults with needs arising from physical, sensory, learning or cognitive disabilities, or from mental health needs. The eligibility framework is graded into four bands, which describe the seriousness of the risk to independence and well-being or other consequences if needs are not addressed.



Critical Need is when:

- life is, or will be, threatened; and/or
- significant health problems have developed or will develop; and/or
- there is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- serious abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out vital personal care or domestic routines; and/or
- vital involvement in work, education or learning cannot or will not be sustained; and/or
- vital social support systems and relationships cannot or will not be sustained; and/or

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- vital family and other social roles and responsibilities cannot or will not be undertaken.

Substantial Need is when:

- there is, or will be, only partial choice and control over the immediate environment; and/or
- abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or
- involvement in many aspects of work, education or learning cannot or will not be sustained; and/or
- the majority of social support systems and relationships cannot or will not be sustained; and/or
- the majority of family and other social roles and responsibilities cannot or will not be undertaken.

Moderate Need is when:

- there is, or will be, an inability to carry out several personal care or domestic routines; and/or
- involvement in several aspects of work, education or learning cannot or will not be sustained; and/or
- several social support systems and relationships cannot or will not be sustained; and/or
- several family and other social roles and responsibilities cannot or will not be undertaken.

Low Need is when:

- there is, or will be, an inability to carry out one or two personal care or domestic routines; and/or
- involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or
- one or two social support systems and relationships cannot or will not be sustained; and/or
- one or two family and other social roles and responsibilities cannot or will not be undertaken.

Appendix 11: Examples of How Telecare Can Help to Address Some of the Specific Care Needs of People with Dementia

The following table provides examples to demonstrate how telecare can benefit someone with dementia and their carer.

The Benefits of Telecare for Meeting the Challenges Posed by Dementia

Challenge Posed by Dementia	How Telecare Can Assist
<u>Poor Medication Compliance:</u> Remembering to take medication or remembering that it has already been taken can be a serious issue for people with dementia experiencing memory problems.	Medication dispensers can improve medication compliance (Curry and Norris, 1997) and reduce the potential for under or over dosing on tablets (Ross <i>et al.</i> , 2009). Ross <i>et al.</i> (2009) concluded that improved medication management reduces hospital admissions and GP visits along with long term conditions brought about by poor medication compliance.
<u>Increased Risk of Falls:</u> The risk of falling is thought to be 3-5 times higher for people with dementia (Tinetti <i>et al.</i> , 1988; Van Doorn <i>et al.</i> , 2003; Milisen <i>et al.</i> , 2007). Research suggests that dementia affects tandem gait, stride frequency and length, as well as increasing the tendency to wander, all of which increase the risk of falling (Nakamura <i>et al.</i> , 1996). Nakamura <i>et al.</i> (1996) also found that the severity of dementia correlated with the number of falls. Declining muscle function in old age reduces a person's ability to get themselves up; lying on the floor for a long time is one of the most serious consequences of falling (Fleming and Brayne, 2008). The inability to get up from a fall, even when no serious injury has occurred, is associated with an increased risk of hospitalisation, nursing home placement and even death (Tinetti <i>et al.</i> , 1993). It increases the risk of pressure sores (often exacerbated by unavoidable incontinence), carpet burns, dehydration, hypothermia and pneumonia (Tinetti <i>et al.</i> , 1993).	Fall detectors can mitigate the risks of spending a prolonged period on the floor following a fall. Although telecare equipment cannot prevent a fall or the injuries that such an incident might cause, it can passively send out a call for help to elicit a timely response.
<u>Risks Posed by Cooking:</u> Cooking is important to ensure that the person gets the nutrition they require. Furthermore, 'a move away from traditional food purchase and preparation can deny the service user the opportunity to participate in activities such as shopping, peeling and cutting that are Activities of Daily Living that need to be maintained to ensure that an adequate Quality of Life is achieved' (Dunk and Doughty,	Gas detectors, extreme temperature sensors, and gas shut off valves can be used to reduce the risks of cooking at home. The Aztec Project (Dunk and Doughty, 2006) trialled telecare for improving cooking safety and found that these approaches were very successful in preventing serious accidents and gaining carer and care worker confidence in the technology

<p>2006, p. 5). People with dementia may omit certain steps when cooking at home, such as switching off the gas or turning off electric hobs.</p>	
<p><u>Safe Walking:</u> It has been recognised that walking, as a form of exercise can be beneficial to a person with dementia (Heim, 1986; Cohen-Mansfield and Werner, 1998; Heyn <i>et al.</i>, 2004; Marshall and Allan, 2006). Walking can increase fitness, improve cognitive function, enhance positive behaviour (Heyn <i>et al.</i>, 2004), improve circulation, and promote more regular sleep patterns (McCurry <i>et al.</i>, 2005). Olsson <i>et al.</i> (2013) found that independent outdoor activities contributed to sense of self-worth and wellbeing.</p> <p>However, dementia can impact on communication and ‘way-finding’ abilities (Bartlett, 2015). If a person with dementia is away from the home and becomes disorientated and lost it can be very distressing for them, as well as incredibly worrying for the person’s family. Furthermore, it can be costly for the police, if they are called out to search for them (Bartlett, 2015). Sadly, 50% of people with dementia who are missing for more than 24 hours die or are seriously injured (Bartlett, 2015). ‘The risk of patients with dementia getting lost is substantial and requires frequent intervention by caregivers. This risk is a major reason for institutionalisation.’ (McShane <i>et al.</i>, 1998a, p. 253).</p>	<p>GPS enabled devices use satellites to provide specific information on a person’s location (Miskelly, 2005); therefore they can enable a person to continue to go out for walks, while managing the risk of them becoming lost. By enabling people with dementia to maintain or take up forms of gentle exercise, such as walking, telecare can help to maintain or improve the physical and mental health of the individual. Carers in Bantry White <i>et al.</i>’s (2010) study reported that the technology enhanced independence for themselves and for the person with dementia.</p> <p>GPS technology for dementia care divides ethical opinion, with some seeing it as an infringement on a person’s privacy, autonomy, and civil liberties (Robinson <i>et al.</i>, 2007; O’Neill, 2013). Proponents of the technology feel that it provides a means for maintaining a person’s safety and managing risk (Hughes and Louw, 2002; Bail, 2003; Miskelly, 2004; McShane, 2013), while also offering reassurance to carers (Robinson <i>et al.</i>, 2007; White <i>et al.</i>, 2010).</p>
<p><u>Wandering Behaviour:</u> As dementia progresses, people may become increasingly restless and feel a desire to walk around; in clinical publications, this is often referred to as ‘wandering’</p>	<p>In instances, where it is no longer sufficiently safe for the person with dementia to go out alone, a property exit sensor may be appropriate. This is an unobtrusive device which raises an alert if the person leaves the house. The system can be set up to operate at night and can raise the alarm if the person exits at an unusual time of day or if the person leaves the property for longer than normal. This reduces the risk to the person with dementia and it may enable their carer to sleep at night, as they will not be constantly on edge.</p>

<p><u>Early Detection:</u> As mentioned in Chapter 2, four out of the five of the most common comorbidities that result in a hospital admission for someone with dementia are preventable (Scrutton and Brancati, 2016) and could be mitigated through simple measures such as: closer monitoring and regular reviews (Van Doorn et al., 2003).</p>	<p>Telecare, such as Lifestyle Monitoring Equipment, can help maintain a person's health through the early detection of signs of deterioration (Bayer <i>et al.</i>, 2007); this enables accelerated diagnosis and treatment (Wright, 1998). Through monitoring patterns of behaviour, a carer or care worker can detect if a person is eating and drinking regularly by patterns of kitchen use, sleeping regularly by monitoring bedroom access, and even whether they may be developing a urinary tract infection by frequency of bathroom visits. Using this information can enable early intervention, potentially avoiding hospital admission and deferring institutional care.</p>
<p><u>Assessment:</u> People with dementia cannot necessarily express their ability to complete daily tasks. This may be due to a lack of insight or because of communication difficulties. If they are assessed in hospital they may be distressed and disorientated, and therefore unable to convey how they cope within their familiar surroundings. Passive monitoring provides the person with a voice and facilitates the assessment process.</p>	<p>Lifestyle Monitoring equipment can also assist care workers when making assessments, helping them to identify needs, and consequently to plan suitable care packages (Roworth-Gaunt <i>et al.</i>, 2009; Schneider <i>et al.</i>, 2010). The equipment enables carers to feel they can respond quickly in a crisis (Schneider <i>et al.</i>, 2010). The use of passive sensors for lifestyle monitoring means that people can be discharged from hospital earlier and observed in their own home (Curry and Norris, 1997).</p>

Sources: Various (see text for specific references)

Appendix 12: Ethical Considerations

The use of telecare involves various ethical considerations, particularly when it is being used for people with cognitive impairments. It is therefore 'essential that professional practice develops in parallel with the expansion of telecare, to ensure the benefits are realised and the risks are managed' (Francis and Holmes, 2010, p. 2).

Capacity to consent is a significant concern in the delivery of telecare for people with dementia. Capacity in legal terms must always be presumed. The Mental Capacity Act, which came into force in 2007, aims to protect people who lack the capacity to make certain decisions. It also provides important guidance for acting in a person's best interests. The Mental Capacity Act can provide useful guidance to telecare providers when considering a person's capacity to consent (Penny, 2009). The five statutory principles that underpin the legal requirements of the Mental Capacity Act are as follows (Department of Health, 2005b):

1. A person must be assumed to have capacity unless it is established that he lacks capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Central to dementia care are the principles of autonomy, beneficence, non-maleficence and justice. These principles are sometimes referred to as the 'four principles of medical ethics' (Hughes and Baldwin, 2006). The researchers who produced the SCIE Report 30: 'Ethical issues in the use of telecare', used these principles as the basis of an 'ethical framework', see Figure 12.1.

Autonomy – the ability of an individual to make choices

Autonomy is related to the independence and choice in everyday life that is often taken for granted. When people rely on professionals or family carers for their care or for safety monitoring, the introduction of a telecare service can drastically promote or restrict autonomy.

Beneficence – the principle of working for the benefit of the individual

Telecare has the potential to benefit people. It can provide assurance and confidence and can reduce unwanted dependence on professional staff or family carers. It can also increase comfort through environmental sensors and controls.

Non-maleficence – the principle of doing no harm

While telecare can benefit an individual, it also has the potential to expose people to risk. A balance must be achieved between ensuring safety and invading privacy. The potentially stigmatising effect of telecare should be recognised and minimised.

Justice – the moral obligation to act on a fair adjudication between conflicting claims

In the interests of justice, resources for telecare services should be allocated so as to balance the needs of the individual with those of the wider community.

Figure 12.1: The Four Ethical Principles (SCIE, 2010)

The following information is extracted from the Social Care Institute for Excellence's publication: '*At a glance 24: Ethical issues in the use of telecare*' (SCIE, 2010). This document provides a summary of '*SCIE Report 30: Ethical issues in the use of telecare*'. For a more detailed exploration of the ethical issues relating to the use of telecare with vulnerable people, please see the full report published by Francis and Holmes (2010).

'At a glance 24: Ethical issues in the use of telecare':

The main ethical concerns identified in Francis and Holmes (2010) can be categorised into two groups: ethical concerns relating to the pre-installation phase, and ethical concerns relating to the post-installation phase.

Pre-installation phase: The principal ethical concern during the pre-installation phase is that services should be tailored to the individual and that when considering appropriate telecare, the risks of the person coming to harm should be balanced against their right to autonomy.

Post-installation phase: The main ethical concern during the post-installation phase is that telecare information should be collected for a positive purpose and with the consent of the person concerned. The risks of invading individual privacy should be balanced

against independence. Telecare should not isolate people socially, and the allocation of funding for telecare should be fair and just.

The points below give an overview of the ethical issues which are covered in greater detail in the main SCIE report (Francis and Holmes, 2010).

➤ **Pre-installation:**

Assessment

- Assessment is a pre-requisite for needs-based telecare service design.
- Assessment is critical to achieving the right balance between independence, social wellbeing, privacy, and protection.
- Assessment for telecare requires appropriately trained assessors.
- Telecare must be embedded in the wider care-planning process and involve joined-up working between organisations.
- Assessment of need and assessment for telecare should be regularly reviewed.

Consent to use telecare

- Informed consent relates directly to the principle of autonomy.
- Telecare should not be imposed on people.
- Gaining informed consent from people with cognitive impairments requires effective presentation of information and judgement of mental capacity.
- In seeking to gain consent, it should not be assumed that eccentricity in an individual implies impaired mental capacity.
- The best approach to gaining consent should be determined on an individual basis.
- When judging the best interests of people without mental capacity to give informed consent, practitioners should strive to find the right balance between quality of life outcomes, including independence, and safety.

Risks associated with telecare

- Everyone involved in the commissioning and use of telecare should have realistic expectations of its capabilities and should understand its limitations.
- Problems can arise in any aspect of telecare services. All possible steps should be taken to avoid problems and careful business continuity planning is needed to cover the possibility of system faults (technical or human).
- Quality standards should be set and enforced for all aspects of service provision including installation, equipment, monitoring and response.

Sourcing equipment

- Currently, the consumer market for telecare is undeveloped and this limits choice and control.
- Equipment should be sourced to enhance individualisation and best value.

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- Manufacturers and suppliers should be subject to quality standards to improve how effectively different devices operate together.
- Commissioners should encourage a competitive market in the tendering process.

Installation

- Installation can either enhance or inhibit autonomy and beneficence, depending on how it is carried out.
- Installers need training and education to acquire the core competencies necessary to support a person-centred service for people with cognitive impairments.
- Quality standards need to be established for the installation process.

➤ **Post-installation:**

Privacy

- As in all direct care services, any infringement on privacy needs to be justified.
- Information generated from telecare services can help service providers determine whether the overall care plan is effective. However, this is dependent on data-sharing arrangements.
- Service providers must be clear about the purpose of collecting information generated from telecare.
- Telecare users and their carers should be informed about what information will be collected and how it will be used.
- The emphasis should be on using information from telecare to drive improvement and to promote people's independence as well as their safety.
- Data should be securely stored and transferred between agencies using industry good practice standards and agreed joint protocols.

Social isolation and wellbeing

- Telecare has a potentially isolating effect. It must not be considered as an alternative to direct social care or informal support, unless this is the expressed wish of the person using the service with full mental capacity.
- Local commissioning strategies should recognise the potential of telecare for meeting low-level needs.
- It is important to recognise that a telecare service cannot monitor changes in a person's wellbeing as sensitively as human beings can and this should be reflected in care planning.
- Telecare should be combined with direct social care and informal support to maximise people's motivation and to facilitate carers' support of social engagement.

Fairness in the allocation of resources

- The wide range of outcomes that telecare and telehealth can achieve supports the argument for joint funding by the NHS, local authorities/Northern Ireland health and social care trusts, and other agencies.

- Manufacturers and telecare providers should work towards greater interoperability of equipment.
- In order to maintain fairness of provision in the context of personal budgets and self-funding, high-quality information and advice on telecare equipment and installation are needed.

Appendix 13: Randomised Control Trials Examining the Role of Assistive Technology and Telecare in Dementia Care

- **ATTILA - UK**

'Assistive Technology and Telecare to maintain Independent Living At Home for People with Dementia' (ATTILA) commenced in 2013 and is described as a pragmatic, multi-centred randomised control trial. The primary objective of the trial is to establish whether Assistive Technology and Telecare (ATT) assessments and interventions 'extend the time that people with dementia can continue to live independently in their own homes and whether it is cost effective' (Leroi *et al.*, 2013. P. 3). The study will also look at the impact ATT has on unplanned hospital admissions, family and care giver stress, and the quality of life of people living with dementia.

ATTILA is being led by Kings College London and funded by the Health Technology Assessment (HTA) Programme (part of the National Institute for Health Research). The study completed participant recruitment between August 2013 and June 2015 with the aim of recruiting 500 people with memory difficulties and their carers living in community settings. Following on from this, the RCT will run for a period of 104 weeks, with the aim of finalising data analysis by the end of 2017 and publishing the study's findings by 2019. The trial is working alongside the NHS and CASSRs (Councils with Adult Social Services Responsibilities) who were already responsible for establishing and developing local ATT services across the UK in Cambridge, Lancashire, London, North Staffordshire, Oxford, and Suffolk. The participants were divided into two study groups, both receiving an initial semi-structured Occupational Therapy assessment for ATT. Group 1 then had ATT devices installed with a response service provided by the CASSRs. Whereas Group 2 were provided with a restricted ATT package, this was limited to a smoke detector, CO detector and a pendant alarm, also arranged by the CASSR (NIHR, 2013). Further information on the research methods being deployed for the ATTILA trial can be found in the study protocol compiled by Leroi *et al.* (2013).

- **UP-TECH - Italy**

UP-TECH is a multi-component, randomised, controlled trial, that was set up in 2013. It lasted 12 months, and involved 438 participants, comprised of community-dwelling people with Alzheimer's disease and their carers from the Marche region of Italy. Full details of the study are provided in Chiatti *et al.* (2013) and Chiatti *et al.* (2015). Participants were randomised into three groups: two experimental and one control. One of the experimental

groups, consisting of more than 100 households, received a package assistive technology, alongside a case-management intervention. The package of assistive technology included 'housing adaptations, such as luminous paths, home leaving sensors, sensors to detect night falls, gas and water leak sensors, and automatic lights' (Chiatti *et al.*, 2013, p. 6). All participants were visited at month zero, six, and twelve by a trained nurse and then followed up in month 24 with a telephone interview. The main aim of the research was to measure carer burden using the Caregiver Burden Inventory (CBI), and to measure the number of days each person spent at home during the study period, as opposed to being hospitalised or institutionalised (Chiatti *et al.*, 2013). Although the full outcomes of the RCT were, at the time of writing, yet to be disclosed, preliminary results presented at the 6th Italian Forum on Ambient Assisted Living appeared to be promising, with high levels of user satisfaction reported (Olivetti *et al.*, 2015).

TECH@HOME – Sweden

The TECH@HOME study was established to examine the impact of a technological intervention on reducing carer burden for the informal carers of people with dementia. It started recruiting in March 2016 with assessments scheduled to continue until December 2017. The study set out to recruit 320 dyads, including people with dementia and their primary informal caregivers (640 participants in total). Full details of the study protocol are available in Fänge *et al.* (2017). The participants will be randomised into intervention or control groups. The intervention group will receive a control unit and a set of sensors that immediately notify carers, through their phones, of any potential risks for the person with dementia. The package will have property exit sensors, bed-occupancy sensors, smoke and water leak detectors, automatic lights, and other interactive functions (Fänge *et al.*, 2017). In the event of an alert being raised a text message or phone call will notify the primary carer; if they do not respond the control unit will make its way through a list of alternative contacts. The technology will raise an alert if the person with dementia:

- leaves the home without notice, since this might occur in a moment of disorientation and the person might wander away and get lost (magnetic contacts must be placed on critical doors and windows)
- leaves a water tap open and floods the room (water sensors must be placed in critical places)
- forgets something on the stove while cooking and causes a fire (smoke detection sensors must be placed in critical places)
- gets out of bed during the night and does not come back within a specified time interval (bed-occupancy sensor and configurable time control)

- never goes to the bathroom in 24 hours (passive infrared sensor and configurable time control)
- never opens refrigerator door in 24 hours (magnetic contact and configurable time control) (Fänge *et al.*, 2017, p. 4)

The package of equipment can also be set up, depending on personal preferences, to:

- automatically turn on a light to help avoid a fall (via a bed-occupancy sensor, passive infrared sensors and automatic lights) when the person gets out of bed during the night
- alert the caregiver when the temperature in the house falls or rises excessively (temperature sensor with configurable threshold)
- act as burglar alarm in some areas of the home (via magnetic contacts and passive infrared sensors) (Fänge *et al.*, 2017, p. 5)

The study aims to evaluate the effects of the assistive technology on carer burden by reducing the time spent on supervision. The study will also look at:

- Quality of life of the person with dementia
- Fear of falling of the person with dementia
- Caregiver health-related quality of life
- Caregiver anxiety
- Caregiver burden
- The incidence of domestic accidents
- The cost-effectiveness of the technological intervention (Fänge *et al.*, 2017, p. 5)

Appendix 14: Other Simulation Models Applied to Social Care

Although the development of social care simulation models within Operational Research has been relatively limited, 'other' relevant simulations have been produced by different disciplines. It is therefore valuable to explore a few of these models in more detail. This section will focus on macro and micro-simulations, which are more commonly constructed by social scientists. Micro-simulations are more generally referred to as an 'individual sampling model' (Kuntz *et al.*, 2013). They simulate one individual at a time, whereas macro-simulations aggregate the individual level data (Onggo, 2012b). Micro-simulations track the past health states of the individual and then model the risk of future events stochastically (Kuntz *et al.*, 2013). Micro-simulations assume independence between individuals, therefore unlike DES, SD and ABS, they cannot be used to model interactions among individuals.

One example of a macro-simulation set within a social care context, was produced by the Personal Social Services Research Unit (PSSRU). The PSSRU long term care projections model was developed as part of a research project to examine the financing of long term care for older people. The project, funded by the Department of Health, focused on the sustainability of expenditure on long term care over the coming decades under a range of scenarios. It also focused on the balance between public and private spending on long term care. The first incarnation of the model is described in a detailed report by Wittenberg *et al.* (1998). However, the model has been developed and redeveloped with updated projections several times, see Comas-Herrera *et al.* (2003), Wittenberg *et al.* (2004), Wittenberg *et al.* (2006), Comas-Herrera *et al.* (2007), Wittenberg *et al.* (2008) and Wittenberg and Hu (2015) for more details.

In the 2006 paper entitled: 'Future Demand for Long-Term Care, 2002 to 2042: Projections of Demand for Long Term Care for Older People in England', Wittenberg *et al.* describe the PSSRU model as follows. The model divides the older population according to their level of functional disability (measured by ADLs), marital status, housing tenure, who they live with or whether they live alone, and their receipt of informal care. These characteristics are considered to have the greatest influence over an individual's use of care services. The model uses data from the Government Actuary Department (now known as the Office for National Statistics) to generate population projections for each age band up to the year 2041. Further information relating to the data used can be found in Shaw (2006). A range of other data sources, including the Census and the Family Resources Survey, are then used to inform and populate the model. Wittenberg *et al.*

(2006) explains how the model was expanded and updated using data from the 2001 – 2002 General Household Survey (GHS) in order to include six categories of functional disability. This was considered to be an important development, as disability, rather than age, is considered to have the greatest impact on level of care need.

The model requires a range of assumptions to be made about the way the government will deploy resources to meet needs, taking into account factors such as the targeting of people with 'high' levels of need, the availability of informal care, and the balance between the provision of care at home and in a residential setting. The model assigns costs to the various service arrangements, and then projects future levels of Gross Domestic Product (GDP), so that the proportion of national economic wealth required to support older people with long term care needs can be calculated. Finally, the model can be used to vary the initial set of assumptions in order to explore the outcomes of different scenarios.

In 2007, the Alzheimer's Research Trust funded further development of the PSSRU model in order to make projections specifically for dementia (Comas-Herrera *et al.*, 2007). The model was renamed the Personal Social Services Research Unit Cognitive Impairment (PSSRU CI) model, and aimed to make projections for England to 2031 of three key variables: the expected number of older people with dementia, their likely level of demand for long term care services, and the costs associated with meeting this demand. The model was updated using data from the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS), a nationally representative longitudinal study of 13,004 community-dwelling and institutionalised residents aged 65 years and over (Medical Research Council, 1998). This data was used to provide the characteristics of people with dementia and their propensity to receive care services. The results from the modelling showed that spending on long term care services for older people with cognitive impairments is set to rise, with a projected increase from £5.4 billion of GDP in 2002 to £16.7 billion in 2031, under base case assumptions.

Comas-Herrera *et al.* (2011) went on to develop the model further by using a Delphi-style approach to gather the views of experts, incorporating these views into projections of future expenditure in long term care for people with dementia. This article concluded that the incorporation of expert opinion into the modelling process resulted in projected expenditure growing more slowly than it would otherwise.

Another example of macro-simulation modelling was produced by Jagger *et al.* in 2009. They built a dynamic macro-simulation projection model to estimate the number of older people with disabilities in England and Wales by 2026. The case study also utilised data

from the MRC CFAS survey, and particularly focused on the impact of dementia on disability among older people. Consequently, the model incorporates dementia prevalence rates among older people, and the probability of death and disability due to dementia. The model was used to assess a range of early interventions and concluded that the greatest reduction in the disabled population was from delayed onset, reduced disability, and improved survival, achieved through optimal control of vascular risk factors. However, this improvement only represented a reduction of 1% in the size of the disabled population. The model also confirmed that population ageing will result in 'an 82% increase in numbers disabled over the next 20 years' (Jagger *et al.*, 2009, p. 323).

Lagergren's studies (2005a, 2005b) use micro-simulation to focus on population projections in Sweden for the time periods 1985-2000 and 2000-2030 respectively. Lagergren's (2005a) study using micro-simulation describes the development of the Swedish care system for older people in terms of service provision and costs per needs group. Lagergren calculated cost of care by multiplying the demand for various types of care services by their retrospective standard costs, which vary according to age, gender, marital status, and degree of disability or ill-health.

Appendix 15: Consent Form for Interview Participants



[The Use of Telecare to Support People with Dementia]

CONSENT FORM

Researcher name: Katherine E. E. Penny

Ethics reference:

**Please initial
box**

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without my legal rights being affected. ☐
3. I confirm that I am happy for this session to be recorded using an audio recorder for the purposes of data collection. ☐
4. I agree to take part in this research project and agree for my data to be used for the purpose of this study. ☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of Participant

Date

Signature

Researcher

Date

Signature

When completed: 1 for participant, 1 for researcher

Researcher Contact Details:

Katherine Penny, PhD Research Student
School of Management
University of Southampton
Southampton, SO17 1BJ
Telephone: 01202 421182

Appendix 16: Information Sheets for Stakeholder Interviews



Participant Information Sheet - Key Stakeholders

Study Title: The Use of Telecare to Support People with Dementia

Researcher: Katherine E. E. Penny

Ethics number:

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form at the start of the interview.

What is the research about?

My name is Katherine Penny and I am a PhD Research student at the University of Southampton. My research is part of the Care Life Cycle Project, a large multi-disciplinary project, funded by the Engineering and Physical Sciences Research Council (EPSRC), looking at meeting the health and social care needs of an ageing population. My specific contribution to the project will be to examine the use of telecare to support people with Dementia to live independently for longer.

As part of my data collection I am arranging a series of informal interviews with a range of key people whose professional roles give them particular insights into the use of telecare. These professionals include policymakers, clinicians, technology developers, representatives from telecare manufacturers, Local Authority service managers and researchers. Consequently I have contacted you, as I would like to hear your perspective, as a *[insert job title]*, on the use of telecare to support people with dementia.

Ultimately, I will be using this data, along with data provided by local governing bodies, national datasets and current literature, to build a model to simulate the experiences of hundreds or even thousands of different hypothetical individuals using the equipment. This model will contribute to the overall cost-benefit analysis of telecare.

Why have I been chosen?

You have been invited to participate because your role as a *[insert job title]* means you can offer a particular insight and therefore, your view on the use of telecare for people with dementia would be particularly useful to my research.

What will happen to me if I take part?

Firstly, if you reply to the e-mail I sent through to you, we can arrange an interview time and location that is convenient to you. I have access to a car, so I am happy to travel. Otherwise we can conduct the interview over the telephone. This initial conversation will also be an opportunity for you to ask me any questions that you might have prior to the interview.

On the day of the interview I will ask you to initial and sign two consent forms, so that we can have a copy each. If we are carrying out the interview over the phone I will send you a stamped addressed envelope in which to return your signed form. The interview will last between 60 to 90 minutes and will begin with a brief introduction to the research. With your permission, I will be using an audio recorder, which will be switched on at the start of the session.

The interview will be based around a series of questions regarding the use of telecare to support independent living for people with dementia. We will focus on the factors that you feel impact upon telecare uptake, the strengths and weaknesses of the equipment and the role you feel it can play in supporting carers.

Are there any benefits in my taking part?

Appendices

There is no direct benefit to you personally, but you would have the satisfaction of knowing that you had contributed to the research of telecare as a means of supporting people with dementia. I also hope you would find the experience interesting.

Are there any risks involved?

There are no physical risks posed by participating in this study, nor is the study likely to cause psychological distress. However, I do recognise that asking questions regarding the care of someone with dementia could be upsetting; therefore if you would like me to redirect the conversation, or you would like to end the session early, you would be very welcome to do so, as you are under no obligation, legal or otherwise to complete the study.

Can I be personally identified as a result of taking part?

You will be anonymous in any publications or reports produced in this study. If we need to refer to you individually, you will be assigned a letter. Although I will know which data is yours, there will be nothing transmitted or stored which would identify you personally to anyone else. Within six months of the study ending, all identifiers (name, address and contact details) will be deleted. The university provides facilities for the secure storage of such data; all transmitted data will be encrypted, and the data, including all audio files, will be kept on a secure password-protected server in a locked room.

What happens if I change my mind?

You have the right to withdraw at any time, without needing to give a reason.

Is there an independent person I can contact if I am unhappy about the research?

If you are unhappy about any aspect of the research and do not wish to raise it with me as the researcher, you can contact the Head of Research Governance, Dr Martina Prude, at the University of Southampton. Tel 023 8059 8848, email: mad1@soton.ac.uk.

Where can I get more information?

You are very welcome to contact me with any further queries regarding the research. Otherwise you can visit the research page of the Care Life Cycle Project at:

<http://www.southampton.ac.uk/clc/>

If I want to participate, what should I do next?

Please contact me on 01202 421182 or e-mail me at K.E.Penny@soton.ac.uk to arrange a time and location for the interview that is convenient to you. I will need you to bring the signed consent form with you, unless you would prefer to be interviewed by phone, in which case I can provide you with a stamped addressed envelope to return the form to me.

Researcher Contact Details:

Katherine Penny, PhD Research Student
School of Management
University of Southampton
Southampton
SO17 1BJ

Telephone : 01202 421182
E-Mail: kep204@soton.ac.uk

Appendix 17: Information Sheets for Informal Carer Interviews



Participant Information Sheet - Informal Carers

Study Title: The Use of Telecare to Support People with Dementia

Researcher: Katherine E. E. Penny

Ethics number:

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form at the start of the interview.

What is the research about?

My name is Katherine Penny and I am a PhD Research student at the University of Southampton. My research is part of the Care Life Cycle Project, a large multi-disciplinary project, funded by the Engineering and Physical Sciences Research Council, looking at meeting the health and social care needs of an ageing population. My specific contribution to the project will be to examine the use of telecare to support people with Dementia to live independently for longer.

I will be collecting data by holding interviews with carers of people with dementia to gain a better understanding of your needs and the needs of the people you support. It will also be useful to find out your perspective on telecare and whether it is something you would consider using.

Ultimately, I will be using this data, along with data provided by local governing bodies, national datasets and current literature, to build a model to simulate the experiences of hundreds or even thousands of different hypothetical individuals. This model will contribute to the overall cost-benefit analysis of telecare.

What is Telecare?

Telecare can be broadly described as care at a distance using information and communication technologies. It manages the risks associated with independent living by providing continuous, automatic and remote monitoring of real-time emergencies and lifestyle changes over time. The telecare equipment is able to send a signal to a carer, community alarm or monitoring service so that assistance can be called for when it is needed. Telecare equipment of particular use for people with dementia is summarised in the following table:

Device	Description
Home Unit	Central to the entire system, the home unit connects all the other telecare sensors to the monitoring centre.
Personal Alarm	Allows the service user to summon help by pushing a portable button or pulling a ceiling mounted cord.
Lifestyle Monitoring	Sensors are positioned around the home enabling the remote assessment of activity/inactivity. Detects changes in movement patterns indicating that assistance may be required.
Fall Detectors	Device is worn by the service user and automatically initiates an emergency alert if the individual experiences a fall.
Flood Detectors	Raises an alert if water is detected above a certain level on the floor, indicating that perhaps a bath has overflowed or pipe has burst.
Gas Detectors	Sounds an audible local alarm and sends an alert to the monitoring centre if dangerous levels of gas are detected.
Carbon Monoxide Detector	As above, but for detecting Carbon Monoxide. Combined gas and CO detectors are available for around £150.
Smoke Detector	As above, but for detecting Smoke.
Extreme Temperature Detectors	Detects extreme changes in temperature. A rapid rise in temperature may indicate a fire, whereas a drop in temperature could pose the risk of hypothermia to the individual.

Medication Reminders and Dispensers	Provides an audible and visual alert to remind the user to take their medication. If the tablets are not accessed an alert is sent to the monitoring centre or carer so that action can be taken to ensure the medication programme is maintained.
Enuresis Sensors	Placed between bedding and the mattress it provides an early warning for service users who are prone to incontinence whilst sleeping.
Property Exit Sensors	Alerts the monitoring centre and/or carer when an individual leaves their property. Can incorporate a range of sensors, for example: basic door contacts that detect if the door opens.
Bed Occupancy Sensors	A pressure sensitive mat is placed under the mattress. If the service user gets out of bed during the night and fails to return after a predefined time, an alarm is raised.
Chair Occupancy Sensors	Operates like the bed sensor, alerting a carer that the user has got out of their chair and therefore may be at risk.
Bogus Caller Devices	Operates in the same way as a personal alarm but is designed to be located by the front door and enables the monitoring centre to reassure the service user and allows them to monitor the conversation between the resident and the visitor to ensure the users safety.
Safe Walking Technology	Devices that are able to locate the service user, usually through GPS functionality, helping carers find the user quickly if they become lost due to wandering behaviour.

Why have I been chosen?

You have been invited to participate because you are a carer of someone with dementia and I would like to hear about your experiences of caring and your view of telecare.

What will happen to me if I take part?

Firstly, you will need to contact me so that we can arrange an interview time and location that is convenient to you. I have access to a car, so I am happy to travel. Otherwise we can conduct the interview over the telephone. This initial conversation will also be an opportunity for you to ask me any questions that you might have prior to the interview.

On the day of the interview I will ask you to initial and sign two consent forms, so that we can have a copy each. If we are carrying out the interview over the phone I will send you a stamped addressed envelope in which to return your signed form. The interview will last between 60 to 90 minutes and will begin with a brief introduction to the research. With your permission, I will be using an audio recorder, which will be switched on at the start of the session.

The interview will be based around your experiences of caring for someone with dementia. I will also ask you to imagine a range of scenarios and we will discuss the role that you feel telecare could play in supporting you and the person you care for.

Are there any benefits in my taking part?

There is no direct benefit to you personally, but you would have the satisfaction of knowing that you had contributed to the research of telecare as a means of supporting people with dementia. I also hope you would find the experience interesting.

Are there any risks involved?

There are no physical risks posed by participating in this study, nor is the study likely to cause psychological distress. However, I do recognise that asking questions regarding the care of someone with dementia, whether in a real or hypothetical scenario, could be upsetting. Therefore if you would like me to change the conversation, or you would like to end the session early, you would be very welcome to do so, as you are under no obligation to complete the study.

Can I be personally identified as a result of taking part?

You will be completely anonymous in any publications or reports produced in this study. If we need to refer to you individually, you will be assigned a letter, e.g. "Participant A". Although I will know which data is yours, there will be nothing transmitted or stored which would identify you personally to anyone else. Within six months of the study ending, all identifiers (names, address, and contact details) will be deleted. The university provides facilities for the secure storage of such data; all

transmitted data will be encrypted, and the data, including all audio files, will be kept on a secure password-protected server in a locked room.

What happens if I change my mind?

You have the right to withdraw at any time, without needing to give a reason.

Is there an independent person I can contact if I am unhappy about the research?

If you are unhappy about any aspect of the research and do not wish to raise it with theme as the researcher, you can contact the Head of Research Governance, Dr Martina Prude, at the University of Southampton. Tel 023 8059 8848, email: mad1@soton.ac.uk.

Where can I get more information?

You are very welcome to contact me with any further queries regarding the research. Otherwise you can visit the research page of the Care Life Cycle Project at: <http://www.southampton.ac.uk/clc/>

If I want to participate, what should I do next?

Please contact me on 01202 421182 or e-mail me at K.E.Penny@soton.ac.uk to arrange a time and location for the interview that is convenient to you. I will need you to bring the signed consent form with you, unless you would prefer to be interviewed by phone, in which case I can provide you with a stamped addressed envelope to return the form to me.

Researcher Contact Details:

Katherine Penny, PhD Research Student
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University of Southampton
Southampton
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Telephone : 01202 421182
E-Mail: kep204@soton.ac.uk

Appendix 18: Interview Information Sheets for People with Dementia



Participant Information Sheet – Person with Dementia

Study Title: The Use of Telecare to Support People with Dementia

Researcher: Katherine E. E. Penny

Ethics number:

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form at the start of the interview.

What is the research about?

My name is Katherine Penny and I am a PhD Research student at the University of Southampton. My research is part of the Care Life Cycle Project, a large multi-disciplinary project, funded by the Engineering and Physical Sciences Research Council, looking at meeting the health and social care needs of an ageing population. My specific contribution to the project will be to examine the use of telecare to support people with Dementia to live independently for longer.

I will be collecting data by holding interviews with people who have been diagnosed with dementia to gain a better understanding of the disease. I would like to speak to you about your dementia and learn more about your experiences of the condition. It will also be useful to find out your perspective on telecare and whether it is something you would consider using.

Ultimately, I will be using this data, along with data provided by local governing bodies, national datasets and current literature, to build a model to simulate the experiences of hundreds or even thousands of different hypothetical individuals. This model will contribute to the overall cost-benefit analysis of telecare.

What is Telecare?

Telecare can be broadly described as care at a distance using information and communication technologies. It manages the risks associated with independent living by providing continuous, automatic and remote monitoring of real-time emergencies and lifestyle changes over time. The telecare equipment is able to send a signal to a carer, community alarm or monitoring service so that assistance can be called for when it is needed. Telecare equipment of particular use for people with dementia is summarised in the following table:

Device	Description
Home Unit	Central to the entire system, the home unit connects all the other telecare sensors to the monitoring centre.
Personal Alarm	Allows the service user to summon help by pushing a portable button or pulling a ceiling mounted cord.
Lifestyle Monitoring	Sensors are positioned around the home enabling the remote assessment of activity/inactivity. Detects changes in movement patterns indicating that assistance may be required.

Appendices

Fall Detectors	Device is worn by the service user and automatically initiates an emergency alert if the individual experiences a fall.
Flood Detectors	Raises an alert if water is detected above a certain level on the floor, indicating that perhaps a bath has overflowed or pipe has burst.
Gas Detectors	Sounds an audible local alarm and sends an alert to the monitoring centre if dangerous levels of gas are detected.
Carbon Monoxide Detector	As above, but for detecting Carbon Monoxide. Combined gas and CO detectors are available for around £150.
Smoke Detector	As above, but for detecting Smoke.
Extreme Temperature Detectors	Detects extreme changes in temperature. A rapid rise in temperature may indicate a fire, whereas a drop in temperature could pose the risk of hypothermia to the individual.
Medication Reminders and Dispensers	Provides an audible and visual alert to remind the user to take their medication. If the tablets are not accessed an alert is sent to the monitoring centre or carer so that action can be taken to ensure the medication programme is maintained.
Enuresis Sensors	Placed between bedding and the mattress it provides an early warning for service users who are prone to incontinence whilst sleeping.
Property Exit Sensors	Alerts the monitoring centre and/or carer when an individual leaves their property. Can incorporate a range of sensors, for example: basic door contacts that detect if the door opens.
Bed Occupancy Sensors	A pressure sensitive mat is placed under the mattress. If the service user gets out of bed during the night and fails to return after a predefined time, an alarm is raised.
Chair Occupancy Sensors	Operates like the bed sensor, alerting a carer that the user has got out of their chair and therefore may be at risk.
Bogus Caller Devices	Operates in the same way as a personal alarm but is designed to be located by the front door and enables the monitoring centre to reassure the service user and allows them to monitor the conversation between the resident and the visitor to ensure the users safety.
Safe Walking Technology	Devices that are able to locate the service user, usually through GPS functionality, helping carers find the user quickly if they become lost due to wandering behaviour.

Why have I been chosen?

You have been invited to participate because you can provide insight into what having dementia is actually like and how it affects your quality of life. It would also be really useful as a potential future service user, to see what your thoughts are on telecare equipment.

What will happen to me if I take part?

Firstly, you will need to contact me so that we can arrange an interview time and location that is convenient to you. I have access to a car, so I am happy to travel. Otherwise we can conduct the interview over the telephone. This initial conversation will also be an opportunity for you to ask me any questions that you might have prior to the interview.

On the day of the interview I will ask you to initial and sign two consent forms, so that we can have a copy each. If we are carrying out the interview over the phone I will send you a stamped addressed envelope in which to return your signed form. The interview will last between 60 to 90 minutes and will begin with a brief introduction to the research. With your permission, I will be using an audio recorder, which will be switched on at the start of the session.

The interview will be based around your experiences of caring for someone with dementia. I will also ask you to imagine a range of scenarios and we will discuss the role that you feel telecare could play in supporting you and the person you care for.

Are there any benefits in my taking part?

There is no direct benefit to you personally, but you would have the satisfaction of knowing that you had contributed to the research of telecare as a means of supporting people with dementia. I also hope you would find the experience interesting.

Are there any risks involved?

There are no physical risks posed by participating in this study, nor is the study likely to cause psychological distress. However, I do recognise that asking questions regarding dementia could be upsetting. Therefore if you would like me to change the conversation, or you would like to end the session early, you would be very welcome to do so, as you are under no obligation to complete the study.

Can I be personally identified as a result of taking part?

You will be completely anonymous in any publications or reports produced in this study. If we need to refer to you individually, you will be assigned a letter, e.g. "Participant A". Although I will know which data is yours, there will be nothing transmitted or stored which would identify you personally to anyone else. Within six months of the study ending, all identifiers (names, address, and contact details) will be deleted. The university provides facilities for the secure storage of such data; all transmitted data will be encrypted, and the data, including all audio files, will be kept on a secure password-protected server in a locked room.

What happens if I change my mind?

You have the right to withdraw at any time, without needing to give a reason.

Is there an independent person I can contact if I am unhappy about the research?

If you are unhappy about any aspect of the research and do not wish to raise it with theme as the researcher, you can contact the Head of Research Governance, Dr Martina Prude, at the University of Southampton. Tel 023 8059 8848, email: mad1@soton.ac.uk.

Where can I get more information?

You are very welcome to contact me with any further queries regarding the research. Otherwise you can visit the research page of the Care Life Cycle Project at: <http://www.southampton.ac.uk/clc/>

If I want to participate, what should I do next?

Please contact me on 01202 421182 or e-mail me at K.E.Penny@soton.ac.uk to arrange a time and location for the interview that is convenient to you. I will need you to bring the signed consent form with you, unless you would prefer to be interviewed by phone, in which case I can provide you with a stamped addressed envelope to return the form to me.

Researcher Contact Details:

Katherine Penny, PhD Research Student
School of Management
University of Southampton
Southampton
SO17 1BJ

Telephone : 01202 421182

E-Mail: kep204@soton.ac.uk

Appendix 19: Debriefing Sheet for Key Stakeholder Interviews



[The Use of Telecare to Support People with Dementia]

Debriefing Statement – Key Stakeholders

Thank you so much for taking part in this study. Your participation was very valuable and the time you have given up for this interview has been really appreciated.

What is the research about?

My research is part of the Care Life Cycle Project, a large multi-disciplinary project at the University of Southampton, looking at meeting the health and social care needs of an ageing population. My specific contribution to the project is to examine the use of telecare to support people with Dementia to live independently for longer.

By taking part in this research you have contributed to my data collection, helping me to understand telecare as a service and how it can fit into the Dementia Care Pathway. Sharing your views of the equipment will help me to build a more realistic model of telecare for my PhD, enabling me to carry out an accurate cost benefit analysis of the equipment.

I hope this clarifies the purpose of the research, and the reason why your contribution was so valuable.

For information on other work being carried out by the Care Life Cycle Project, please visit: <http://www.southampton.ac.uk/clc/>

Just to reaffirm, the results of this study will not include your name or any other identifying characteristics. If you have any questions or concerns, you may contact me, Katherine Penny at K.E.Penny@soton.ac.uk. Thank you again for your participation!

Appendix 20: Debriefing Sheet for Interviews with Informal Carers and People with Dementia



[The Use of Telecare to Support People with Dementia]

Debriefing Statement – Potential Service Users: Individuals with Dementia and Informal Carers

Thank you so much for taking part in this study. Your participation was very valuable and the time you have given up for this interview has been really appreciated.

What is the research about?

My research is part of the Care Life Cycle Project, a large multi-disciplinary project at the University of Southampton, looking at meeting the health and social care needs of an ageing population. My specific contribution to the project is to examine the use of telecare to support people with Dementia to live independently for longer.

By taking part in this research you have contributed to my data collection, helping me to gain a better understanding of the experience of living with dementia. This has given depth and meaning to my work, ultimately helping me to assess the role telecare could play in supporting people and their carers.

I hope this clarifies the purpose of the research, and the reason why your contribution was so valuable. For further information on the Care Life Cycle Project, please visit:

<http://www.southampton.ac.uk/clc/>

For more information on telecare: please visit www.tunstall.co.uk. The website links to the document "Dementia care solutions for independent living: key information for health and social care professionals and carers" as well as a video link. Alternatively you can call Tunstall on 01977 660479.

For more information on telecare in Dorset: please contact the Adult Access Team on 01305 221016 or visit Dorset County Council's website: www.dorsetforyou.com/telecare

Just to reaffirm, the results of this study will not include your name or any other identifying characteristics. If you have any questions or concerns, you may contact me, Katherine Penny at K.E.Penny@soton.ac.uk. Thank you again for your participation!

Appendix 21: Interview Schedules

i) Interviews with Key Stakeholders

The interview will start with introductions, the participant will be thanked for their time and made a cup of tea/coffee if the location allows. The introduction will include a brief overview of the research, stating the aim of the interview, for example:

“Hello, firstly I would like to thank you for taking the time to meet with me today; as you know, my name is Katherine Penny and I am a PhD student at the University of Southampton. My research is part of a bigger project, called the Care Life Cycle Project that is looking at meeting the needs of an ageing population; my specific contribution is looking at the use of telecare to support people with dementia.

As part of my research I am holding interviews with professionals with insights into the development and delivery of telecare, such as yourself. Ultimately I want to build a model of telecare uptake and I believe that these interviews will help me build a more accurate and complete model.

Today’s interview should last between 60 and 90 minutes, during which time I would like to discuss the use of telecare for people with dementia, and more specifically [Insert specific topics that relate to the individual’s role...these topics will be incorporated into the questioning as and when the participants are identified and will focus on their specific area of expertise].

If you are happy for the interview to go ahead, please could you initial and sign these two consent forms. Point three on the form asks if you are happy for me to record this interview. Is that ok? If not, I can take notes instead.”

At this point consent forms will be signed and collected and the audio-recorder will be switched on (with the participant’s permission). The interview will then be carried out with these topics in mind:

Prompt Questions

What do you see as the main aim of telecare?

What do you think are the key benefits for telecare users with dementia/their carers?

What particular pieces of equipment do you think work well for people with dementia?

Are there any pieces of equipment that should be useful but aren’t? and if so, why is this?

Are there any problems with using telecare for people with dementia? If so, what are these problems?

Are there any circumstances where you would consider telecare to be inappropriate for someone with dementia?

What other forms of support need to be in place for telecare to be successful?

Based on your experience, could you give any examples when telecare has been particularly helpful for someone with dementia and/or their carer?

Based on your experience, could you suggest what the most common causes are for telecare to be unsuccessful?

How often, in your experience is telecare equipment removed because the service user feels uncomfortable with its presence in their home?

What is the most common reason for telecare to be removed from a person's home?
In what circumstances do you believe telecare can postpone a residential care admission?
How do you think health and social care services could benefit from telecare?
How would you judge whether or not telecare has benefited service users/the way services are run?
Do you think telecare can help meet the increasing demand on social care within an ageing population?
What do you consider to be the main problems with mainstreaming telecare for supporting people with dementia?
What are the main factors that you think affect telecare uptake by people with dementia/their carers?
What do you think could be done to increase awareness of telecare for people with dementia?
Conclusion of Interview
Is there anything else you would like to add regarding the use of telecare for people with dementia?

At the end of the interview the participant will be thanked once again for their time and they will be provided with a debriefing sheet.

ii) Interviews with Informal Carers for People with Dementia

The interview will start with introductions, the participant will be thanked for their time and made a cup of tea/coffee if the location allows. The introduction will include a brief overview of the research, stating the aim of the interview, for example:

"Hello, firstly I would like to thank you for taking the time to meet with me today; as you know, my name is Katherine Penny and I am a PhD student at the University of Southampton. My research is part of a bigger project, called the Care Life Cycle Project that is looking at meeting the needs of an ageing population; my specific contribution is looking at the use of telecare to support people with dementia.

As part of my data collection I am holding interviews with Carers of people with dementia, which is why I have invited you here today.

Today's interview should last between 60 and 90 minutes, during which time I would like to discuss two different areas with you. Firstly, I would like to hear about your experience of caring for someone with dementia and secondly I would like to ask you some questions to find out what you think about telecare equipment.

If you are happy for the interview to go ahead, please could you initial and sign these two consent forms. Point three on the form asks if you are happy for me to record this interview. Is that ok? If not, I can take notes instead."

At this point consent forms will be signed and collected and the audio-recorder will be switched on (with the participant's permission). The interview will then be carried out with these topics in mind:

Main Question	Additional Prompt Questions	Clarifying Questions
I understand that it can be very challenging caring for someone with dementia; please could you tell me a little about your experience?	<ul style="list-style-type: none"> What are the main symptoms of dementia that your [<i>person with dementia</i>] exhibits? What are the main ways you provide support for your [<i>person with dementia</i>]? How regularly do you have to provide support? How does this impact on your quality of life? / your relationship with the person you care for? Do you live with the person you care for? Is it important to you and/or your [<i>person with dementia</i>] to remain at home? What particular reasons make remaining at home important? Do you currently receive any help with providing care? E.g: Paid carer, meals on wheels, cleaner, respite care etc What trigger factors might lead you to seek additional support? Do you have support from family / friends? Do you have friends and family based nearby? Are you a member of any organisations that support you as a carer or the person you care for? E.g. Church, group, club, charity 	<ul style="list-style-type: none"> Can you expand a little on this? Can you tell me anything else? Can you give me some examples?
What factors would you consider to be most important to maintaining your quality of life?	E.g. Remaining in your own home, safety and security, Family support, privacy, living independently, healthcare support, friend/neighbour visits, family visits, socialising etc	
*What are your thoughts on the use of telecare to support people with dementia?	<ul style="list-style-type: none"> Were you aware of telecare prior to this interview? Have you or [<i>the person you care for</i>] ever been offered telecare equipment? If you have previously declined telecare, why did you do so? Do you think telecare could be something that you would be interested in using? What would be your main concerns about using the equipment? 	<ul style="list-style-type: none"> Can you expand a little on this? Can you tell me anything else? Can you give me some examples?

	<ul style="list-style-type: none"> • What pieces of equipment do you think could be most useful for you? And why? • If you were not able to provide care for your [person with dementia] do you think telecare could still play a role in supporting them? 	
<p>Is there anything else you would like to add regarding your experiences as a carer or the use of telecare for people with dementia?</p>		

** I will give an overview of the telecare equipment currently available if necessary.*

At the end of the interview the participant will be thanked once again for their time and they will be provided with a debriefing sheet.

iii) Interview Schedule for Individuals who have Dementia

The focus group will start with introductions, the participants will be thanked for their time and made a cup of tea/coffee if the location allows. The introduction will include a brief overview of the research, stating the aim of the interview, for example:

The interview will start with introductions, the participant will be thanked for their time and made a cup of tea/coffee if the location allows. The introduction will include a brief overview of the research, stating the aim of the interview, for example:

“Hello, firstly I would like to thank you for taking the time to meet with me today; as you know, my name is Katherine Penny and I am a PhD student at the University of Southampton. My research is part of a bigger project, called the Care Life Cycle Project that is looking at meeting the needs of an ageing population; my specific contribution is looking at the use of telecare to support people with dementia.

As part of my data collection I am holding interviews with people with dementia, which is why I have invited you here today.

Today’s interview should last between 60 and 90 minutes, during which time I would like to discuss two different areas with you. Firstly, I would like to hear about your experience of dementia and secondly I would like to ask you some questions to find out what you think about telecare equipment.

If you are happy for the interview to go ahead, please could you initial and sign these two consent forms. Point three on the form asks if you are happy for me to record this interview. Is that ok? If not, I can take notes instead.”

At this point consent forms will be signed and collected and the audio-recorder will be switched on (with the participant’s permission).

The interview will then be carried out with these topics in mind:

Topics	Prompt Questions	Clarifying Questions
Diagnosis	<ul style="list-style-type: none"> • How did you find out you had dementia? • Who gave you a diagnosis • How long ago were you diagnosed? • How much information were you given about your diagnosis? • Were you aware that you were developing dementia? • How did you feel about your diagnosis? 	
Living with dementia...	<ul style="list-style-type: none"> • What activities do you enjoy the most? • What tasks do you find hard? • What tasks do you find easy? • How have you adapted/how do you manage? • How do you feel when you have experienced a period of confusion? • How does this impact on your quality of life? • Do you live with someone who helps care for you? • Do you have support from friends or family living nearby? • How does the dementia impact upon you friends/family? • Is it important to you to remain at home? • What particular reasons make remaining at home important? • Do you currently receive any outside support? E.g: from friends, family, council, paid carer (self-funded), meals on wheels, cleaner, respite care etc • What trigger factors might lead you to seek additional support? • Are you a member of any organisations that support you? E.g. Church, group, club, charity 	<ul style="list-style-type: none"> • Can you expand a little on this? • Can you tell me anything else? • Can you give me some examples?
What factors would you consider to be most important to maintaining your quality of life?	E.g. Remaining in your own home, safety and security, Family support, privacy, living independently, healthcare support, friend/neighbour visits, family visits, socialising etc	
*What are your thoughts on telecare equipment...	<ul style="list-style-type: none"> • Were you aware of telecare prior to today? • Have you ever been offered telecare equipment? • If you have previously declined telecare, why did you do so? 	<ul style="list-style-type: none"> • Can you expand a little on this?

Appendices

	<ul style="list-style-type: none">• Do you think telecare could be something that you would be interested in using?• What would be your main concerns about using the equipment?• What pieces of equipment do you think could be most useful for you? And why?	<ul style="list-style-type: none">• Can you tell me anything else?• Can you give me some examples?
Conclusion of Interview	Comments:	
Is there anything else you would like to add regarding your experiences of dementia or the role of telecare?		

** I will give an overview of the telecare equipment currently available if necessary.*

At the end of the interview the participant will be thanked once again for their time and they will be provided with a debriefing sheet.

Appendix 22: Output from the Stakeholder Engagement

This appendix is divided into four sections. The first section highlights the key themes identified during the initial stage of the study working with Dorset County Council, as described in Chapter 5, Section 5.2. The second section displays the summary notes taken during the three 'Category One' interviews with professionals involved in the development and delivery of telecare. The final two sections provide the summary notes from the 'Category Two' and 'Category Three' interviews respectively. The Category Two interview was with a lady with dementia and the Category Three interview was with a carer of someone with dementia (see Chapter 5, Section 5.3 for further information).

All interviewees were contacted at least a week before the interview, either by phone or e-mail and they were provided with a participant information sheet, detailing the purpose of the study and how their responses would be used. The interviews were face to face, and on the day each person was provided with a consent form to initial and sign, to confirm their willingness to participate. The interviews were recorded on an audio recorder and hand-written notes were taken. Once the interviews were complete a debriefing sheet was given to the participant, reiterating the purpose of the research, and providing contact details, should they have any questions or concerns.

Section 1: Key Themes from the Initial Stage of the Study

The key themes identified while initiating the study formed the basis of further discussion when defining the system during the conceptual modelling building process as described in Chapter 5, Section 5.4. These themes are summarised below:

- Attendance at team meetings during the initial stage of the study highlighted the importance, for many people with dementia, of remaining in their own home for as long as possible. This was repeatedly emphasised by members of staff through anecdotal evidence, with one Occupational Therapist noting that enabling someone to spend a 'just few additional weeks at home', could make a significant difference to their wellbeing and acceptance of their transition to residential care.
- Telecare needs to be checked regularly and maintained to ensure that it continues to meet people's needs.
- Stakeholder feedback supported the grey literature in asserting that telecare has role to play in supporting people with dementia to remain living in their own homes by:
 - Promoting independence

- Creating a safer environment to live in, by reducing risks
 - Supporting carers
 - Enabling care services to offer proactive care, rather than planning for 'just in case'. Telecare can help to identify when help is actually needed.
- Telecare is not suitable for everyone. Comprehensive holistic assessment is essential.
- In dementia care, support needs to be reviewed regularly. The person's condition and circumstances can change quickly as their level of dependency increases.
- Telecare can only be effective if the appropriate response is available when an alert is raised. A care network needs to be in place. If there is no responder service available and the person does not have a carer, then telecare has limited use, particularly as dementia advances.
- Telecare has a key role to play in supporting carers. It reduces carer burden, by providing reassurance and reducing the perceived risks of independent living.
- People with dementia lose their skills in a similar order as to how they gained them. Learning to walk is one of the last things to go, followed by swallowing.
 - In the initial stages of dementia, telecare can help with memory prompts.
 - During the moderate to severe stages, a more complex array of passive sensors can be useful to monitor activities of daily living and movement.
 - In the end stages, a person with dementia needs 24-hour care. Once someone is immobile, telecare has less of a role to play. However, equipment such as enuresis sensors, can still play a role in maintaining dignity and wellbeing.
- Telecare is still a peripheral service, and therefore it is not covered in all staff training. Staff confidence can often be a barrier to telecare. Thorough staff training is central to overcoming many of the barriers to telecare.
- There is a lack of awareness of telecare to support older people with dementia. Public awareness of telecare equipment needs to be raised.

Section 2: Notes from the Category One Interviews - Professionals Involved in the Development and Delivery of Telecare

General Information:	
Name:	Helen Nicholson
Date of interview:	14 th November 2013
Job Title at the time of interview:	Telecare Officer at Dorset County Council
Involvement with telecare:	Helen qualified as an Occupational Therapist in 2006; a role which frequently involved working with people with dementia. Helen then took on her role at Dorset County Council focusing on telecare service delivery in 2011. Helen was responsible for establishing the Lifestyle Monitoring Pilot study for people with dementia that was due to launch in February 2012.

Opening question

- **What do you see as the main aim of telecare?**
 - Basically, to help people to remain in their own home for as long and as safely as possible.
 - Helping people to be in their own home and engage in the community.

Implementing telecare

- **What are the main factors that affect whether a person with dementia can have telecare?**
 - If the person is functioning, is impaired to the point that day to day activities carry a risk that could be managed if we knew it was happening. Telecare is about minimising that risk.
 - People could benefit from telecare much earlier but the council will focus on minimising the risk associated with independent living
 - Carers – supporting unpaid carers. Telecare can really lift the threat of the perceived risk which can affect their ability to care.
 - Telecare can help both with the real risks, for example, by using 'Just Checking', but it can also help with the perceived risk.
 - How we deliver the service, telecare provides support in a different way. It means we can be less heavy handed with proactive care rather than planning for just-in-case. More of a light touch. Reactive care because we are alerted sooner.
- **What other forms of support need to be in place for the individual for telecare to be successful?**
 - For the level of need that comes in to social services, it is about how we tailor support, make use of family carers and informal carers. They need to have someone to respond to a pager. "Telecare is only as good as the person responding to the alerts."
 - Telecare is about people, not about equipment, it is about maintaining independence.
 - Independent living depends on local resources linked into care lines. Protocols need to be in place.
 - In urban areas, response services are easier to implement and are being used in other parts of the country successfully.
 - Dorset County Council are piloting a response service in Dorchester and Weymouth with Care South. They've had success in Somerset, but the challenge is how to supply an equitable service across Dorset as there is the issue of rurality.

Appendices

- *Re-ablement is a massive opportunity to install and embed telecare whilst support is in place.*
- *The fall back for any care line is the emergency service. However this is a finite resource, it is important to retain a good relationship with the local service and important not to abuse that relationship. If they are called out for too many false alarms, they can decline to attend. It is about partnership working. False alerts could be caused by equipment failure, or be down to a bad assessment.*

➤ **What particular pieces of equipment do you think have the greatest benefit for people with dementia?**

- *Any passive trigger, but it depends on stage. For people with the early stages of dementia, which is usually before the person gets to Dorset County Council, mobile phones, reminders and apps; these pieces of interactive technology can be good for the early stages whilst the person still has the capacity to understand.*
- *GPS devices are good for mild to moderate dementia.*
- *In the later stages the person with dementia is less likely to engage.*
- *Moderate to severe dementia, people tend to be at home more, they leave their house less, this is when passive triggers are useful to monitor the risks of activities of daily living. For example, cooker and heat sensors.*
- *If the person has a carer, the telecare can help support and continue to care. This is where a lot of stand alone stuff is useful. However, stand alone equipment is not driven towards independent living.*
- *If the person lives alone, passive sensors going through to Care Line are great as an incident could just be a phase or a one off and the telecare can highlight if it is a potential problem beginning.*
- *Frequency of alerts can give an indication of problems and aid assessment.*

➤ **What are the main factors that you think affect telecare uptake by people with dementia/their carers?**

- *People's awareness of telecare affects the uptake. "People just don't know this stuff exists".*
- *"They don't know how to use it". Then there is too much information when they do find out. There is insufficient impartial/simple information.*
- *There is a culture of not wanting telecare, even though the person may use phones and remote controls. However, this can change as technology becomes more acceptable; for example, skype, internet etc.*
- *People are not making informed decisions about the equipment, they are deciding based on the marketing.*

Impact on Quality of Life

➤ **What do you think are the key benefits for telecare users with dementia/their carers?**

- *The benefits depends on the stage of dementia*
 - *It provides a huge support to well-being*
 - *Huge reassurance*
 - *They can continue day to day lives*
 - *It is non-intrusive*
 - *It is for their convenience*

- *In terms of quality of life, it is about the services around the telecare. You cannot give a person a piece of kit and just expect that to help. It is about appropriate application with follow-ups etc.*
- *Telecare can absolutely help to improve the quality of life for carers. The more support provided alongside the telecare, the better the outcome, but it does depend on the point of installation.*
 - *There was one man caring for his wife in a caravan park, everything he did was for his wife. She had attachment issues, he struggled to leave her in a room on her own as she would always get up and try to find him, which put her at risk of falling. He was so stressed he wouldn't accept anything. With encouragement, he had one chair sensor installed. The success of this one installation led to him being willing to accept more support, a bed sensor and bathing equipment.*
 - *It's about how telecare is introduced to people, you shouldn't try and overwhelm them with equipment.*
 - *"Try to find the smallest thing to make the biggest difference".*
- **Based on your experience, could you give some examples of when telecare has been particularly helpful for someone with dementia and/or their carer?**
 - *Lady with dementia who was generally happy sat home watching TV had a son living just round the corner. She didn't drink a lot due to her dementia, and consequently developed a UTI which caused her to wander. She ended up in hospital for several days because the police picked her up and took her to a place of safety. They installed a property exit sensor so that the son could intercept her if she tried to wander at night.*
 - *There is a lady living at home with a daughter living 20 minutes away. Her other daughter lived up North and denied that the Mum had a problem. Neighbours started to notice her leaving the property and wandering at night, so they installed a verbal prompt at the door to remind her to go back inside and they all had a giggle whilst installing it. The pattern of alerts raised by the property exit sensor really helped the sister up North to understand the situation better, so this was really fantastic.*

Issues with using telecare for people with dementia

- **What are the limitations of using some of the pieces of kit? Are there any pieces of equipment that should be useful but aren't? and if so, why is this?**
 - *Acceptance of something new*
 - *Not wanting gizmos*
 - *Don't recognise what it is for*
 - *Don't recall why it is there*
 - *Situated cognition. Someone with dementia uses environmental cues instead of memory, which is why hospital admissions can be so difficult.*
 - *The person may be distressed by the equipment*
 - *They may struggle to remember how to operate it*
 - *You have to ask at assessment, 'does the equipment interfere with their routine?'*
 - *There was a lady who turned off all the sockets at night, therefore she turned off all the equipment. Understanding this helps to know whether the equipment is appropriate. The key is a good assessment, you cannot know enough about a person.*
 - *Most kits should be useful, it is lack of awareness and lack of priority of individual's unique nuances that impact the equipment's effectiveness. Effectiveness is often associated with equipment, but in reality it relies on assessment.*

➤ **What are the main difficulties with using telecare for someone with dementia?**

- People think they need to gain consent, but in reality telecare could be the least restrictive way of keeping the person in their own home, which may be their expressed wish.
- It is important to educate carers to understand dementia as well as telecare. Telecare might not help if there is a social or interactive problem between the carer and person with dementia.

➤ **Are there any circumstances where you would consider telecare to be inappropriate for someone with dementia?**

- This is down to assessment and what fits in for that person.
 - “Make the telecare fit the person, not the person fit the telecare”.
- Yes it can definitely be inappropriate if it is making the person change their routine, and their routine is what is keeping them at home.
- It needs to be set up appropriately for the person. It needs to be customised for the person. It needs to be reviewed, it should not just be put in and left.

➤ **Based on your experience, could you suggest the most common reasons for telecare not to have the intended benefit for the person and their carer?**

- Bad/incomplete assessment
- Bad installation
- Insufficient support
- Poor reviewing
- People have not taken into consideration that telecare will not do the work, it still needs the people. It has to be installed, reviewed and tweaked.
- Sabotage by the person or by someone else who might move it
- If it is not set up right or is faulty, that can quickly burn out a carer's patience.

➤ **What are the most common reasons for telecare being removed from the home of a person with dementia?**

- Death. Although more often than not it is not removed, but is left in there when the person has moved on.
- It can be unsuccessful because it wasn't right in the first place
- Because their needs have changed

➤ **How often, in your experience is telecare equipment removed because the service user feels uncomfortable with it or uses it in an inappropriate manner (e.g. places it in the fridge or drawer, unplugs it etc)?**

- No recent experience of installations. However, it can be common for people to be disturbed by the equipment or be distressed by the appearance of a care line.
- If the equipment is faulty, a carer may insist that it is removed.

Impact of telecare on care pathway

➤ **In what circumstances do you think telecare can postpone a residential care admission for someone with dementia?**

- This is so individual.

- *Where it allows the risk to be managed in such a way that negates the need for an individual to continually check on the person or have them in their sight.*
 - *Telecare is not going to replace the care of a person if they require someone to physically take care of them.*
 - *Wandering at night used to be a trigger for residential care, now that risk can be managed with telecare.*
- **What are the key factors that affect how long someone can be supported to remain living within their own home?**
- *This depends on the resilience of the support network.*
 - *Skill and resources of formal carers and the cost of providing that care.*
 - *Care is always debated based on need, not on cost.*
 - *At times care packages can exceed the cost of residential care*
- **Can telecare reduce the number of monitoring based care visits?**
- *Yes. What is the quality of a fifteen minute interaction? We have a duty to provide something a bit better than that. Allow the person to engage with the community, allow the person to re-engage and maintain independence.*
- **Can telecare reduce the frequency of hospitalisation or length of stay for people with dementia?**
- *Yes, depending on the reason. If there is a fire risk, telecare can raise the alert earlier. Falls, the quicker the response mitigates the consequences due to a long lie.*
- **Can telecare help care staff to better allocate their time?**
- *Yes. Appropriate the use of telecare assuming that it is being used appropriately.*
 - *Before Just Checking, we could still use movement sensors to check the occurrence of particular behaviours. "Lifestyle monitoring is invaluable as an electronic advocate for people who cannot reliably report on their routine".*
 - *Lifestyle monitoring supplies a true picture in the least restrictive way possible and shows what their routine actually is.*

Groups which benefit most from telecare

- **Are there particular client/ patient groups of people with dementia for whom telecare is more or less beneficial?**
- *It is of most benefit to people with the early stages who can understand what it is for and can interact with it.*
 - *It has a perceived benefit and they understand it can help them.*
 - *For people with moderate dementia, the passive sensors are best for keeping someone independent. But in reality, it is the carers who are the main people to benefit. It provides peace of mind to unpaid carers, for example, it can allow someone to sleep in their own bed at night, knowing they will be alerted to an emergency.*
- **How significant is the stage of dementia when considering how beneficial telecare can be?**
- *Depends on the kit.*
 - *In the early stages you can have gadgets for support.*
 - *The mid to end stages need to be passive monitoring.*

- *At the end stages the person is not going to engage, therefore sensors like bed sensors and chair sensors to aid 24-hour care. These community based telecare packages are more focussed on the carer. At the end stages, you are more likely to need a telecare home package that supports the carer, or move the person to a care home.*
- *In the early stages of dementia people could be benefitting by responding to the alerts themselves. For the later stages, it is more an issue of safety. In the very end stages, there is very little to help. A person with dementia becomes child-like in their need for human contact. They need 24-hour warmth, nurture and comforting.*
- *Attachment theory*
- *People lose their skills in the same order as they gained them. Learning to walk is one of the last things to go, followed by swallowing.*

Telecare as a service

➤ **What are service user's experiences of using telecare and related services?**

- *Depends on the competence of the assessor and the competence of the installer. If the assessment and installation are good then the feedback is usually positive or neutral because the equipment has gone unnoticed. A bad installation can cause havoc.*
- *You should look into Mick's house, he trials telecare.*

➤ **In what circumstances would you envisage telecare being more cost effective than alternative care packages?**

- *If a person needs care, they need care. Sometimes people are given care when they don't actually need it. Care should be given to sustain, maintain and retain. Maintain skills and retain independence.*
- *We've got into bad habits of providing care.*
- *It is about making sure people are aware earlier that there are choices.*
- *We can make cost savings by changing the way we meet someone's assessed needs. "What is the smallest change that can make the biggest impact? It is about making sure that telecare is considered at this stage".*

➤ **What changes need to be made locally to provide an effective and cost-effective telecare service?**

- *Machine gun providers.*
- *A lot of focus on equipment and services*
- *Money focused*
- *Duty of care comes onto local authorities to lead a movement towards need and meeting need.*
- *Money and cost saving is the focus of manufacturers. They have a scatter gun approach, at some point it will hit and help someone.*
- *Staff need to know about outcomes. They need to learn about making referrals, to know when it is appropriate.*
- *Seeing it as a cost saving tool makes people kick back against it.*
- *Telecare relies on people to assess, maintain and review, to make sure it is meeting people's needs. Telecare won't work until services around it are improved.*
- *People will focus on the negatives and get put off easily.*

- *Providers do a lot of private work and often don't take into account that social service referrals are often far more complex. Providers don't seem to have the same sense of duty of care.*
- ***What criteria would you apply if you had to evaluate telecare services?***
 - *Outcomes for the people*
 - *How long did they remain at home?*
 - *How long did their care package remain stable?*
 - *Effect on hospital admissions*
 - *Return home post-respite*
 - *Cost of care over time with and without telecare*
 - *Length of time in hospital/residential care admission*
- ***How do you think health and social care services could benefit from telecare?***
 - *They can benefit by working together on it. Telehealth and telecare can both work to help people to remain at home independently. Anything to support people to remain independent should be promoted.*
 - *The raised profile of telehealth makes telecare look like the poor relation.*
 - *It also helps in terms of information sharing, making sure people get what they want.*
 - *People either get nothing or have everything thrown at them at once.*
- ***What do you consider to be the main problems with mainstreaming telecare for supporting people with dementia?***
 - *There are a lot of outdated beliefs on what the equipment is and does.*
 - *Staff are so busy and hold on to any negative views.*
 - *The focus on cost means staff reject the equipment.*
 - *People think it is complicated and worry that they will need to know everything.*
 - *Nervousness*
 - *Budget pressure – who is going to pay?*
- ***What do you think could be done to increase awareness of the benefits of telecare for people with dementia?***
 - *"Clone me"*
 - *Create a good single point for information.*
 - *Avoid the information overload of the world wide web.*
 - *Has to focus on the model/culture of telecare use. People need to realise they don't need to know everything, just about the person. They need to be willing to try new things.*
 - *"If we do what we've always done, you'll get what you've always got. If people want different outcomes, then they need to be willing to try new things."*
 - *Telecare needs to be more in the public domain, there is a huge gap in public awareness. People need to know it can support at different stages. There need to be bigger marketing campaigns, get it on Eastenders.*

General Information:	
Name:	Katherine Barbour
Date of interview:	20 th November 2013
Job Title at the time of interview:	Telehealth/care Programme Manager from the Wessex Health Innovation Education Cluster
Involvement with telecare:	Katherine has extensive experience and knowledge relating to both telecare equipment and dementia. From 2009 to 2011 she was a consultant for the Department of Health, South East England and was involved with deploying the National Dementia Strategy in the South East Region.

Opening question

- **What do you see as the main aim of telecare?**
 - *Maintaining independence*
 - *Enabling people to choose to remain at home, as long as they wish to remain in that situation.*
 - *Telecare has a role for supporting carers to make sure they feel their relative is safe.*

Implementing telecare

- **What are the main factors that affect whether a person with dementia can have telecare?**
 - *Structural factors, such as how telecare is established in that area. Is it something that is discussed at every panel? Is there leadership for it?*
 - *Strategy – part of the way to deliver care*
 - *Process – embedded when you go to panel. A simple system with a range of products.*
 - *Finance*
 - *People – people need training and understanding (Hampshire County Council found in areas such as Petersfield where the project office is based, had the highest referral rates. Telecare needs champions in all offices. Telecare uptake can be affected by location of the telecare officer.*
 - *These four things should be seen as interlinking circles*
 - *Specific to dementia: “Staff’s fears about the complexity of dementia can lead to people thinking that telecare is not suitable. They may decide not to use it as there are so many issues around capacity to consent. There is a fear of bringing in the mental capacity act.”*
 - *For the individual, it is an issue of accepting technology to deliver care. At present, we will be dealing with mostly people over 80, who are less exposed to technology.*
 - *If the worker has confidence in what they are offering, the user will have more confidence.*
 - *The device must be simple to use or require no interaction. If interaction is required, then degree of dementia becomes an issue.*
 - *There needs to be sufficient awareness of the range of products. Finding the product that matches for the person.*
 - *There is an issue of cost. If a person actually has to pay, this can be a factor in people saying no.*
 - *There is also the issue of a person having to accept that there is something wrong with them. They might not accept that they are having problems. “A pendant alarm can be*

seen as a badge of disability.” Acceptance of a disability can be a block. “It can be a hard sell for the individual”.

- *The limited range of equipment that a Local Authority has can restrict, as they might not be able to offer the right kit.*

➤ ***What other forms of support need to be in place for the individual for telecare to be successful?***

- *The Local Authority can sub-contract training etc and supply. There needs to be a technician with people skills who can follow up and fix things, or Social Workers could be trained to install.*
- *There needs to be family acceptance.*
- *The building you live in needs to be happy for you to install the equipment, some places won't let you.*
- *Internet signal; 3G, 4G.*
- *Concern that the family may be misuse the equipment or sell the equipment.*

➤ ***What particular pieces of equipment do you think have the greatest benefit for people with dementia?***

- *GPS*
- *Fall sensors. If you think of the costs associated with falls, if it is a critical fall resulting in a hip fracture that could result in surgery, and therefore anaesthetic, and then rehabilitation.*
- *Just Checking to help assessment and help decision making.*

➤ ***What are the main factors that you think affect telecare uptake by people with dementia/their carers?***

- *Lack of awareness. There is a lot of health and care staff who do not understand telecare.*
- *People don't ask for it.*
- *Staff worry, “What are the ethical issues? Could there be a comeback if I prescribe this kit?” or “How long will this take me to prescribe this?”*

Impact on Quality of Life

➤ ***What do you think are the key benefits for telecare users with dementia/their carers?***

- *Key benefits for the individual is piece of mind, and for the carers it is piece of mind. Having this piece of mind can improve quality of life.*
- *Telecare allows for a rapid response, preventing harm to others; for example, a smoke alarm allows people to still use a gas cooker etc.*

➤ ***Based on your experience, could you give some examples of when telecare has been particularly helpful for someone with dementia and/or their carer?***

Appendices

- *When I worked with a woman in Southampton with paranoid delusions, she wanted to blow up her house. By providing her with medication and giving it time to take effect and installing a gas switch-off valve, she was able to return home.*

Issues with using telecare for people with dementia

- ***What are the limitations of using some of the pieces of kit? Are there any pieces of equipment that should be useful but aren't? and if so, why is this?***
 - See below
- ***What are the main difficulties with using telecare for someone with dementia?***
 - *The main limitations are not getting support to someone early enough in their care pathway.*
 - *Solutions often need to involve carers, who are often at the end of their tether.*
 - *Cognitive impairment is an issue when starting to use something new.*
 - *Some people are incredibly grateful for support and help put it in.*
 - *People typically want carers and day centres to help them provide support, but we should include telecare in the range of services offered.*
 - *Social Worker's confidence can often be the main barrier to telecare.*
- ***Are there any circumstances where you would consider telecare to be inappropriate for someone with dementia?***
 - *If the dementia is overlaid by psychosis and paranoia. The paranoia is likely to be an issue with the installation of the equipment.*
- ***Based on your experience, could you suggest the most common reasons for telecare not to have the intended benefit for the person and their carer?***
 - *Lack of time – not giving the person chance to get used to it.*
- ***What are the most common reasons for telecare being removed from the home of a person with dementia?***
 - *Death/I'm not sure*

Impact of telecare on care pathway

- ***In what circumstances do you think telecare can postpone a residential care admission for someone with dementia?***
 - *In terms of putting in place a blanket of services, it means you know the person is getting up etc, which alleviates family anxiety.*
 - *You could set up a service so that the person could just simply call for reassurance. This would prevent the repetitive calls to carers.*
 - *You could set up skype calls to alleviate loneliness*

➤ **What are the key factors that affect how long someone can be supported to remain living within their own home?**

- Physical health
- Faecal incontinence
- Death of a carer
- A step change in physical/mental health
- Cuts in budget for the Local Authority
- House burning down. *I knew a man in a caravan that burnt down, he was a lovely old boy.*

➤ **Can telecare reduce the number of monitoring based care visits?**

- Yes, it can provide medication support. *You could have a phone or skype conversation instead.*
- TV reminders to remind someone that their carer is coming, or that the day centre is within three hours time.
- It cannot replace washing or making breakfast.

➤ **Can telecare reduce the frequency of hospitalisation or length of stay for people with dementia?**

- Welcome Home scheme. *If a carer is not available for four days when someone comes out of hospital, then telecare can be used instead.*
- In terms of preventing admissions, if you can get to a person within an hour of falling, rather than 24 hours, you are much more likely to prevent a hospital admission.

➤ **Can telecare help care staff to better allocate their time?**

- Clearly, you can get a series of conversations.
- Just Checking helps with decision making relating to visits.

Groups which benefit most from telecare

➤ **Are there particular client/ patient groups of people with dementia for whom telecare is more or less beneficial?**

- Telecare should be used as standard, so that it predates any cognitive impairment.
- Not seeing people early enough means there is less opportunity for the successful deployment of telecare.

Telecare as a service

➤ **In what circumstances would you envisage telecare being more cost effective than alternative care packages?**

- In the instances where you just want to check in on someone, Just Checking is a more cost effective system. *The same goes for medication dispensers.*
- Preventing fires. *The cost of a person dying in their own home due to fire is over £1,000,000.*

➤ **What changes need to be made locally to provide an effective and cost-effective telecare service?**

- Some counties have sub-contracted telecare, some have it in-house.
- You need sufficient numbers for it to be cost effective – economies of scale.
- Many telecare services are heavily subsidised.
- To make it more cost effective, you can add in extra functions, such as lone working, telehealth and CCTV monitoring.
- There are structural issues, for example, training, there needs to be a strict process in place. You need to incorporate the right senior leadership. All elements need to be addressed.
- People have to stay around and stay in their jobs.

➤ **What criteria would you apply if you had to evaluate telecare services?**

- From a customer's perspective, you need to look at what impact this has had on the individual.
- For the staff, you need to look at the impact on the care pathway.
- For the process managers, you need to look at a number of factors.
 - Outcomes for the person
 - Individual cost savings
 - Cost savings for the organisation
 - Environmental impact
- Functionality of the kit. You need to look at problems with its operation. Key Performance Indicators for install and follow up.

➤ **How do you think health and social care services could benefit from telecare?**

- Opportunity for integration.
- Enabling conversations.
- I think you need to rephrase this question, from a strategic/structural point of view
- It's a huge enabler, "I would be really pushing for that to be integrated."
- Chris Ham pushes for the integration of areas
 - Coordination
 - People meeting
 - Shared budget
 - Shared goals
- But it was upsetting for me that IT was so far down the list.
- By getting that data about people, you can make better decisions across health and social care. Smart decision making. You could anonymise telecare data to make better decisions.

➤ **What do you consider to be the main problems with mainstreaming telecare for supporting people with dementia?**

- Very conservative, is a risk adverse service model.
- Dementia only recently started to have a higher profile thanks to the National Dementia Strategy in 2009. There is still a lot of work to be done on modernising.
- Dementia advisors and the Alzheimer's Society. They are there but the coverage of them is not huge.

- *Because telecare is still a peripheral service, it is not covered in everyone's training.*
- *The preventative technology grant in 2006 helped to embed telecare, but not with a dementia focus.*
- *In the mainstream support for older people, there is a lack of awareness for telecare products. There is no high street shop with products on show, we need to publicise them more and have a good range of products.*

➤ ***What do you think could be done to increase awareness of the benefits of telecare for people with dementia?***

- *Originally, London telecare, now UK telehealthcare has a role in raising awareness. They did an advertising campaign in London on the back of buses.*
- *There needs to be a public awareness campaign.*
- *We need Carers UK and other big charities to come together.*
- *We need other carrots to dangle, like EU funding, for example, projects like 'Dallas'.*
- *I went to Scotland, up there they have a joint strategy for telecare and telehealth. They have a hub for running events, they are a smaller country with a closer government. They have huge rural areas, and therefore pursuing telecare was a no-brainer.*
- *Clinical leadership is the key for telecare development.*
- *People need to be given more scope.*
- *Digital health institute established.*
 - *Explore – bringing academics and others together.*
 - *Experience – make GP's surgery or family home to test equipment*
 - *Laboratory – deploy products for final refinements*
 - *In the future there needs to be partnerships – evaluate as you go along.*

Any Further Comments:

- *Telecare is the right direction. It is how care needs to be delivered. Our generation will expect care to be delivered in that way, we are used to apps etc.*

General Information:	
Name:	Celia Price
Date of interview:	8 th January 2014
Job Title at the time of interview:	Co-founder of Just Checking
Involvement with telecare:	<p>Celia started off working in a consultancy that got a project working with the European Research and Development Programme looking at assisted living. They were specifically interested in technology and dementia. Listening to family concerns lead them to develop a series of sensors for monitoring; they specifically wanted to use sensors and not cameras in order to respect privacy. Working with her husband, Celia developed a prototype and took it to Northamptonshire County Council. The idea was for it was to be used for family members, to provide reassurance, but they took this prototype to a social worker who was keen to use it in her work to aid assessments. It had not occurred to them that it would be useful for this purpose, so this really was a grass roots company and developed from this feedback. This lead to Celia doing a Masters in gerontology as she was interested in the sociology of ageing and felt this would be good for her professional development. Eighteen months in, she could see that a trial could be set up for Just Checking, and she had contacts in Warwickshire. This lead to her running a pilot study for her Masters dissertation. After the trial, the preventative technology grant came in, which gave councils a pot of money to play with and use towards telecare, which gave Just Checking the opportunity to take off.</p> <p>In 2014, out of the 205 councils with adult social service responsibilities (CASSRs)*, Just Checking was used by 160 – 165 of them. Social services are the main interest to Just Checking because they are responsible for meeting social care needs. Just Checking monitors the kit held by the Councils on an on-going basis.</p> <p><i>*CASSRs are generally County Councils unless they are a unitary authority like Southampton City Council</i></p>

Opening question

- **What do you see as the main aim of telecare?**
 - The main aim is to promote independence using technology, allowing people to do more for themselves.
 - Allowing people to call for help when they need it.
 - To provide data to identify when help is needed.
 - Helps them to be more independent most of the time.
 - Puts the control back with the service user.

Implementing telecare

- **What are the main factors that affect whether a person with dementia can have telecare?**
 - Just Checking is passive, so is different to most telecare systems. It is a monitoring system.
 - Looking at routines
 - Assessment
 - Scheduling care appropriately

- *An example of bad scheduling is when for example, a person is getting out of bed to let in a care worker and then returning to bed. This suggests that this is just bad timing.*
 - *An information system on which to base other care, including telecare.*
 - *Using telecare to remind people what to do is a good use of telecare.*
 - *Having an alarm activated is less useful as it can be distressing.*
 - *In most cases, passive devices are the most suitable.*
- **What other forms of support need to be in place for the individual for telecare to be successful?**
 - *Any person with dementia needs to have a care network around them. For Just Checking to work, someone needs to take an interest in that person. For a care worker to become involved, that assessment has to be triggered by something.*
 - *Just Checking can show that yes, there are lapses in memory, but that person is a long way off residential care.*
 - *Using telecare can help informal carers to focus on social interaction rather than focus on monitoring the person, more meaningful visits.*
 - *Helps the carer to start putting effort into more meaningful social activities.*
- **What are the main factors that you think affect telecare uptake by people with dementia/their carers?**
 - *Difficulty is timing; there is only a certain period when someone may be open to the idea of telecare or Just Checking.*
 - *With the early stages of dementia, people delay responding. During this period, they are not ready to accept any help. Then there will be a crisis, an incident or two that causes people to concede that there is an issue. If the crisis results in a social services referral or a GP visit, then they can highlight the usefulness of equipment like Just Checking.*
 - *Finding the point in time where they are ready to accept that help is needed. This needs to coincide with them acknowledging that there is a real problem.*
 - *Just Checking makes a good number of sales through social service installations, when families do not want to let go of the equipment. They end up buying it privately.*
 - *Using Google ad words to ensure Just Checking comes up in Google searches. They invest a lot of time in making sure the equipment is flagged up. There is a lack of awareness about telecare equipment. You need to hide the information on the back of something else...for example, someone had searched for 'CCTV for dementia' when a son was trying to find a way of keeping an eye on his Mum. At which point, Just Checking was flagged up in his search results.*
 - *There needs to be a family agreement on using the system. The decision to buy or rent is not made by one person, it is usually a family decision.*
 - *You need to present the equipment at the right point in time.*
 - *If people get the opportunity to sample the equipment, then they are usually sold and love it. That is why local authorities being able to offer the equipment for a trial is a good way to stimulate uptake.*
 - *Just Checking do a lot of work with memory clinics which fall under the NHS. They signpost on to other services. However, memory clinics are still following a medical model. It is not in their ethos to promote other information or other companies.*

Impact on Quality of Life

- **What do you think are the key benefits for telecare users with dementia/their carers?**
 - *Giving back independence*
 - *Focussing on what they can do, and not what they can't, and letting them get on with it.*
 - *The more you rush in and do for someone, the less independent they will be.*
 - *The person may have little concept of how needy or how able they are. Just Checking provides more objective information, so that care can be pitched at the right level.*
 - *The phrase 'peace of mind' comes back to us all the time.*
 - *A recent survey of our family users said that they felt it helped them to understand the situation and therefore allowed them to move forward.*
 - *It is easy to tackle the problem when you know the size of the problem, rather than basing it on pieced together information.*
 - *People will often try to hide their problems with dementia, they will try and control the situation to avoid making a mistake in front of people. Therefore, they can appear quite passive in front of family members, but are then quite happy to get on with it when they are alone as there is no one to chastise them when they are alone because it doesn't matter.*

Issues with using telecare for people with dementia

- **What are the limitations of using some of the pieces of kit? Are there any pieces of equipment that should be useful but aren't? and if so, why is this?**
 - *Interpreted as limitations of Just Checking. Ideally, they would like to know if someone has fallen. Vascular dementia effects balance and increases the risk of falls. They would like Just Checking to help with the perceived risk/fear of falling. Just Checking are currently working on algorithms to flag up falls. Quiet care uses algorithms, but they are not that sophisticated, they basically just count bathroom visits for example.*
 - *Just Checking now has alerts for family users*
 - *Not up and about*
 - *Visitor not arrived*
 - *Exit at inappropriate times*
 - *Front or back door left open*
 - *These alerts are easy to generate from the data, whereas falls need to look at transitions from rooms using baseline data. Fall detection is seen as the holy grail.*
 - *Pets can trigger the sensors, but they can just be placed higher to avoid this. When you know the person and their situation, you learn to recognise certain blips in the data; for example, a cat jumping onto the work surface may trigger a funny. So it is all about understanding the context, the person, and their situation.*
 - *In the Warwickshire trial, there was a mouse detected. They guessed this was the cause of the strange pattern on the graph in the middle of the night, so set a trap and caught a mouse.*
 - *They commonly pick up care visits being missed. In the Warwickshire pilot study, they picked up that the carers were not visiting one client at weekends.*
 - *You need to go in with an open mind, the equipment reveals what is really happening.*
 - *You might install because the neighbours say that someone is out at night, but then it might turn out that it is a one-off.*
 - *The equipment puts a stop to wrong assumptions.*

- *In Just Checking's experience, people are often better off than first thought; better than the worst fears of the family, as families often over-worry.*
 - *Local Authorities are very interested, as there might not need to be as much care as first thought. Initial approach was to slap in three care visits a day around meal times, whereas this is not needed for a lot of people.*
- **What are the most common reasons for telecare being removed from the home of a person with dementia?**
- *Assessments are the main reason for Just Checking to be removed. Only a tenth of the systems are sold to private individuals, therefore, the assessment is for a set period, so removal happens at the end of this time. Very few pieces of equipment are used for on-going monitoring.*
 - *Social services have to assess and commission care, they do not directly provide it.*
 - *Death is the main reason for removal or because the person has moved in to residential care. In other words, a major change in circumstance.*
 - *Introducing someone to the system needs care, those with capacity can permit the install, if no capacity, then it is installed in the best interest. If it is being installed for an assessment, then you can almost always argue it is being installed for the best interests. One Local Authority is looking into the legal side of making it a rule that Just Checking can be used for assessment. If the person wants to stay at home, then, in my experience, people are willing to do anything if it helps them stay at home.*
 - *People removing the sensors is a more an issue with learning disabilities. People generally seem to forget about the sensors once the kit has been installed. The main hub can be easily concealed. We've learnt where to put the kit, so that it is not in your face/discrete.*

Impact of telecare on care pathway

- **In what circumstances do you think telecare can postpone a residential care admission for someone with dementia?**
- *Many examples. Staffordshire County Council produced a report with the department of health for which twenty one people at the point of residential admission were assessed with Just Checking, thirteen remained at home as a consequence of this assessment.*
 - *Just Checking helps to find other options to residential care. It offers a true picture in order to consider other options.*
 - *For people with dementia, staying at home is an important framework to hold on to. People have set routines in familiar surroundings. If you move them somewhere unfamiliar, the scaffolding supporting them is gone. It can be very powerful for people to remain at home.*
- **What are the key factors that affect how long someone can be supported to remain living within their own home?**
- *The circle of care, the people who are interested in you and are able to support you.*
 - *The media focus on loneliness and isolation, but people are often quite self-contained.*
 - *Understanding the person means we can gauge them better.*
 - *Someone interested enough to keep checking on them.*

Telecare as a service

➤ **What changes need to be made locally to provide an effective and cost-effective telecare service?**

- *Local Authorities are not going to provide Just Checking, they use it for assessments. The funding situation makes it very difficult. Should it be free? But there are very few free services. It is often a misconception that Social Services is free. Unlike the NHS, Social Services is means tested, and not universally free for all.*
- *Local Authorities are not very good at running services, they don't go out there and promote them. They are usually the gatekeepers trying to slow the flow of people, so it does not come naturally to them to seek customers. Therefore charities are better at this as they are used to fighting for their customers.*
- *Social Services are almost in the way, they act as a middle man for home care. This is the not the way to provide care. The relationship should be between the home care and the person. At present, if you have a complaint, it has to go via Social Services, which slows the whole process down. The individual is more in control if it is a direct relationship.*
- *Hampshire County Council focus on getting people to help themselves, they only assist those with the highest needs. Whereas, the Northern Counties are more paternalistic about their services, giving them out with high subsidies or even for free, but this is not sustainable. Councils were told to make a 3% saving annually, they only achieved 2.7% and now the aim is to raise the saving to 3.7%. Councils have already trimmed where they can, now they will have to target Social Services. In the end, Local Authorities will have to end up simply being the safety net for those who can't help themselves. I don't know how telecare will fit with this, because of telecares preventative role.*

➤ **What do you think could be done to increase awareness of the benefits of telecare for people with dementia?**

- *Local Authorities are the point of contact in a crisis. They need to do more to offer telecare in the mix, they are a good point of contact in the advice chain. They have been very mixed in their success for information provision.*
- *Social workers need to be able to advise on a range of things. Local Authorities push to outside services, for example, Age Concern. They often help to fund these services or provide space to third sector organisations. For example, Alzheimers Society to provide information.*
- *Suppliers need to promote to consumers, which requires quite a big budget. Traditionally, this was a business to business industry, not set up for the consumer market. For example, lots of Care Line alarms being sold to a Local Authority.*
- *It would be lovely to see telecare sold in Asda, but it is not possible yet due to the margins.*
- *Telecare has come up through the social alarm systems, but social alarms were very cheap and installed on-mass in social housing. People expect the low cost associated with these alarms at just £3 per week, yet Just Checking is more like £16.*
- *The main problem is the lack of awareness, we should be targeting the next generation down, the family members. The older generation are not looking for technology solutions. However, attitudes will change as technology develops.*
- *Someone Googled, 'Can I monitor my parents through my phone?', this search term lead them to Just Checking.*
- *Just Checking can now be accessed via a mobile, last year they developed an app.*

Any Further Comments:

- *Just Checking is not there to control, actually if anything, it is the opposite, handing the control back to the person. Not having to overstep the mark. Door sensors are the alternative to locking the door.*

Section 3: Notes from the Category Two Interview – *An Individual with Dementia*

General Information:	
Name:	Mrs P
Date of interview:	10 th October 2013
Involvement with telecare: <p>Mrs P was diagnosed with Posterior Cortical Atrophy (PCA), a rarer form of Alzheimer's disease, in 2008. In the early stages of PCA people experience problems with their vision, literacy, and numeracy; as the disease progresses people develop the symptoms of Alzheimer's disease, such as memory loss and confusion.</p> <p>Mrs P is retired and lives at home with her husband. Mrs P has issues with her vision, which heavily affect her IADLs. Although Mrs P is excellent at adapting, she does require assistance. Mrs P's husband provides all of her care within their home; Mrs P relies heavily on him to maintain her lifestyle.</p>	

Opening question

➤ ***Please can you tell me a little about your diagnosis?***

- *Diagnosed in 2008 with PCA, a rarer form of Alzheimer's disease, which affects the back of the brain and sight.*
- *Eyes are healthy, the issue is in the part of the brain that receives and interprets the signals from the eyes.*
- *Started with loss of peripheral vision. Now all peripheral vision has gone. Narrow field of view directly ahead, which can be very disorientating, as she has no full view. Very easy to get lost.*
- *Neurologist says that memory is pretty good. Mrs P feels it is 95% intact. Sometimes finds that things fly out of her mind. Like a butterfly. However, at the moment, they do still come back.*
- *Feels short term memory issues link directly to loss of sight, as hard to remember where things are when you cannot visualise them.*

➤ ***How did you feel about your diagnosis?***

- *"I was less concerned by my sight; I was more worried about memory loss. The doctor merely said 'memory loss will be in later life hopefully'. It's a horrible thought. I cannot imagine it. It's just scary to know what is to come, that eventually my memory will go."*
- *"My friend's husband was diagnosed with it in his mid – 50s, he only lived for another 3 years. I feared the same happening to me."*
- *"It makes you enjoy life more; otherwise you are just taking it all for granted. The first thing we did after I was diagnosed was to go to Australia and take a trip on the Ghan Train."*
- *Very good overall health. Keeps active.*
- *Swims ½ a mile twice a week, by following a friend in the pool.*
- *Rides a tandem with her husband. Cycles up to 30-40 miles.*
- *Loves walking.*
- *Has a healthy diet.*

Living with dementia

➤ **What are your main symptoms?**

- *First symptom:*
 - *Had been driving 30 years, started to notice it was becoming more difficult; drove through a red light. Became worried about vision, so went to the Opticians. Noticed an issue when doing the Peripheral vision test. Was referred to hospital, where they did an MRI scan. They diagnosed mini-strokes and suggested she adjusted her diet and took aspirin*
- *Additional symptoms:*
 - *Kept tripping over, fell and broke wrist, walked into a door.*
 - *Returned to the doctor in 2008. There was a few months wait, so went to see a neurologist privately.*
 - *Scans showed the brain had shrunk in the particular area associated with PCA. They started with Aricept, which is used to treat Alzheimer's. Feels this has slowed the progression but does not really know how bad it would be without treatment.*
 - *Over the last 4 years vision has got less and less. Gave up reading in 2011. Using a magnifier won't work as it is not her eyes with the problem.*
 - *Father had Glaucoma.*

➤ **What factors would you consider to be most important to maintaining your quality of life?**

- *Still has a good social network.*
- *Meets friends regularly for coffee.*
- *They do the crossword together daily.*
- *Goes to the pub and enjoys live music.*
- *Goes cycling, swimming and walking.*
- *Friends understand what is wrong and help when out.*

➤ **What tasks do you find easy? What do you find hard? How have you adapted? How do you manage?**

- *Can no longer drive or read.*
- *Can no longer make dresses, decorate, or play badminton.*
- *Cooking – can prepare some dishes but has to be careful of burning herself.*
- *Shopping became an issue, so now she makes a list and they go together. Still in control.*
- *"I get very frustrated when trying to do something I used to so easily; for example I used to make dresses and decorate the house. So I try and find ways round things. At first dressing was very hard, I used to find myself wearing things the wrong way round or inside out; so I cleared out all the clothes I didn't wear anymore and then ordered those that remained. I also grouped things by colour. Now when I get dressed I lay my clothes out on the bed first, then I feel round them for the labels and seams. At night I make sure I put everything back in the right place. It is the same in the kitchen with the utensils; that way I can find them again. It's about taking it slowly and breaking the problem down to find new ways of doing things."*

- **How do you feel when you have experienced a period of confusion?**
 - Initially distressed
 - Frustrated

- **How does this impact on your quality of life?**
 - “There been a drastic impact on my quality of life, but what’s gone has gone, you can’t let it bother you too much. I can no longer sew or play badminton; but I focus on what I CAN do, and I let that take over.”

- **Do you live with someone who helps care for you? /Do you have support from friends or family living nearby?**
 - Lives with husband.
 - Daughter lives 2 hours away in Essex with her children.
 - Son lives in Brazil, they visit him once a year.
 - Last year went on her own as BA provided assisted travel.

- **How does the dementia impact upon your friends/family?**
 - Husband shocked at diagnosis, they both really struggled to come to terms with it at first but now they take each day as it comes.
 - Friends understand what is wrong and help/guide when out.

- **Is it important to you to remain at home?**
 - Would like to remain at home as long as possible, however: “I have told my husband when I get to the point where I don’t know what’s going on ‘don’t be afraid to put me in a home’. He needs to know he has my blessing. He shouldn’t have to cope with this on his own.”

- **Do you receive any outside support?**
 - After a fall she got in touch with the council, they provided a white stick. Will use the stick on certain occasions, but not all the time. For example, if catching the bus, it lets people know that there is a problem and that you may need some help. People tend to be really helpful when they see the stick.
 - Contacted a charity called Opensight (www.opensight.org.uk) based in Eastleigh, Hampshire. They will come and fill out forms for you. 60 pages of forms to fill out to register a disability with the council. With the charities help, now have access to disability living allowance. They also helped with a talking clock, audiobooks and a buzzer that can go over cups and sounds an alert when the liquid reaches a certain level to prevent the cup being over filled or over flowing.
 - No one tells you anything, you have to find it all out yourself. NO COMMUNICATION, between hospital, healthcare and social care.
 - Councils can be very helpful, but only if you speak to the right people. Retirement secretary from John Lewis suggested joining the Alzheimer’s society. Lady provided a lot of information and consequently they found out they can claim a council tax deduction which all helps.
 - Doctors don’t have enough knowledge about the condition to know disease progression. Could suddenly get worse quite quickly, they have no idea.

The use of telecare to support people with dementia

- **Were you aware of telecare prior to this interview?**
 - Yes, had attended Wessex HIEC telecare and dementia event.
- **Have you ever been offered telecare equipment?**
 - Not directly. Mainly just assistive technology, such as a speaking clock etc.
- **Do you think telecare could be something that you would be interested in using?**
 - Yes...they are happy to try any options to find the best fit for them. "If one route doesn't work, we try another".
- **What would be your main concerns about using the equipment?**
 - Concerns about using technology. Not confident with technology. Would worry if needed to interact with the equipment. Needs husband to use their current 'technology'.
- **What pieces of equipment do you think could be most useful for you? And why?**
 - Interested in Buddi, in particular for getting off the bus and becoming disorientated.
 - Concerned about the stairs, therefore lights that are triggered by movement might be beneficial.
 - Down the line: sounds alerts that let her husband know she is up. Alerts in the kitchen to remind her to turn things off.

Any Further Comments:

- "I think I'm quite lucky that I have got this far. Our generation has been lucky – born after the war, with no wars in our lifetime that have directly impacted on us. All the great music... What a lovely life to have lived."

Section 4: Notes from the Category Three Interview – A Carer's Perspective

General Information:	
Name:	Ms J
Date of interview:	28 th October 2013
Role as unpaid carer for person with dementia	
Ms. J, along with her father and uncles are providing ongoing support for Ms. J's Grandmother, who currently lives at home alone.	

Opening question

- ***I understand that it can be very challenging caring for someone with dementia; please could you tell me a little about your experience?***
- It is difficult to admit that my Grandma's dementia didn't really become apparent until my Grandad passed away. She had been becoming more forgetful, and slower, for example, in telling stories, but nothing that the family had been too concerned about. My Grandma had always been very active in the house and garden, but my Grandad had slowly been taking over doing all the jobs around the house. He had been ill himself, and required his meals to be cooked a certain way, it was for this reason that he took over doing the cooking that my Grandma had always done in the past. The family were not really in the house to be witness to any of the other jobs that my Grandad had slowly started taking over doing (for example, cleaning or washing), and he had been taking on these jobs, and caring for my Grandma up until he died without confiding in anyone in the family. This was upsetting for the family in itself, that we had not noticed that this had happened, and we had not been there for my Grandad. He had been witnessing a marked change in his wife of over 50 years without any support.*
 - My Grandad passed away in 2010, and it became quickly apparent that my Grandma was struggling with day to day activities. Something that the family has, and still does find challenging, is working out exactly what it is my Grandma struggles with, and what level of help she needs. My Grandma's needs, and therefore level of support, have changed over time.*
 - Initially, it worked well for my Grandma to have her shopping delivered to her, and she would microwave a ready meal and prepare some vegetables for herself at dinner time. Now, she is no longer able to remember that she needs to have lunch or dinner (let alone prepare these meals for herself) - we're not sure why, but she can have her breakfast no problem!*
 - At first my Grandma would still attend her group activities, getting there by her own means; church on a Sunday; walking on a Wednesday morning; and a church group on a Wednesday afternoon. However, my Grandma is no longer able to leave the house alone as she becomes quickly disorientated and distressed. We are lucky to have a day-centre that she goes to twice per week, where she is collected and dropped home by the staff there; and she still attends the church activities, picked up and dropped home by old friends. However, a frequent problem arises when she cannot locate her key, handbag, coat, or shoes.*
 - My Grandma can also no longer do the laundry, she would not know where to start in doing so, but it seems that the step in her mind to think to do the laundry has gone. My*

Grandma also struggles to remember to wash regularly, and she now has regular help to have a bath.

- My Grandma also struggles with remembering to take her medication. Initially it was fine to have a day-by-day medication box, but we now make sure she has her medication at dinner time.
- These are changes that have occurred slowly since 2010. In the past couple of months, we have become increasingly concerned that she is not remembering to have regular drinks during the day, and to go to the toilet.

➤ **What factors would you consider to be most important to maintain your loved one's quality of life?**

- To both myself and most importantly, my Grandma, it is important that she remains at home. She has lived in her home for almost sixty years, and it is where she feels safe. When having a relaxed sit-down conversation with my Grandma (not when we are out, or when we are in the middle of doing something, as this is when she can get quickly nervous and stressed), she is lovely company; so thankful for everything in her life, and "so pleased with how everything is going", but that will always be followed with "I'm so lucky to be able to stay here. I don't want to go anywhere else you know". I also think that there are certain elements of care for my Grandma that, at the outset, I found upsetting – mainly because I thought that she would hate it – but I think the fact that, for example, someone gives her a bath is fine, as it is in the bath in her own home. Although the family have discussed at a few points since 2010 whether a residential home would be better for my Grandma, we are all keen for her to remain where she is, as it is where she is most happy. Although she enjoys going out, you can tell that there is an underlying anxiety, which disappears when she is at home.

➤ **What are your thoughts on the use of telecare to support people with dementia?**

- I think that the use of anything that can help people to live in their own homes for longer is a good thing, and I am sure my Grandma would agree. I may be completely wrong, but I think that my Grandma has remained in her own home, and doing so well, because she still does as much as for herself as she can. If she were to be in a residential home, the need for her to think at all for herself would be taken away, and I could see her easily getting worse.
- Using telecare equipment would also relieve some of the 'background' worry that the family has. For example, whether my Grandma has left the front door open, or whether she has left a tap running. As far as we are aware these things have never been a problem, but there is always a concern in the back of your mind that this could happen one day.

Appendix 23: Full List of Labels used in the TeleDem Simulation

Label	Description
Personal Attributes	
lbl_person	Unique identifier recorded
lbl_GENDER	Male/female
lbl_hours of care required	This label is updated with each dependency state transition. It details the number of hours of care the person requires based on their level of dependency.
lbl_Age on Arrival	Life Span Calc
lbl_age at death	Life Span Calc
lbl_Updated Age at Reassessment	Used to update age at each review
lbl_Dependency Level	Records dependency level as a number: 1,2,3,4,4.5 or 5
lbl_Current Stage of Dementia	Records the person's current stage of dementia as a number 111=mild, 222= moderate, 333= severe, 999= dead
lbl_LifeSpan	Used for recording the life span of each person when they exit the model (die)
lbl_unmet need	Holds the value for unmet need based on the unmet need calculation.
lbl_informal carer	Type of informal Carer 0= no carer, 1 = cohabiting spouse, 2 = other co habiting, 3 = local/not cohabiting
lbl_InformCareHrs_ AVAIL	Maximum number of hours the carer can be available to provide care/supervision
lbl_Carer ZBI Score	The Carer's perceived level of care burden, recorded as a ZBI score.
Routing	
lbl_complex TC unavailable	Used to aid routing from the 'Referral' work centre if telecare was unavailable at last referral.
lbl_TC Unavailable	
lbl_MILESTONE	Used to represent the person reaching a milestone point in disease progression. This label is assigned through the Dependency Statechart and directs people through review to referral.
lbl_First_ReferralRouting	Main routing label for directing work items (people) out of the referral work centre.
lbl_care package check routing	Routing label for whether someone receives Telecare alongside a Community Care Package.

lbl_comcare routing check	Routing label that checks for existing package of care.
lbl_Review Routing	Used to route out of the 'Review of Care Needs' work centre. VL is used to determine if people should be routed back to their previous care service or onwards for a referral.
lbl_routing Complex TC equip check	VL checks whether the person currently has Telecare equipment installed at home. Then this label is used to route either straight to the care service if they have existing equipment or via a work centre to allow the person to collect the equipment resource if it is available.
lbl_routing TC equip check	
lbl_service routing	This routing label allows the entities to be routed back to their previous care service if they do not need a new referral. It also acts as an information label in various blocks of code, to identify which care service is currently being used by the work item (person).
lbl_carer stressed or coping at diagnosis	These labels are used in the 'Decide if Support is Required' work centre, immediately after arrival and diagnosis; to establish whether a person needs to be routed to referral after they receive their initial diagnosis or whether they should be routed to 'No Support' or 'Informal Care ONLY'. 'lbl_post diagnosis decision routing' is known as label based distributions, and contains the probability profile for people being routed to referral or choosing to return home without additional support.
lbl_requires support following diagnosis	
lbl_post diagnosis decision routing	
Calculations	
lbl_time stamp arrival	Simulation time when person arrives in the model.
d	Label used to record the number of days a person has been in the simulation by subtracting 'lbl_time stamp arrival' from the current simulation time.
y	Represents the number of years a person has been in the model by dividing the number of days since they arrived in the model (d) by 365 (number of days in a year)
lbl_Updated Age at Reassessment	This label is the age of the person on arrival, plus the number of years they have been in the model.
lbl_rounded age	The rounded age of each person.
lbl_care service time	Calculation for meeting unmet need
lbl_unmet need	Calculation for meeting unmet need - hours required - hours of informal care available

Ibl_TOTAL Care AVAIL	Part of a calculation to calculate unmet need.
Ibl_InformCareHrs_ AVAIL	Carer Attributes
Ibl_TC_ZBI Calc	Calculation for adjusted ZBI
Ibl_TC_ZBI Calc 2	Calculation for adjusted ZBI
Ibl_TC impact on ZBI	Carer Statechart Variables - adjusts the ZBI score
Ibl_adjusted Carer ZBI	Adjusted ZBI once TC impact is accounted for
Ibl_Carer ZBI Score	ZBI score based on dependency level before any telecare factor calculation
Ibl_LifeSpan	Used for calculating and recording the life span of each person when they exit the model (die)
Ibl_lifespanCalc	
Ibl_Age on Arrival	
Ibl_age at death	
Dementia Statechart	
DEAD	Labels representing different states in the Core Dementia Statechart.
MILD	
MODERATE	
SEVERE	
Transitions to Death	
Ibl_TRANSITION death from MODERATE	Labels used identify the transitions from each state to death from the corresponding spreadsheet, depending on age and gender.
Ibl_TRANSITION_death from MILD	
Ibl_TRANSITION_death from SEVERE	
Dependency Statechart	
Mild Dependency Level 1	Labels representing different states in the Dependency Statechart
Mild Dependency Level 2	
Moderate Dependency Level 3	
Moderate Dependency Level 4	
Severe Dependency Level 4pnt5	
Severe Dependency Level 5	
Carer Burden Statechart	
Coping Carer	Labels representing the different states in the Carer Burden Statechart. Each state relates to a level of carer burden as calculated using the Carer's Adjusted ZBI.
Coping with Extreme Burden	
Coping with Severe Burden	
Informal Care Collapse	Label representing the informal carer no longer being able to provide support at home.

Informal Carer Seeking Extra Support	Labels representing different states in the Carer Statechart.
No Informal Carer	
No longer providing informal care	
High Level of Unmet Need	
Ibl_TRANSITION_seeking extra support	Labels that assign transition rates between states within the carer burden statechart.
Ibl_TRANSITION_Informal Care Collapse	
Results Labels for Counting Days	
Ibl_a CountDays_CCare	Labels used to record the simulation time that each person begins each care service (arrive labels) and then to record the time that a person releases each care service resource (exit labels). The 'current' and 'previous' labels are used to calculate the total time spent in each service.
Ibl_a CountDays_CCare Hold TC	
Ibl_a CountDays_Informal Care (ONLY)	
Ibl_a CountDays_No Support Sought	
Ibl_a_CountDays_Basic TC and CCare	
Ibl_a CountDays_Nursing Home	
Ibl_a CountDays_ResCare	
Ibl_a CountDays_Telecare ONLY	
Ibl_a CountDays_Complex TC and CC	
Ibl_b CountDays_Arrive	
Ibl_b CountDays_Arrive in Community Care	
Ibl_b CountDays_Arrive in Community Care Hold TC	
Ibl_b CountDays_Arrive in Complex TC and ComCare	
Ibl_b CountDays_Arrive in Nursing Home	
Ibl_b CountDays_Arrive in Res Care	
Ibl_b CountDays_Arrive in Telecare ONLY	
Ibl_b CountDays_Current	
Ibl_b CountDays_Current in Community Care	
Ibl_b CountDays_Current Basic TC and CCare	
Ibl_b CountDays_Current in Community Care hold TC	
Ibl_b CountDays_Current in Complex TC and ComCare	

Ibl_b CountDays_Current in Nursing Home	
Ibl_b CountDays_Current in Res Care	
Ibl_b CountDays_Current in Telecare ONLY	
<i>Ibl_b CountDays_Exit</i>	
Ibl_b CountDays_Exit Community Care	
Ibl_b CountDays_Exit Community Care hold TC	
Ibl_b CountDays_Exit Basic TC and CCare	
Ibl_b CountDays_Exit Complex TC and com care	
Ibl_b CountDays_Exit Nursing Home	
Ibl_b CountDays_Exit Res Care	
Ibl_b CountDays_Exit Telecare ONLY	
<i>Ibl_b CountDays_Previous</i>	
Ibl_b CountDays_Previous Com Care	
Ibl_b CountDays_Previous Basic TC and CCare	
Ibl_b CountDays_Previous Com Care Hold TC	
Ibl_b CountDays_Previous Complex TC and ComCare	
Ibl_b CountDays_Previous Nursing Home	
Ibl_b CountDays_Previous Res Care	
Ibl_b CountDays_Previous Telecare ONLY	

Source: TeleDem Simulation

Appendix 24: Model Parameters

Parameter	Input Type	Description	Location in Thesis	Source
<u>Arrival into the DES Model:</u>				
Arrivals into the model	Fixed rate	The arrival rate is based on the annual diagnosis rate for dementia in Southampton (1500 people per annum)	Section 7.3	<ul style="list-style-type: none"> Age Concern Hampshire (2017)
<u>Assigned on arrival into the DES Component:</u>				
Age and gender	Probability Profile	Distributions for age and gender for the modelled population within the TeleDem Simulation were based on the 2013 mid-year figures as estimated by the ONS.	Section 7.2	<ul style="list-style-type: none"> (ONS, 2014)
Severity and prevalence	Probability Profile	Severity and prevalence of dementia by age and gender.	Section 7.2	<ul style="list-style-type: none"> Prince <i>et al.</i> (2014)
Stage of dementia	Probability Profile	Distribution assumed: <ul style="list-style-type: none"> – 65% mild – 30% moderate – 5% severe The person is assigned the corresponding state in the Dementia Statechart.	Section 7.3	Assumption made based on a variety of sources. Including consultation with domain experts and: <ul style="list-style-type: none"> Bond <i>et al.</i> (2005); Prince <i>et al.</i> (2014)
<u>Dementia Statechart:</u>				
Disease progression	State Transition Probability	State transition probabilities between stages of dementia, used to inform the core Dementia Statechart.	Section 7.4	<ul style="list-style-type: none"> Spackman <i>et al.</i> (2012)
Mortality	State Transition Probability	Age and gender-specific state transition probabilities, to reflect the mortality rates of the modelled population.	Appendix 25	<i>Derived from the model used in:</i> <ul style="list-style-type: none"> Spackman <i>et al.</i> (2012)
<u>Dependency Statechart:</u>				

Progressive levels of dependency	State Transition Probability	The levels of dependency for the Dependency Statechart are based on the work of Kahle-Wroblewski <i>et al.</i> (2015), however the paper did not provide rates of progression, so state transition probabilities were derived from Spackman <i>et al.</i> (2012).	Section 7.6	Derived from: <ul style="list-style-type: none"> • Spackman <i>et al.</i> (2012); • Kahle-Wroblewski <i>et al.</i> (2015)
<u>Assigned in the Dependency Statechart:</u>				
Hours of Care Required	Dependency level 1 – Uniform Distribution	‘Caregiver Time’ from Kahle-Wroblewski’s (2015) work has been used as a proxy for hours of care required. The upper value for the confidence interval from the paper was used as the upper bound of the Uniform distribution and the lower bound was set to zero to reflect that some people in the early stages of dementia require no additional support (Caro <i>et al.</i> , 2002). A Uniform Distribution was selected based on the following definition used by SIMUL8: “A Uniform Distribution tends to be used when it is not possible to collect data about the actual situation but there is knowledge about the broad range of the data” (SIMUL8, 2018b).	Section 7.7 Appendix 6	<ul style="list-style-type: none"> • Kahle-Wroblewski <i>et al.</i> (2015); • Caro <i>et al.</i>, (2002).
	Dependency level 2 – Uniform Distribution	As above, with the upper and lower confidence intervals used as upper and lower bounds for the uniform distribution.	Section 7.7 Appendix 6	<ul style="list-style-type: none"> • Kahle-Wroblewski <i>et al.</i> (2015);
	Dependency level 3 – probability profile	A probability profile for this dependency level was derived from Caro <i>et al.</i> (2002). Caro <i>et al.</i> (2002) found that 20% of those at dependency level 3 required under 12 hours of supervision per day. The remaining 80% required more than 12 hours of supervision. They found a great deal of variation in the number of hours of care	Section 7.7	<ul style="list-style-type: none"> • Caro <i>et al.</i>, (2002)

		required, which reached up to 24 hours a day for approximately 32% of the group. Therefore, the probability profile effectively took the shape of a slightly stepped uniform distribution with a 30% peak at 24 hours and a slightly lower distribution representing 20% of the group under 12 hours. The remaining 48% (>12 but <24) is distributed uniformly between 12 and 24 hours to represent the variation mentioned by Caro <i>et al.</i>		
	Dependency level 4 – triangular distribution	Lower bound set to 12 hours, upper bound set to 24 hours and mode set to 22 hours. To reflect the elevated level of supervision required at this stage of dementia. Including supervision with BADLs (Kahle-Wroblewski <i>et al.</i> , 2015).	Section 7.7	<ul style="list-style-type: none"> Caro <i>et al.</i> (2002) Draper (2013) Kahle-Wroblewski <i>et al.</i> (2015)
	Dependency level 4.5 – set to 1	Setting the distribution for dependency level 4.5 to one, represents 24-hour care.	Section 7.7	<ul style="list-style-type: none"> Draper (2013); Alzheimer's Association (2017)
	Dependency level 5 – set to 1	Setting the distribution for dependency level 5 to one, represents 24-hour care.	Section 7.7	<ul style="list-style-type: none"> Draper (2013); Alzheimer's Association (2017)
Level of Carer Burden	Normal Distribution	The level of carer burden a person's carer is likely to experience relative to their level of dependency.	Table 7.2	<ul style="list-style-type: none"> Kahle-Wroblewski <i>et al.</i> (2015)
Type of informal care received	Probability Profile	Probability profile distribution to reflect the type of care received. <ul style="list-style-type: none"> 10% - no carer 57% - 'co-habiting spouse' 10% - 'co-habiting other' 23% - 'local/non-co-habiting carers' 	Section 7.8	Derived from: <ul style="list-style-type: none"> Miranda-Castillo <i>et al.</i>, 2013; Quince, 2011

Hours of Informal Care Availability	Probability Profile	Probability distributions based on logical assumptions and data presented by Beesley (2006) from the General Household Survey 2001 on carers of people aged 65+, by number of hours per week spent caring, and living arrangement.	Section 7.9	<ul style="list-style-type: none"> Beesley (2006)
<u>Carer Burden Statechart:</u>				
Transition to 'High Level of Unmet Need'	Simple calculation	Calculation relating to unmet need	Section 6.5.2	<i>Not Applicable.</i>
Transition to 'Informal Carer Seeking Extra Support'	State Transition Probability	Based on level of dependency and whether or not the person is receiving informal care only (no formal care services) or basic telecare only.	Section 7.12	<ul style="list-style-type: none"> Scherer <i>et al.</i> (2008)
Transition to 'Informal Care Collapse'	State Transition Probability	Increased likelihood of carer collapse based on increasing levels of carer burden as dependency levels increase	Section 7.11	Based on: <ul style="list-style-type: none"> Hébert <i>et al.</i>'s (2001) Neumann <i>et al.</i> (2001) And informed by expert opinion
<u>Need for support following diagnosis:</u>				
Routing following diagnosis	Probability Profile	The probability of someone requiring support from a formal care service following diagnosis is assigned based on estimates derived from the results of the DEMHOM questionnaire (Quince, 2011).	Section 7.13	<ul style="list-style-type: none"> Quince, 2011
<u>Referrals to Traditional Care Services within the DES Component:</u>				
Referrals to community care vs institutional care	Visual Logic: If statements	Referrals are made based on a series rules that were guided by the literature and expert opinion.	Section 7.14	<i>Assumption made based on a variety of sources. Including consultation with domain experts and:</i>

				<ul style="list-style-type: none"> • Kahle-Wroblewski <i>et al.</i> (2014); • Kahle-Wroblewski <i>et al.</i> (2015); • Caro <i>et al.</i>, (2002) • Beesley (2006); • Quince (2011).
<u>Referrals to Telecare Services:</u>				
Referrals to Telecare Services	6 Probability Profiles	Referrals to basic telecare or complex telecare are made in each instance as an alternative to traditional community care. The percentage of traditional community care referrals that are diverted to telecare based services is varied through the different scenarios which the TeleDem Simulation is used to test.	Section 7.14	<i>Not Applicable.</i>

Source: TeleDem Simulation

Appendix 25: Mortality State Transition Probabilities

These transition probabilities were derived from the model used in Spackman *et al.* (2012).

Age	Male				Female		
	Mild	Moderate	Severe		Mild	Moderate	Severe
65	0.0000317	0.0001760	0.0008147		0.000027	0.000128	0.000613
66	0.0000335	0.0001849	0.0008560		0.000028	0.000135	0.000645
67	0.0000354	0.0001943	0.0008991		0.000030	0.000141	0.000679
68	0.0000375	0.0002041	0.0009439		0.000031	0.000149	0.000714
69	0.0000397	0.0002143	0.0009906		0.000033	0.000156	0.000751
70	0.0000420	0.0002251	0.0010392		0.000035	0.000164	0.000789
71	0.0000444	0.0002364	0.0010897		0.000037	0.000172	0.000829
72	0.0000469	0.0002482	0.0011422		0.000039	0.000181	0.000871
73	0.0000497	0.0002606	0.0011968		0.000042	0.000190	0.000915
74	0.0000525	0.0002735	0.0012533		0.000044	0.000200	0.000960
75	0.0000556	0.0002871	0.0013119		0.000046	0.000210	0.001008
76	0.0000587	0.0003013	0.0013727		0.000049	0.000220	0.001057
77	0.0000621	0.0003161	0.0014355		0.000052	0.000231	0.001108
78	0.0000657	0.0003316	0.0015005		0.000055	0.000242	0.001161
79	0.0000695	0.0003479	0.0015677		0.000058	0.000254	0.001216
80	0.0000735	0.0003648	0.0016371		0.000061	0.000267	0.001273
81	0.0000777	0.0003826	0.0017087		0.000065	0.000280	0.001333
82	0.0000821	0.0004011	0.0017825		0.000069	0.000294	0.001394
83	0.0000868	0.0004204	0.0018585		0.000072	0.000308	0.001457
84	0.0000918	0.0004407	0.0019367		0.000077	0.000324	0.001523
85	0.0000970	0.0004617	0.0020172		0.000081	0.000339	0.001591
86	0.0001025	0.0004837	0.0020998		0.000086	0.000356	0.001661
87	0.0001084	0.0005067	0.0021847		0.000090	0.000373	0.001733
88	0.0001145	0.0005306	0.0022717		0.000096	0.000391	0.001808
89	0.0001210	0.0005556	0.0023609		0.000101	0.000410	0.001884
90	0.0001279	0.0005815	0.0024523		0.000107	0.000429	0.001963
91	0.0001351	0.0006086	0.0025458		0.000113	0.000450	0.002044
92	0.0001428	0.0006368	0.0026414		0.000119	0.000471	0.002127
93	0.0001508	0.0006661	0.0027391		0.000126	0.000494	0.002213
94	0.0001593	0.0006966	0.0028389		0.000133	0.000517	0.002300
95	0.0001682	0.0007282	0.0029406		0.000140	0.000541	0.002390
96	0.0001777	0.0007612	0.0030443		0.000148	0.000566	0.002482
97	0.0001876	0.0007954	0.0031500		0.000156	0.000593	0.002576
98	0.0001981	0.0008309	0.0032575		0.000165	0.000620	0.002672
99	0.0002091	0.0008677	0.0033669		0.000174	0.000648	0.002770
100	0.0002207	0.0009059	0.0034781		0.000184	0.000678	0.002871
101	0.00127034	0.00127	0.003482		0.001068	0.001068	0.002911
102	0.00135233	0.001352	0.003581		0.001147	0.001147	0.003117

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103	0.00144113	0.001441	0.003684		0.001234	0.001234	0.003293
104	0.00153758	0.001538	0.003791		0.001329	0.001329	0.003482
105	0.00164263	0.001643	0.003902		0.001434	0.001434	0.003581
106	0.00175745	0.001757	0.0044		0.001549	0.001549	0.003791
107	0.00188342	0.001883	0.005184		0.001677	0.001677	0.0044
108	0.00202222	0.002022	0.006289		0.00182	0.00182	0.005184
109	0.00217595	0.002176	0.008174		0.001979	0.001979	0.006289
110	0.00234722	0.002347	0.012538		0.002159	0.002159	0.008174
111	1	1	1		1	1	1
112	1	1	1		1	1	1

Source: Spackman et al. (2012)

Appendix 26: Comparison of Transition Probabilities to Institutional Care

Spackman *et al.* (2012) and Neumann (2001) both published transition probabilities to institutional care. They both show that the likelihood of moving to institutional care increases as dementia progresses from mild to moderate, and then to severe as shown in Table 26.1.

Table 26.1: The Annual Transition Probabilities

	Spackman <i>et al.</i> (2012)			Neumann <i>et al.</i> (2001)		
	Mild	Moderate	Severe	Mild	Moderate	Severe
Annual Transition Probability	1.2	3.4	6.6	3.8	11.0	25.9
%	1.2%	3.4%	6.6%	3.8%	11.0%	25.9%

Source: Spackman *et al.* (2012) and Neumann *et al.* (2001)

To compare these transition probabilities to other published sources, the probability of transitioning was calculated over the average lifespan for a person with dementia. The average lifespan, as reported by the Alzheimer's Society in 2017 is 8 to 10 years. In the absence of data to the contrary, it is assumed that a person will spend equal amounts of time in each stage of dementia; so, for 8 years this will be 2.66 years in each stage.

The formula for calculating each paper's probabilities over the 2.66 year time frame is:

$$Prob_T = 1 - \exp(-T.rate)$$

Where T is the period (in years) and $rate$ is transition rate (probability of the person transitioning per year).

Table 26.2: The Transition Probabilities Over 2.66 Years

	Spackman <i>et al.</i> (2012)			Neumann <i>et al.</i> (2001)		
	Mild	Moderate	Severe	Mild	Moderate	Severe
Transition probability over 2.66 years	3.1%	8.6%	16.1%	9.6%	25.4%	49.8%

Source: Author's Work

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These 2.66 year transition probabilities were then applied to a population of 1000 people with dementia. If P symbolises the starting population at the beginning of each stage of dementia, and Y represents the probability of transitioning over the 2.66 year period (Table 26.2). Then X is the remaining population following a 2.66 year period with the stage's specific transition probability applied:

$$X = P - (P \times Y)$$

Using Spackman *et al.*'s (2012) transition probabilities from Table 26.2, the starting population of 1000 reduces to 968 after 2.66 years in mild dementia; then to 883, after 2.66 years of moderate, and finally to 739 after 2.66 years of severe. By comparison, Neuman *et al.*'s (2001) transition probabilities (Table 26.2) reduced a population of 1000 to 902 people after 2.66 years in mild, 671 after 2.66 years in moderate, and 333 after 2.66 years in severe. Therefore, using Neumann *et al.*'s transition probabilities as an example, this means that after 8 years 339 people from the initial population of 1000 remain in the community, whereas 661 have transitioned to institutional care. Table 26.3 shows the percentage of the initial population that remain in the community vs transitioned to institutional care, using the transition probabilities from the two papers.

Table 26.3: The Proportion of People who have Transitioned to Institutional Care

	Spackman <i>et al.</i> (2012)			Neumann <i>et al.</i> (2001)		
	2.66 Years in Mild	2.66 Years in Moderate	2.66 Years in Severe	2.66 Years in Mild	2.66 Years in Moderate	2.66 Years in Severe
Total time elapsed	2.66 years	5.32 years	8.02 years	2.66 years	5.32 years	8.02 years
Transitioned to institutional care	3% (31 people)	12% (115 people)	26% (258 people)	10% (96 people)	33% (325 people)	66% (661 people)
Remaining in the community	97% (969 people)	88% (885 people)	74% (742 people)	90% (904 people)	67% (675 people)	34% (339 people)

Source: Author's Work

Luppa *et al.*'s (2008) systematic review of articles, relating to the 'prediction of institutionalisation in dementia', reported that the rate at which people with dementia entered institutional care increased from almost 20% in the first year after diagnosis of dementia to around 50% after 5 years, up to 90% after 8 years. Luppa *et al.* (2008) looked at studies from across America and Europe. Therefore, it was concluded that Neumann *et al.*'s (2001) transition probabilities more closely resembled the wider literature.

Appendix 27: State Transition Probabilities for Informal Care Collapse

Carer Burden Statechart (Hébert et al., 2001)	Zarit Burden Score	% Chance of Carer Collapse	Daily State Transition Probability
Coping Carer (low to moderate burden)	0	0.00%	0
	1	0.11%	3.04583E-06
	2	0.22%	6.09504E-06
	3	0.33%	9.14763E-06
	4	0.44%	1.22036E-05
	5	0.56%	1.5263E-05
	6	0.67%	1.83258E-05
	7	0.78%	2.13921E-05
	8	0.89%	2.44617E-05
	9	1.00%	2.75348E-05
	10	1.40%	3.86264E-05
	11	1.80%	4.97631E-05
	12	2.20%	6.0945E-05
	13	2.60%	7.21727E-05
	14	3.00%	8.34464E-05
	15	3.40%	9.47666E-05
	16	3.80%	0.000106134
	17	4.20%	0.000117548
Coping with Severe Burden (severe burden)	18	4.60%	0.00012901
	19	4.99%	0.000140108
	20	5.37%	0.000151251
	21	5.76%	0.000162439
	22	6.14%	0.000173673
	23	6.53%	0.000184954
	24	6.91%	0.000196281
	25	7.30%	0.000207654
	26	7.69%	0.000219075
	27	8.07%	0.000230544
	28	8.46%	0.000242061
	29	8.84%	0.000253626
	30	9.23%	0.00026524
	31	9.61%	0.000276904
	32	10.00%	0.000288617
Coping with Extreme Burden (extreme burden)	33	11.50%	0.00033465
	34	13.75%	0.000405179
	35	16.00%	0.000477566
	36	18.25%	0.000551914
	37	20.50%	0.000628332

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	38	22.75%	0.000706937
	39	25.00%	0.00078786
	40	27.25%	0.00087124
	41	29.50%	0.000957233
	42	31.75%	0.001046008
	43	34.00%	0.001137751
	44	36.25%	0.001232667
	45	38.50%	0.001330985
	46	40.75%	0.001432957
	47	43.00%	0.001538867
	48	45.25%	0.00164903
	49	47.50%	0.001763804
	50	50.00%	0.001897231

Source: Hébert et al. (2001) and Author's Work

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