The Meaning, Construction and Place of Neighbourhood in the Lives of People with Dementia and Their Carers: A Longitudinal Mapping Study

A thesis submitted to The University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health

2018

Xia Li

School of Health Sciences
## CONTENTS

LIST OF TABLES AND FIGURES .................................................................................................................. 8
ABSTRACT: A Neighbourhood Mapping Study of People Living with Dementia ........................... 10
DECLARATION ............................................................................................................................................. 11
COPYRIGHT STATEMENT ........................................................................................................................... 11
DEDICATION .................................................................................................................................................. 12
ACKNOWLEDGEMENTS ............................................................................................................................... 12
GLOSSARY ..................................................................................................................................................... 13
  Definition of Terms and Writing Conventions Used ................................................................. 13
BACKGROUND TO THESIS ........................................................................................................................ 14
  About the Author .................................................................................................................................. 14
  Rationale for Study ............................................................................................................................... 16
  Aim and Objectives of Study ........................................................................................................... 19
  Organisation of Thesis ......................................................................................................................... 19
CHAPTER 1 .................................................................................................................................................... 22
Dementia: Contextual Considerations ....................................................................................................... 22
  1.1 Introduction ................................................................................................................................... 22
  1.2 Dementia: Definition and Demographics .................................................................................... 22
  1.3 Public Health and Dementia .......................................................................................................... 24
    1.3.1 Health Promotion and Dementia .......................................................................................... 25
    1.3.2 Health Services Quality Improvement and Dementia ....................................................... 27
  1.4 The Social, Rights-based, Model of Disability and People Living with Dementia ......... 30
  1.5 Geography Matters ......................................................................................................................... 34
    1.5.1 Space and place ..................................................................................................................... 34
    1.5.2 Neighbourhood ...................................................................................................................... 41
    1.5.3 Home ..................................................................................................................................... 44
  1.6 The Neighbourhood Theme .......................................................................................................... 49
    1.6.1 Environmental Perspectives .................................................................................................. 50
    1.6.2 Age-friendly and Dementia-friendly Communities ............................................................... 55
  1.7 Summary ....................................................................................................................................... 60
CHAPTER 2 .................................................................................................................................................... 62
Neighbourhood and Dementia: A Thematic Review of the Literature .............................................. 62
  2.1 Introduction ................................................................................................................................... 62
2.2 Aims .......................................................................................................................... 62
2.3 Methods .................................................................................................................... 62
  2.3.1 A Thematic Synthesis ......................................................................................... 62
  2.3.2 Search Strategy .................................................................................................. 63
  2.3.3 Inclusion and Exclusion Criteria ........................................................................ 63
  2.3.4 Data Extraction and Quality Assessment ......................................................... 64
2.4 Results Neighbourhood and Dementia: Core Literature ....................................... 65
  2.4.1 Search Results .................................................................................................. 65
  2.4.2 Quality Appraisal ............................................................................................... 65
  2.4.3 Thematic Analysis ............................................................................................... 66
   Theme 1: Social Integration ...................................................................................... 67
   Theme 2: Space, Place and Home ............................................................................. 69
   Theme 3: Neighbourhood Design ............................................................................ 72
   Theme 4: Physical Activity ...................................................................................... 73
   Theme 5: Supportive Resources .............................................................................. 75
2.5 Summary .................................................................................................................... 80

CHAPTER 3 ..................................................................................................................... 82
Study Methodology and Methods .................................................................................. 82
  3.1 Introduction ............................................................................................................. 82
  3.2 Aim and Objectives of Study ................................................................................ 82
  3.3 Environmental Gerontology .................................................................................. 83
  3.4 Epistemological and Ontological Approaches to Narrative Inquiry .................... 87
    3.4.1 Narrative Inquiry .............................................................................................. 88
    3.4.2 Participatory Methods ..................................................................................... 92
  3.5 Co-constructing the Lived Experience of Dementia ............................................ 94
    3.5.1 Narrative Inquiry in Practice .......................................................................... 94
    3.5.2 Participatory Methods Through Narrative in Practice .................................. 96
  3.6 Sample Eligibility Criteria ..................................................................................... 98
    3.6.1 Inclusion Criteria ............................................................................................. 100
    3.6.2 Exclusion Criteria ........................................................................................... 101
  3.7 Recruitment ............................................................................................................ 101
    3.7.1 Sample Characteristics .................................................................................... 103
  3.8 Data Collection ...................................................................................................... 105
3.8.1 Mixed-interviews ................................................................. 105
3.8.2 Participatory Mapping ....................................................... 108
3.8.3 Diaries .............................................................................. 112
3.8.4 Photographs ...................................................................... 113
3.8.5 Demographic Information .................................................... 114
3.9 Data Analysis ........................................................................ 114
3.9.1 Narrative Analysis within Each Case .................................... 115
3.9.2 Cross-case Analysis ............................................................. 119
3.10 Rigour ................................................................................ 120
3.11 Ethical Considerations ........................................................... 121
3.11.1 Capacity to Consent and Use of Data .................................. 121
3.11.2 Participants and Researcher Safety ..................................... 123
3.12 Summary ............................................................................. 124
Chapter 4 .................................................................................. 125
Findings: Co-constructing Neighbourhood Maps with Five Families .... 125
4.1 Introduction .......................................................................... 125
4.2 Presentation of Case Studies .................................................... 125
4.3 Case Study 1 – Mary and Steve ............................................. 126
Main Storyline: Home Matters ..................................................... 126
4.3.1 Background ....................................................................... 126
4.3.2 Family and Relational Dynamics ....................................... 127
4.3.3 Mapping the Neighbourhood ............................................. 131
4.3.4 Explaining the Neighbourhood ......................................... 135
4.3.5 Initial Impressions of the Neighbourhood ............................. 142
4.3.6 Summary .......................................................................... 144
4.4 Case Study 2 – Patricia and Brian .......................................... 145
Main Storyline: Friendly but Fairly Remote ............................... 145
4.4.1 Background ....................................................................... 145
4.4.2 Family and Relational Dynamics ....................................... 146
4.4.3 Mapping the Neighbourhood ............................................. 149
4.4.4 Explaining the Neighbourhood ......................................... 153
4.4.5 Initial Impressions of the Neighbourhood ............................. 161
4.4.6 Summary .......................................................................... 163
4.5 Case Study 3 – Diane and Dave .................................................................163
Main Storyline: The Neighbourhood Hub ......................................................163
  4.5.1 Background .........................................................................................163
  4.5.2 Family and Relational Dynamics ..........................................................164
  4.5.3 Mapping the Neighbourhood ...............................................................168
  4.5.4 Explaining the Neighbourhood ...........................................................173
  4.5.5 Initial Impressions of the Neighbourhood ............................................180
  4.5.6 Summary .............................................................................................181
4.6 Case Study 4 – Jonathan and Jackie ..........................................................182
Main Storyline: Physical and Virtual Places and Outdoor Spaces ..................182
  4.6.1 Background .........................................................................................182
  4.6.2 Family and Relational Dynamics ..........................................................183
  4.6.3 Mapping the Neighbourhood ...............................................................188
  4.6.4 Explaining the Neighbourhood ...........................................................194
  4.6.5 Initial Impressions of the Neighbourhood ............................................199
  4.6.6 Summary .............................................................................................201
4.7 Case Study 5 – Emily and Tim .................................................................202
Main Storyline: Family and Friends ...............................................................202
  4.7.1 Background .........................................................................................202
  4.7.2 Family and Relational Dynamics ..........................................................203
  4.7.3 Mapping the Neighbourhood ...............................................................206
  4.7.4 Explaining the Neighbourhood ...........................................................210
  4.7.5 Initial Impressions of the Neighbourhood ............................................218
  4.7.6 Summary .............................................................................................220
4.8 Summary of Case Studies .......................................................................221
CHAPTER 5 ......................................................................................................223
Findings: Cross-case Analysis of the Five Case Studies ...................................223
  5.1 Introduction ............................................................................................223
  5.2 Theme 1: Connecting to People .............................................................225
    5.2.1 Sub-theme 1: Connecting to Family Members ...................................226
    5.2.2 Sub-theme 2: Connecting to Friends and Neighbours .......................229
    5.2.3 Sub-theme 3: Connecting to the Neighbourhood Support ................234
  5.3 Theme 2: Connecting to Places .............................................................236
Appendix 6. Summary of the Main Activities with Mary and Steve .........................345
Appendix 7. Summary of the Main Activities with Patricia and Brian ......................347
Appendix 8. Summary of the Main Activities with Diane and Dave ..........................349
Appendix 9. Summary of the Main Activities with Jonathan and Jackie ..................351
Appendix 10. Summary of the Main Activities with Emily and Tim ..........................353
Appendix 11. Diary Template ..................................................................................355
Appendix 12. Demographic Questionnaire ..............................................................356

[91,260 words]
LIST OF TABLES AND FIGURES

Tables
Table 1: Key Features for the Age-Friendly and Dementia Friendly Frameworks ...... 58
Table 2: A Summary of Quality Appraisal of the Included Papers ......................... 66
Table 3: Participant Demographics ........................................................................ 104

Figures
Figure 1: Flow Chart of Included Studies ............................................................... 65
Figure 2: A Summary of the Aim and Data Collection Methods of Each Phase ...... 106
Figure 3: The Detailed Process of Gaining (Ongoing) Informed, Written Consent .. 122
Figure 4: Structure of the Family of Mary and Steve ............................................. 130
Figure 5: Mary and Steve’s Neighbourhood Map ................................................ 134
Figure 6: Front Room ........................................................................................... 136
Figure 7: Summer House ..................................................................................... 137
Figure 8: The View of the Local Secondary School ............................................. 138
Figure 9: The Garden in Winter ........................................................................... 139
Figure 10: Structure of the Family of Patricia and Brian ...................................... 147
Figure 11: Patricia and Brian’s Neighbourhood Map 1 ....................................... 154
Figure 12: Patricia and Brian’s Neighbourhood Map 2 ....................................... 154
Figure 13: Conservative Club .............................................................................. 157
Figure 14: Local Garden Centre .......................................................................... 158
Figure 15: Local Store .......................................................................................... 160
Figure 16: Structure of the Family of Diane and Dave ......................................... 166
Figure 17: Two Good Friends of Diane and Dave ................................................. 169
Figure 18: The First Stage of the Neighbourhood Map Drawn by Diane and Dave .. 171
Figure 19: The Final Neighbourhood Map Drawn by Diane and Dave ................. 172
Figure 20: The Deaf Event ................................................................................... 177
Figure 21: The Games Afternoon ...................................................................... 179
Figure 22: Structure of the Family of Jonathan and Jackie ................................. 186
Figure 23: The Road ............................................................................................ 188
Figure 24: Local Park .......................................................................................... 189
Figure 25: Paisley ................................................................................................. 190
Figure 26: Local Grocery Shopping Centre ......................................................... 191
ABSTRACT: A Neighbourhood Mapping Study of People Living with Dementia

Background: Dementia is a public health priority due to the growth in the ageing population, resulting in an increase of people living with dementia both nationally and internationally. Whilst dementia has been framed as an economic and societal burden, this is not the whole story. People living with dementia have rights and an asset-based approach outlines the contribution that they bring to relationships in the everyday places and spaces where life is lived. To continue to enable people living with dementia to stay in their own home and community and to offer opportunities for social participation and contribution, the neighbourhood is one focus of ageing and dementia policy supporting enabling environments. Although the literature illustrates the significant impact, from multiple dimensions, of the neighbourhood on people living with dementia and their carers, there is a scarcity of evidence about how they define, construct, and interact with their neighbourhood.

Aims: This longitudinal study employed narrative inquiry as a methodological frame and used a participatory approach, together with multiple data collection methods, to uncover the meaning, construction and place of neighbourhood in the lives of people with mild dementia and their carers to gain in-depth knowledge of the dynamic relationships between people and environment and of their daily lived experience of dementia.

Findings: A total of five couples, where one partner had mild dementia, located in an East Midlands county of England, participated in the study and the age range for people living with dementia was from 66 to 86 years. Participation was longitudinal with the researcher conducting a total of 65 home visits and collecting over 57 hours of interview data alongside other data sources, such as participatory neighbourhood maps. Each case was outlined using the same headings allowing for cross-case analysis and emphasis was placed on the creation and pictorial representation of the neighbourhood maps with data collection led by the persons living with dementia and/or their carers. A cross-case analysis was then applied to the data set where a meta-theme of ‘biographical connectivity to the neighbourhood’ emerged, supported by two themes of ‘connecting to people’ and ‘connecting to places’. The meta-theme highlighted the significance of personal biographies in influencing neighbourhood connectivity, which further shaped personal biographies. Within this cumulative process, ‘resources’ and ‘relationships’ had an effect on biographical connections to the neighbourhood, particularly affecting how the persons living with dementia negotiated environmental opportunities and challenges. The resulting model illustrated the fluid, dynamic relationships between participants and their neighbourhood through the lens of personal biographies.

Conclusions: The meta-theme of ‘biographical connectivity to the neighbourhood’ presented the significance of personal and relational biographies in influencing the subjective view of the experiences of interactions with the neighbourhood. This is the first study where people living with dementia and their carers co-produced neighbourhood maps with the researcher to bring their understanding of spaces, places, and people to life. The study is also an early attempt to support a ‘bottom-up’ approach to neighbourhood constructions and meanings where the intersection of the person’s life to their self-identified neighbourhood becomes the focal point for supportive interventions. The thesis concludes with a re-contextualisation of ‘biographical connectivity to the neighbourhood’ and its supporting properties to the literature and outlines its implications for policy, practice, education, and research.
DECLARATION

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

COPYRIGHT STATEMENT

i. The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the “Copyright”) and s/he has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.

ii. Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made only in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.

iii. The ownership of certain Copyright, patents, designs, trademarks and other intellectual property (the “Intellectual Property”) and any reproductions of copyright works in the thesis, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.

iv. Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see http://documents.manchester.ac.uk/DocuInfo.aspx?DocID=24420), in any relevant Thesis restriction declarations deposited in the University Library, The University Library’s regulations (see http://www.library.manchester.ac.uk/about/regulations/) and in The University’s policy on presentation of Theses.
DEDICATION

This thesis is dedicated to the people living with dementia and their spousal caregivers who took part in this study. They welcomed me into their homes, spent time in sharing their life stories, and expressed their trust towards me. Their patience and enthusiasm in sharing experiences has made this study possible and I sincerely thank them for this.

ACKNOWLEDGEMENTS

I would like to sincerely thank my supervisors, Professor John Keady and Dr. Richard Ward for their expert guidance and support throughout this study and for what I have learned from their professional field along the way. I would also like to thank Professor Gunn Grande for her support during the earlier stage of this PhD programme.

I am grateful to my previous colleagues in the National Health Service who provided me with their professional knowledge on my work and enabled me to be involved in dementia related work, and particularly to Sarah Hood and Karen Meadows. I am also thankful for the expert advice from Dr. John Woolham on the earlier stage of this study. His knowledge and advice was very much appreciated.

I would also like to thank my parents-in-law and my parents for all the help and support both practically and emotionally, and their encouragement meant a great deal for me. Finally, but most importantly, I would like to thank my husband Phil Bushell, my greatest supporter, for helping me read through this thesis and for his valuable support throughout this journey. Without my family’s support and encouragement, I would not have made the first step which led me to the completion of this PhD programme.
GLOSSARY

Definition of Terms and Writing Conventions Used

Within the thesis numbers from one to nine are written out, with numbers 10 and above represented in their numerical form. Exceptions to this are descriptive statistical measures and sample measures (‘n’); when a number begins a sentence; when in a list with other numbers; and when numbers form part of a title, for instance: Figure 1; Table 1 and so on.

Direct quotations from literature are presented with double quotation marks, while direct quotations from data collected within this study are shown with double quotation marks and are italicised. For longer quotations more than 40 words, they are separated from the body of the text and indented from the left-hand margin. Single quotation marks are used within the thesis to denote the use of a phrase or colloquialism.

References listed in the thesis used American Psychological Association sixth edition. As such, for the cited publications with three to five authors, all the author names are cited for the first time the reference occurs and then subsequently include only the first author followed by et al.; for the cited publications with six or more authors, only the name of the first author is cited, followed by et al. and the year; for two or more studies in the same parenthetical citation, the reference list is cited in alphabetical, then chronological order of publications. References listed in the final bibliography names are up to seven authors. For eight or more authors, the first six authors’ names are listed and then use ellipsis points (...) before ending with the last author’s name.
BACKGROUND TO THESIS

About the Author

This thesis adopted qualitative research methods throughout its design and findings. As such, the research design demanded that I was reflexive and empathetic to the experiences that were being shared. During the knowledge production process I documented the situation, research process, my own personal thoughts and observations as part of self-reflection which was then analysed alongside other qualitative data to enhance the authenticity of this study. The importance of reflexivity for a researcher is being fully aware of the ‘self’ as a research instrument which can capture and critique the meaning of various interactions with participants. Accordingly, I believe that it is important that I commence this thesis with a short biographical outline that locates my own life experiences and reasons for undertaking this PhD at the start so that the whole thesis can be placed in a rounded and meaningful context.

Before coming to the United Kingdom (UK) in 2005 I had completed a Bachelor Degree in Computing Information Management at the TianJin University and a Diploma in Western Medicine at the TianJin Medical University in China. I came to the UK to study for a Master’s degree in ‘International Business Management’ at the University of Northampton, completing this Master’s Degree in 2007 with a Merit. After graduating, I started my professional career in the National Health Service (NHS) in the area of research. This provided me with an opportunity to obtain an understanding about healthcare services, and their associated challenges, in the UK. Through working on local implementation plans of Lord Darzi’s ‘Next Stage Review’ - that aimed to improve the quality of care provided by the NHS - I developed an interest in policy-making based on best practice to improve the health of the local population.

Within the first three months of joining the NHS, I was promoted to the position of ‘Researcher’ within the Policy and Best Practice team at a county level. This enabled me to become involved in a variety of projects to support policy-making and pathway redesign and to see, at close hand, how the internal mechanisms of the NHS were applied in real-time. Working closely with local commissioners and providers from mental health services, and being involved in a major project to improve its services
across an East Midland county, helped to develop my interests in this area, and particularly dementia care. My interest in dementia was further developed through my experience of working as a Research Associate in the Research and Development team within the Public Health Directorate in the same organisation. I held this position for nearly three years and this role provided me with an opportunity to obtain a better understanding about why dementia is a significant public health priority and how public health contributes to the dementia agenda.

The Research Associate role also enabled me to gain significant public health research knowledge and experience in a range of areas with several methodologies. My passion for dementia then developed further alongside my career which progressed in July 2012 when I took a position as an Audience Insight Manager in the National Institute for Health and Care Excellence (NICE) in Manchester, UK. This role also offered me an opportunity to gain in-depth knowledge and understanding of NICE dementia guidance and quality standards, and to be able to engage with their underpinning operational frameworks. To this day, this post enables me to obtain and apply additional research skills and obtain further applied research experience. With NICE’s remit extending to social care and NHS reorganisation (i.e. public health moving into local authorities), research from both public health and social care perspectives continues to increase in importance. The PhD, therefore, is timely as dementia continues to remain a political imperative with the public health agenda taking an increasing role in the development of support services and the empowerment of those men and women who live with the condition.

Perhaps more significant than my professional career is my personal exposure and understanding about dementia. My father is living with dementia and my mother is the main carer. They both live at home in China after sharing a life together for nearly 50 years. My mother ‘keeps an eye’ on my father all the time and is unable to leave him alone for more than half an hour at a time. It is fair to say that my mother’s life is centred around my father and she does not have time for herself; she constantly worries about him. The impact of living in the UK, and so being unable to offer more hands-on and direct support to both my mother and father, is difficult for me on both a practical and emotional level. Therefore, my personal experience of having a loved parent living
with dementia offers me further understandings about how dementia ripples through the entire family dynamic and how everyday challenges need to be faced and overcome. We all hold multiple identities and my role as a distant carer is one that helps to inform and shape my personal exposure to what I saw, and what I encountered, in this research study. Home is definitely where the heart is.

**Rationale for Study**

Dementia is one of the most significant global health and social care challenges of modern times and requires an increased focus on policy, practice, research, and public attention (Department of Health, 2015). Dementia has been acknowledged as a public health priority by the World Health Organisation and Alzheimer’s Disease International (2012). To implement this priority, there is a need to articulate the existing public health approach. The World Health Organisation and Alzheimer’s Disease International (2012) highlight that this action aims to make a significant contribution to dementia care and improve the quality of life of people living with dementia and their family carers. This indicates that health promotion and health services quality improvement have an important role to play in contributing towards the implementation of this priority. Consequently, people living with dementia can be supported to maintain their autonomy and independence, have access to appropriate health services and, more importantly, be exposed to human rights-based initiatives that enshrine and secure the rights of people living with dementia as equal to others in society (Mental Health Foundation, 2015).

Dementia is associated with ageing; therefore, to tackle this age-related condition and improve the quality of life of people living with dementia, it is logical to first support the ageing population to live well through ageing policy and practice. ‘Ageing in place’ is one focus in ageing policy and it seems to be the preference of older people who could be enabled to maintain autonomy and independence (Frank, 2002; Wiles, Leibing, Guberman, Reeve & Allen, 2011). ‘Ageing in place’ is about being able to continue living in one’s own home and neighbourhood by adapting, or changing, needs and conditions to maintain certain levels of independence, autonomy and connection to social support (Davey, de Joux, Nana & Arcus, 2004; Fänge, Oswald & Clemson, 2012; Lawler, 2001). This notion relates to creating age-friendly cities or communities, which is one major
response to the rise in an ageing population to enable a ‘good life’ (Lawton, 1983). Developing age-friendly communities is underpinned from environmental perspectives on ageing and health as people’s health and well-being are affected by their interactions with their environment, such as social contacts with residents and physical surroundings at a neighbourhood level, and these interactions will unfold through a life span (Maddox, 2000). A neighbourhood theme is therefore raised by this ageing-related initiative.

In the UK, ‘living well with dementia’ has been a key government priority in raising dementia awareness and understanding, amongst both the public and professionals, through early diagnosis and intervention to post-diagnosis support in the community (Department of Health, 2009, 2015; World Health Organisation & Alzheimer’s Disease International, 2012). This priority has put public health at the forefront in tackling the challenges caused by dementia and focuses upon the role of ‘neighbourhood’ in dementia care. Neighbourhood is an emphasis of public policy in a variety of areas and in which public health action should be developed (Blackman, 2006), such as promoting health and improving services for people affected by dementia and their carers at a neighbourhood level. This neighbourhood approach to improving the health of people living with dementia emerges from the concept of health improvement strategies that often target where people live to enhance neighbourhood-based health (Blackman, 2006).

A neighbourhood theme is further raised by creating dementia-friendly communities as two-thirds of people living with dementia live in the community (Alzheimer’s Society, 2013). Creating dementia-friendly communities is reinforced in the Prime Minister’s Challenges on Dementia 2015 and 2020 (Department of Health, 2012, 2015) and is now underway, with 82 communities signing up to the national dementia-friendly communities recognition process across England (Department of Health, 2015). By 2020, the UK Government’s aim is to ensure that over half of people living with dementia can live in areas that meet the standards of dementia-friendly communities (Department of Health, 2015). To contribute towards these policy priorities and initiatives from a public health perspective, a neighbourhood model for dementia could be considered essential.
in supporting a bottom-up approach where services become needs-led to meet service user’s requirements, and ultimately improving lived experience (Baldwin, 1993).

To help aid understanding, and provide clarity in the thesis that follows, it is important to distinguish between the meanings of ‘community’ and ‘neighbourhood’. ‘Community’ refers to a small or large social unit of individuals with diverse characteristics who are linked by social ties, share common interests, and engage in joint activities (MacQueen et al., 2001; McMillan & Chavis, 1986) within boundaries tacitly, or explicitly, agreed by members (Douglas, 2010). ‘Community’ often shares a sense of place located in a physical area (such as a village, town, or country) and in virtual space through modern technologies (Douglas, 2010). In contrast, ‘neighbourhood’ is more localised and boundaried. According to La Gory, Ward and Sherman (1985), a neighbourhood is:

“A physical, social, and cultural setting ... affecting the choices and actions of its residents. Indeed, the degree to which neighbourhoods are congruent with the capacities and needs of inhabitants appears to affect the residents’ quality of life, as well as the local community’s dynamics.” (p.406)

In this sense, the ‘neighbourhood’ is a multi-dimensional place where residents live and interact with various properties and operates within a geographical boundary (La Gory, Ward & Sherman, 1985). This ‘lived place’ influences ‘social health’ (Huber et al., 2011; Ward et al., 2017) and impacts upon the quality of life of people living with dementia interacting with such environments (Blackman, 2006; McGovern, 2016). Moreover, the literature suggests that people living with dementia influence their environments through four methods, namely evocation, selection, behavioural manipulation, and cognitive transformation (Buss, 2009; Kihlstrom, 2013). Consequently, the neighbourhood provides an important, geographical lens to understand the person-environment relationality where people and environment influence one another in an everyday context (Conradson, 2005; Cutchin, 2003, 2004).

Although the term ‘neighbourhood’ has been widely used in policy and research, its unique meanings to people living with dementia and their carers, and how they interact with their neighbourhood, is just beginning to emerge (Keady et al., 2012). This
knowledge gap raises an important research question, namely: “how do people living with dementia and their carers understand and interact with their neighbourhood?” This indicates that it is crucial for this study to gain an understanding of neighbourhood meanings from the perspectives of people living with dementia and their carers and to obtain in-depth knowledge of their relational dynamics in a context of everyday lived experience. As such, this study supports a person-centred principle by putting people living with dementia first and by developing a bottom-up approach towards a neighbourhood model of dementia.

**Aim and Objectives of Study**

The main research question was: “how do people living with dementia and their carers understand and interact with their neighbourhood?” To answer this research question, the primary aim of this study was to explore the meaning, construction and place of ‘neighbourhood’ in the lives of people with a diagnosis of mild dementia [hence forward referred to as ‘people living with dementia’ in the context of the study design and findings] and their carers living in one East Midlands county of England. The primary aim of this longitudinal, narrative study was supported by four objectives:

- To work collaboratively to understand people living with dementia and their carer’s self-defined neighbourhood.
- To map how people living with dementia and their carers interact with their self-constructed neighbourhood using a variety of approaches to document life activities.
- To identify the main factors that impact upon how people living with dementia and their caregivers negotiate with, and assign meanings to, their self-defined neighbourhood.
- To develop creative methods of working and maintain researcher reflexivity during all research encounters.

**Organisation of Thesis**

There are six chapters in this thesis.
Chapter 1 locates the need for this study within the contemporary knowledge base. It describes the definition of dementia and its demographics as a context for placing dementia as a public health priority. This is followed by an explanation of how public health can make significant contributions to dementia care and improve the quality of life of people living with dementia and their carers. To maintain autonomy and independence, and engage in the society, the social model of disability with human rights and social citizenship principles clearly has a significant role to play. This chapter will then move towards presenting why, and how, a neighbourhood theme as a public health focus influences the health and well-being of older people/people living with dementia from environmental perspectives. This chapter will conclude with discussing the need for combining age-friendly and dementia-friendly communities to meet the requirements of both the ageing population and people living with dementia to further raise the neighbourhood theme which provides a setting for social cohesion.

Chapter 2 presents a thematic review of the literature to emphasise the ‘theories’ that underpin the impact of neighbourhood on people living with dementia and their carers. A thematic synthesis was adopted to collate the literature of neighbourhoods and dementia and contextualise how neighbourhoods affect people living with dementia and their carers. This provided a conceptual framework about how different elements of the neighbourhood were associated with dementia and how these elements affected people living with dementia and their carers from a public health perspective. The findings of this review helped to inform and shape the fieldwork reported in this study.

Chapter 3 critically discusses the methodology and methods employed in the study. It states the rationale for using narrative inquiry as the methodological frame and participatory methods to construct the lived experience of dementia through a neighbourhood lens. This is followed by a detailed description on how the sample eligibility criteria were determined, and how the sample was recruited. This chapter then describes the methods of data collection, data management and analysis. Next, the chapter outlines how rigour was achieved in this study, and ends with an explanation about how the ethical issues were addressed, specifically focusing upon the topic of process consent.
Chapter 4 describes the five case studies in greater depth and they are presented sequentially based on when data collection took place, starting with the first family recruited into the study and ending with the last recruited family. Each couple’s story is presented in a similar format using the same headings; however, the details under each heading are different, reflective of each couple’s approach to co-constructing and representing their neighbourhood map. This chapter will end with a summary to prepare for cross-case analysis.

Chapter 5 presents a cross-case analysis of the five in-depth and longitudinal case studies discussed in chapter 4. The chapter begins by identifying and describing the recurring features of the construction of neighbourhood, and then turns to discuss mediating factors that influenced the couples’ interactions and negotiations with their neighbourhood. This chapter concludes with a discussion of the meta-theme of ‘biographical connectivity to the neighbourhood’ to explain the complex, continually evolving dynamic interactions between people living with dementia, their carers and their self-constructed neighbourhood.

Chapter 6 summarises the findings of the study and then discusses how the study findings contribute to the existing knowledge base in the fields of public health, geography, and environmental gerontology in relation to the lived experience of dementia in a neighbourhood context. This will be followed by describing the implications of ‘biographical connectivity to the neighbourhood’ and what it means for policy, practice, and education. Recommendations for further research will also be proposed in light of the understandings gained in regard to the limitations of the present study. This chapter will conclude with reflections on the methods used in this study.

References and appendices follow and conclude this thesis. This includes a full list of the ethical approval processes, research materials used in the field work, and the outputs achieved after the field work was concluded.
CHAPTER 1

Dementia: Contextual Considerations

1.1 Introduction
This chapter begins by presenting the definition of dementia and its demographics as a context for placing dementia as a public health priority. This is followed by describing how public health can make significant contributions to dementia care and improve the quality of life for people living with dementia and their carers. This chapter will move towards discussing the concepts of ‘space’ and ‘place’ at various scales and then detailing why and how a neighbourhood theme as a public health focus influences the health and well-being of older people/people living with dementia. This chapter will conclude with presenting an argument for combining age-friendly and dementia-friendly communities to meet the requirements of both the ageing population and people living with dementia to further raise the neighbourhood theme which provides a setting for social cohesion.

1.2 Dementia: Definition and Demographics
When the brain is damaged by Alzheimer’s disease, strokes or other conditions, this causes the onset of dementia (Alzheimer’s Society, 2017). Dementia is a set of symptoms, consisting of memory loss and difficulties with thinking, problem-solving, language, and carrying out daily tasks (Alzheimer’s Society, 2017; Mental Health Foundation, 2015). Although these changes are often minor to start with, they can become severe enough to affect all activities of daily life (Alzheimer’s Society, 2017). Based upon the Global Deterioration Scale for Assessment of Primary Degenerative Dementia, the dementia states can be classified as mild, moderate, and severe and each stage is detailed as follows (Reisberg, Ferris, de Leon & Crook, 1982):

i. Mild dementia - This stage refers to moderate cognitive decline, including difficulty concentrating, declined short-term memory loss, and difficulties managing instrumental (complex) activities of daily life.

ii. Moderate dementia - This stage means (moderately) severe cognitive decline, presenting memory continuing to worsen and deficits in ability to carry out basic daily activities.
iii. Severe dementia - People in this stage have very severe cognitive decline; require assistance with most activities; and have lost most communication skills. In general, the brain cannot control the body.

Dementia is in close association with ageing, so the increase of the ageing population has led to a growing number of people living with dementia, with the probability of developing dementia almost doubling every five years after the age of 65 (Department of Health, 2015; World Health Organisation & Alzheimer’s Disease International, 2012). It is estimated that, globally, 44 million people live with dementia, with the numbers set to nearly double by 2030 (Department of Health, 2015). In the UK, there are currently around 850,000 people living with dementia (Alzheimer’s Society, 2017; Mental Health Foundation, 2015) and the annual societal cost of dementia is £26 billion, which is more than the combined cost of stroke, heart disease, and cancer (Alzheimer's Society, 2014).

People living with dementia usually require high levels of care and are often cared for by informal or family carers; this support helps them to maintain their quality of life and stay at home for as long as possible. In the UK, an estimated 670,000 people act as primary carers for people living with dementia, this equates to a saving of £11 billion each year to care services (Alzheimer’s Society, 2014). However, providing such support can cause distress and reduce the quality of life for carers, meaning that dementia not only affects the persons living with dementia, it is often overwhelming for the carers and families as well (Brodaty & Donkin, 2009; World Health Organisation & Alzheimer’s Disease International, 2012).

Dementia has been framed as an economic and societal burden which pays attention to a medical model and problematises dementia in relation to ageing demographics (Mental Health Foundation, 2015; Ward et al., 2017). However, this medical view of dementia does not represent the full picture and neglects the role of the environment, both socially and physically, in creating barriers for people living with dementia which often leads to their marginalisation and social exclusion (Mental Health Foundation, 2015; Ward et al., 2017). This stimulates a need to focus upon the environmental barriers, including attitudinal, psychological, architectural, and institutional, as people living with dementia have a right to be treated, and a right to access care services,
equally as all other citizens (Mental Health Foundation, 2015). However, a lack of awareness of dementia and of understanding the risks of developing this condition may result in stigmatisation and barriers to diagnosis and care (World Health Organisation & Alzheimer’s Disease International, 2012). To tackle these issues, national dementia strategies were launched and implemented in many countries around the world to enable living well with dementia (see for example: Alzheimer's Disease International, 2009; The Scottish Government, 2010).

In addition, dementia as a public health priority and requiring public health actions has also been recommended by the World Health Organisation and Alzheimer’s Disease International (2012). Central to this philosophy is the need to raise awareness of dementia and to articulate a public health approach to improve the care and quality of life of people living with dementia and their family carers. This approach is in line with the principles of inclusion, integration, equity, and evidence to support an asset-based approach for dementia (Social Care Institute for Excellence, 2017; World Health Organisation & Alzheimer's Disease International, 2012). Furthermore, a public health approach in risk reduction and prevention of dementia has been set as one priority in Public Health England’s (2014) ‘From Evidence into Action’ report to reduce the numbers of people developing dementia, delay its onset, and mitigate its impact. More recently, the Prime Minister’s Challenge on Dementia 2020 sets out priorities to transform dementia care, support, and research by 2020 to improve health outcomes for people living with dementia and their families (Department of Health, 2015). This initiative further raises the public health agenda in reducing the risk of dementia and its incidence and prevalence amongst older people (Department of Health, 2015).

1.3 Public Health and Dementia

In England, the Public Health Outcomes Framework emphasises a whole system approach to improve the health of local populations through effective collaboration between Public Health, the NHS, and Adult Social Care (Department of Health, 2013). This Framework aims to protect and improve the population’s health in order to deliver better public health outcomes for the local population (Department of Health, 2013). To do this, Public Health England (2016) has set out a strategic plan for the next four years to tackle the main causes of years of life lost in England, and dementia is one key area to
raise awareness and reduce the risk of dementia through tackling lifestyle risks. To understand how public health influences and contributes to dementia care, it is important to first understand the meaning of public health. The UK's Faculty of Public Health (2010) provides a well-accepted definition of public health: “the science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised efforts of society” (para.2).

To improve the health of the population, public health is organised through three key domains: i) health improvement (or health promotion); ii) health protection; and iii) health services quality (UK's Faculty of Public Health, 2010). The following sections will detail how health promotion and health services quality improvement influence, and contribute towards, dementia care.

1.3.1 Health Promotion and Dementia

Health promotion is the process of enabling people to increase control over the determinants of health, thereby improving their health to reach a state of complete physical, mental, and social well-being (World Health Organisation, 1986a, 2005a). Health promotion goes beyond healthy lifestyle to well-being; it is a resource for everyday life (World Health Organisation, 1986a) and focuses on the positive, dynamic and empowering aspects of health (World Health Organisation, 1986b). To reach a state of complete physical, mental, and social well-being, an individual or group must be able to identify and realise aspirations, to satisfy needs, and to change or cope with the environment (World Health Organisation, 1986a). This can be achieved through empowerment, which is the core guidance for a health promotion plan (World Health Organisation, 1986a).

Empowerment is a process of enabling people to express their needs and concerns for involvement in decision-making, to have control over their lives, and achieve political, social, and cultural action to meet those needs (World Health Organisation, 1998). Empowerment originated from the ‘social movement’ which focused upon raising awareness of self-help (Che, Yeh & Wu, 2006). In dementia care, empowerment aims to enable people living with dementia and to give choices around aspects of their daily living (Martin & Younger, 2000) so that they have control over the decisions to help
maintain autonomy and independence (Lezwijn et al., 2011; Ward, Howorth, Wilkinson, Campbell & Keady, 2011). Empowering people living with dementia can be assisted by a person-centred care approach, which is where the person is placed at the centre of their own care, considering humanistic, dignified, and morally ethical aspects (Perez-Merino, 2014; Rogers, 1961). One theoretical basis for person-centred care for people living with dementia is Kitwood’s work on personhood. Kitwood (1997) defines this as:

“A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood, and the failure to do so, have consequences that are empirically testable.” (p.8)

Kitwood’s concept of personhood is associated with the social model of disability (Mental Health Foundation, 2015) and it is one of the most influential for dementia practice and research (Bartlett & O’Connor, 2007). For example, the person-centred care approach can be adhered to in practice by using both verbal and non-verbal communications, facial expressions and body language, listening to people living with dementia and being willing to understand their perspectives (Aoki, 2002). Moreover, empowerment can enable caregivers for people living with dementia to overcome difficulties and improve their situation as they often face a number of physical, psychological, social, and financial challenges (Che, Yeh & Wu, 2006).

To strengthen personhood via empowerment, health promotion is considered a key factor in dementia care to support the maintenance of autonomy and independence and to improve people’s health (Ward et al., 2011; World Health Organisation, 1986a, 2005a). Health promotion can be strengthened by operationalising the right to health, to retain dignity, freedom and equality for everyone (Williams, 2011; World Health Organisation, 2008). The right to health refers to the right to the enjoyment of the highest attainable standard of physical and mental health, and it is a fundamental right of all people (World Health Organisation, 2008). The right to health consists of both freedoms and entitlements (World Health Organisation, 2005b). Freedoms cover the right to control one’s own health and body and to be free from interference, whereas entitlements refers to the right to have an equal opportunity to enjoy the highest
attainable level of health for all people (World Health Organisation, 2005b). The core obligations of the right to health includes primary health care and the underlying determinants of health, such as safe working conditions, adequate housing and nutritious foods (Williams, 2011; World Health Organisation, 2008).

The right to health is part of international human rights law, and it has been codified in a number of international covenants and declaration, such as the Alma Ata Declaration for primary health care, and the Bangkok Charter for Health Promotion (World Health Organisation, 2008). The right to health can, therefore, from its legal standing, bring legitimacy to strategies and practices to strengthen health promotion so that people living with dementia can have control over the determinants of health (Williams, 2011) and their rights can be protected to make decisions, exercise autonomy and self-determination as well as reduce discriminatory practices (World Health Organisation, 2012). In short, to deliver and strengthen personhood in dementia care, the rights of people living with dementia need to be reinforced. This will be further discussed in section 1.4.

1.3.2 Health Services Quality Improvement and Dementia

Health service quality improvement is another key domain of public health. Effective, equitable, accessible, and appropriate health services are equally as important as health improvement and health protection (UK’s Faculty of Public Health, 2010). To achieve better health outcomes it is important to re-orientate health services through expanding health promotion and disease prevention actions into a health care pathway to form a holistic, integrated care pathway to support person-centred care (All-Party Parliamentary Group on Dementia, 2016; World Health Organisation, 1998). This movement is in light of the recommendation of prioritising dementia as a public health priority and of improving public health and social care systems to enhance the quality of life for people living with dementia and their carers (World Health Organisation, 2012).

The integrated approach to dementia contributes to the care and quality of life of the people who live with dementia having other health conditions. Evidence shows that seven in 10 people living with dementia are also living with other health conditions: 41 per cent having high blood pressure, 32 per cent living with depression, and 27 per cent
living with heart disease (All-Party Parliamentary Group on Dementia, 2016). Due to demographic pressures of the ageing population and prevalence of comorbidities, dementia and other chronic diseases are increasing. Attention has therefore been shifted from the focus of acute and episodic care towards prevention and self-care through well integrated services (Imison et al., 2011). This is because self-management can improve health outcomes of patients, such as increasing physical functioning and experience, improving confidence, and reducing anxiety (Challis et al., 2010).

However, dementia can cause a decrease in cognitive functioning and this will prevent people living with the condition from effectively self-managing their symptoms over a prolonged period of time as well as impacting on treatment regimens associated with other conditions. This, in turn, can increase the risk of receiving poor quality of care for their condition(s), resulting in issues such as a lack of diagnosis, misdiagnosis, and mismanagement (All-Party Parliamentary Group on Dementia, 2016). To help people live well with dementia and comorbidities, and enable them to self-manage their conditions effectively, a co-ordinated approach is essential, including access to good quality information, a comprehensive care plan, regular multi-disciplinary assessments and reviews of care and support, and a care co-ordinator (All-Party Parliamentary Group on Dementia, 2016). To implement this co-ordinated, person-centred approach, health and social care systems should focus upon the following areas recommended by the All-Party Parliamentary Group on Dementia (2016):

- Risk reduction of dementia can be improved via Public Health England mandating a dementia component in the NHS Health Check for people at the age of 40 to 65.
- General Practitioner-led holistic review of care and support should be received by people living with dementia and comorbidities at least once per year, and this should be part of the NHS Quality and Outcomes Framework.
- New guidelines on polypharmacy for England need to be developed by the Royal Pharmaceutical Society to treat people living with dementia who have multiple chronic conditions.
• Data on dementia and common comorbidities should be included in the Dementia Intelligence Network by Public Health England so that commissioners can then use the accurate data to commission integrated care pathways.

• The quality and performance of both care pathways, across health and social care systems by individual providers, should be assessed by the Care Quality Commission.

Health services quality improvement is vital in the enhancement of dementia services and the delivery of better outcomes for people who have dementia living with other conditions and their carers. To support this, for example, the World Health Organisation and Alzheimer’s Disease International (2012) state that it is crucial to develop and improve dementia services for earlier diagnosis, to provide community support, and to design a responsive, integrated health and social care system. Additionally, improved community support can reduce family carers’ stress, help families care for people living with dementia for longer and delay or reduce the use of highly costed residential care (World Health Organisation & Alzheimer’s Disease International, 2012). This community-focused support raises the importance of the neighbourhood theme in the influence of the quality of life of people living with dementia and their family carers. The neighbourhood theme is also recommended by the Alzheimer’s Disease International Kyoto Declaration (2004) in action areas, such as to give care in the community, involve communities, families and consumers, and monitor community health. The neighbourhood theme will be further detailed in section 1.6.

In the design and implementation of public health policies and practices, the human rights of people living with dementia can be promoted or violated, such as freedom from discrimination, rights to participation, and rights to health (World Health Organisation, 2008). To embed and strengthen the human rights approach within dementia care, it is essential to combine it with the social model of disability to recognise that individuals with dementia are disabled by society rather than their impairment, thereby the person can be supported to maintain autonomy, independence, and societal engagement (Mental Health Foundation, 2015; Eriksson & Lindstrom, 2008).
1.4 The Social, Rights-based, Model of Disability and People Living with Dementia

Historically, there are two models of disability, the medical model and the social model. The medical model of disability is derived from the biomedical perception of disability and relates disability to a condition or a medical problem (Sullivan, 2011). This model argues that people are disabled by their condition, so they are prevented from making decisions and exercising control, and excluded from mainstream social participation (Mental Health Foundation, 2015). By way of contrast, the social model of disability claims that “the person has an impairment (as a result of a condition) and that they are disabled not by their impairment, but by a broad range of social, economic, attitudinal, physical, architectural and environmental factors” (Mental Health Foundation, 2015; p.17). This statement shifts the emphasis from changing the individual characteristics of the impairment to altering the external barriers and the social and psychological obstacles so that they are enabled to exercise their autonomy and engage in society. This shift is supported by Kitwood’s (1997) concept of personhood and his argument that ‘dementia’ is not the main problem but rather it is ‘our’ (society’s) inability to accommodate ‘their’ (people living with dementia) view of the world. This further draws attention to the social and physical barriers created by society, and how these barriers disadvantage people living with impairments. This point is reiterated by Oliver, Sapey and Thomas’ (2012) claim that disability is built upon impairment, arguing that: “disability is the disadvantage or restriction of activity caused by the political, economic and cultural norms of a society which takes little or no account of people who have impairments and thus excludes them from mainstream activity” (p. 16).

The social model of disability emphasises that “society must adapt to enable the participation of disabled people as equal citizens” (p.6), and this model is centred by a (human) rights perspective (Mental Health Foundation, 2015). However, before applying the social model of disability to people living with dementia, it is beneficial to first understand the developmental journey of this model. Initially, this model exclusively focused upon people with a physical impairment, but in the 1980s and 1990s its initial formulation was expanded to include people with sensory or cognitive impairments who also experienced similar social exclusion and barriers (Milligan & Thomas, 2016). In the
1990s and 2000s, the social model of disability was further refined to include people who live with chronic conditions and mental health issues (Milligan & Thomas, 2016).

The evolvement of the social model of disability has resulted in the United Nations Convention on the Rights of Persons with Disability and Optional Protocol (2006) which defines persons with disabilities as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (p.4). The application of human rights and the rights of persons with disabilities to people living with dementia and their carers is stated in the Scottish Charter of ‘Rights for People with Dementia and their Carers’, and their entitlement and access to services should be warranted on an equal basis with others (Crowther, 2016).

Human rights are moral principles that every person in the world should enjoy and the fundamental rights and freedoms are protected by law (Equality and Human Rights Commission, 2017). The Universal Declaration of Human Rights was the first attempt to bring human rights to life in 1948 and it provided the basis for the European Convention on Human Rights in 1950. The Convention was incorporated in the Human Rights Act 1998 in the UK and the Act protects the fundamental rights and freedoms that everyone is entitled to (Equality and Human Rights Commission, 2016). In practice, the Human Rights Act 1998 allows everyone to defend their rights and to be treated equally with fairness, dignity, and respect in UK courts and compels public organisations (Equality and Human Rights Commission, 2017). To protect equality and tackle unfair discrimination, the Equality Act 2010 certainly has the legal function in preventing people living with dementia from unfair treatment (Legislation, 2011). Therefore, dementia has been classified as a ‘disability’ on the policy landscape and people living with dementia are intended beneficiaries of the Convention and of the Equality Act 2010 (Crowther, 2016; Mental Health Foundation, 2015).

A further claim made by the social model of disability is that people with impairments should have opportunities for self-determination, their voices should be heard and their needs be met in numerous ways, so they can be empowered and involved in determining their own decisions (Campbell & Oliver, 1996; Milligan & Thomas, 2016).
When applying the social model of disability to dementia using the law positively, this process is called ‘a human rights-based approach’ (Mental Health Foundation, 2015). Human rights are a basis for equity, empowerment, and engagement (Eriksson & Lindstrom, 2008) and are at the core of the social model of disability (Mental Health Foundation, 2015).

In dementia care, the human rights-based approach is delivered via five ‘PANEL’ principles in practice, referring to: Participation, Accountability, Non-discrimination and equality, empowerment, and legality of rights (Scottish Human Rights Commission, 2017). ‘PANEL’ enables practitioners or policymakers to apply human rights in dementia care practice and ultimately allow a human rights-based approach to be operationalised (Mental Health Foundation, 2015). The combination of a human rights-based approach and the ‘PANEL’ principles offer a real opportunity to change practice and create innovative ways to develop enabling environments that people living with dementia can determine their own life circumstances through choices (Mental Health Foundation, 2015).

To further support implementing human rights in dementia care, it is essential to link it with citizenship, particularly social citizenship, to enhance equality. Citizenship has a close association with human rights (Kelly & Innes, 2013), with social citizenship having developed as a human rights tenet since 1993 (Davy, 2014). Marshall (1950) saw citizenship as being comprised of three parts: civil, political, and social, and so citizenship encompasses civil rights, political rights, and social rights as a legal status (Davy, 2014). Citizenship does not only mean having rights but also involve responsibilities (Kelly & Innes, 2013), and it brings a more active and political lens to understand the lived experience of dementia (Wiersma et al., 2016). Implementing citizenship is to empower the status of disempowered people to the same status of an equal citizen, particularly participation or inclusion in society shaped by power dynamics (Bartlett & O’Connor, 2007). Being a citizen is something people, with an equality of status and opportunities, do rather than strive to be (Prior, Stewart & Walsh, 1995).

However, citizenship is often denied to people living with dementia (Kelly & Innes, 2013) as the identification of citizens entails knowing who is entitled to social rights, which is
socially constructed within the welfare system (Nordh, 2016). This results in inclusion and exclusion of social rights and of the processes that affect these rights, as such, the determination of citizens is ongoing discussion (Nordh, 2016). To strengthen social rights of people living with dementia, it brings social citizenship to the forefront to address inequality. Social citizenship is “... the rights and duties associated with the provision of benefits and services designed to meet social needs and enhance capabilities...” (Taylor-Gooby, 2008, p.3). More importantly, social citizenship is not about passive acceptance of social rights but, instead, is claiming, and having influences over, social rights via various ways (Taylor-Gooby, 2008). It is, therefore, a fluid process and subject to change within the welfare system (Turner, 2001). For people living with dementia, social citizenship has a direct association with their lived experiences which are shaped and constrained by defining their responsibilities and eligible requirements in society (Nordh, 2016). Moreover, promoting social citizenship for people living with dementia is crucial to ensure they have equal social rights as other citizens, and thus improves their lived experiences and strengthens their human rights.

In summary, the combined lens of human rights and social citizenship broadens society’s view of people living with dementia and enhances the scope of dementia care and practice. Additionally, the social model of disability with human rights and social citizenship principles has the potential to reshape the direction of the dementia discourse to achieve social change, rather than attempting to modify the unalterable individual characteristics of the condition. To support this collaboration and improve community health, the development of enabling environments is essential to empower people living with dementia to have equal social rights and control over the determinants of their own health. Consequently, the ageing and dementia policy has focussed upon the creation of age-friendly and dementia-friendly communities at an operational level. Developing such enabling environments is in close association with the key principles of health promotion that, to achieve complete well-being, one must be empowered and enabled to manage the environment and to satisfy needs (World Health Organisation, 1986b). Creating enabling environments is also the emphasis of health service quality improvement via community-focused support. In addition, the creation of enabling environments for people living with dementia also draws attention to a neighbourhood theme. This theme has been a focus within UK dementia policy, such as
‘Dementia and the Big Society Think Tank’ report that sets out the benefits for people living with dementia if they are active and empowered citizens via a neighbourhood theme (Goodchild, 2011). ‘Neighbourhood’ provides a lens to understand how people living with dementia and their carers respond to, and interact with, their environments in an everyday context and what contribution they can bring to relationships in the everyday places where life is lived. Before discussing ‘the neighbourhood theme’ in more detail, it is important to understand the concepts and differences between ‘space’ and ‘place’ at various scales from a geographical perspective as geography matters.

**1.5 Geography Matters**

People are shaped by the environment of their everyday lives and through this process, the spaces that people frequent can be transferred into meaningful places (Rowles & Bernard, 2013). This complex transactional process is the outcome of ‘being in the world’ and evolving through time (Dreyfus, 1991). This dynamic human-environment relationship has a close association with health and well-being in old age (Wahl & Weisman, 2003; Gomez et al., 2010). For example, interaction with outdoor environments increases physical activities, gains a sense of connection, and improves self-confidence (Gibson et al., 2007; Gomez et al., 2010).

**1.5.1 Space and Place**

Space provides a person with both possibilities and constraints and is a source of identity which influences and shapes the person’s sense of self (Brittain et al., 2010). Space is navigated through and situated in time, that is, space and time are intersected and interpreted through human interactions which create specific, special, and personal understandings of the space (Peace, 2013). Here, space is the extent of people’s movement throughout their environment, ranging from the bedroom in their own home to being out of town, as Peace (2013) neatly captures in this straightforward summary “the use of space is the essence of place” (p,27).

Transforming spaces into places that have personal meanings in everyday life is a complex process involving the conversion, at various levels, of something universal into a meaningful expression of an individual’s identity (Rowles & Bernard, 2013). Rowles and Bernard (2013) detail this process, demonstrating how it often starts with the use of a
space and the routines of using the space over time that is then formulated in to a pattern of familiarity and comfort. This sequencing becomes a learned pattern, reinforced by cognitive awareness of the environment which is brought alive when the pre-conscious ‘body subject’ (Seamon, 1979) breaks down, for example when a person bumps into a piece of furniture which has been moved from its usual location in the home by another family member. Use and awareness of space contribute towards the development of emotional attachment and a sense of ownership. Attachment to places can be intensified where significant life events occurred, with these places representing identity. In short, the combination of use, awareness and emotional attachment support the transformation of spaces into places that contain multifaceted layers of meanings, becoming potential sources of self-affirming recollection. It is why places can gradually embody the self as they become the landscape of life stories and experiences that are reconfigured as identity. The outcome of the accumulation and assimilation of layer upon layer of meaning in place can be defined as ‘a sense of being in place’ (Rowles & Bernard, 2013).

However, the process of place-making can be affected at many levels by a decline in personal competence due to the onset of ageing and dementia, for example, that can result in disorientation, difficulties in interpreting and navigating space, and feeling threatened or distressed. As such, a previously familiar, accessible environment can become inhospitable which, in turn, affects a person’s health and well-being (Blackman et al., 2003; Brittain, Corner, Robinson, & Bond, 2010). Eventually, the ability to retain a sense of being in place is challenged, this culminates in a need for greater environmental awareness within the dementia landscape. I will now discuss this further by exploring the concept of ‘place’.

Place is described by Massey (1994, 1995) as a geographical outcome of social-economic processes created on several scales. The social-economic aspect stresses human entities; however, less consideration has been given to non-human entities, such as animals and plants, and created objects, such as homes and personal computers. Such non-human entities play significant roles in contemporary place-making (Conradson, 2005). By recognising the dynamic associations between different entities, place can be rooted in a more relational materialism (Hetherington & Law, 2000). This signifies that place
emerges through various interactions between: people and people; people and other biological entities (e.g. animals and trees); and people and objects (e.g. cars, machines) (Conradson, 2005). This engagement can be material and/or emotional, positive and/or ambivalent (Conradson, 2005). ‘Place’ is thereby a product of complex and multifaceted relations at many levels and can in itself become a dynamic phenomenon. In this way interactions with various elements of place require skills, which can further challenge older people, particularly those living with dementia whose capacity and cognitive abilities become more compromised over time. Accordingly, ‘place-making’ and retaining a sense of ‘being in place’ become increasingly difficult for a person living with dementia and add an extra layer of stress in dealing with everyday life and everyday actions.

Nevertheless, building on the previous ideas of space and place, a sense of place is influenced by time-space compression which is concerned with “movement and communication across space, to the geographical stretching-out of social relations, and to our experience of all this” (Massey, 1994, p.147). An important point here is who is influencing, or receiving, the movement and communication a point Massey (1994) calls the ‘power geometry’ of time-space compression, and divides such social groups into four types:

I. ‘In charge’ of time-space compression, such as those who control the news, organise the investments and the international currency transactions.

II. Doing the physical movements, such as immigrants and refugees.

III. Receiving end of time-space compression, such as older people sitting in a chair at home watching a British film about Chinese culture.

IV. Contributing to, and ‘imprisoned’, in time-space compression, such as those who have contributed enormously to music which has been very popular in a country, but the person has never been to that place.

Additionally, within each group, there are various degrees in relation to the flows and the movements. Hence, people being located within time-space compression paint a highly complex picture that mixes wider social relations with more local ones: a sense of
place is constructed by relating that place to the world, called ‘a global sense of place’ (Massey, 1994).

This global sense of place is reinforced by globalisation which stretches social relations over geographical places, from local to global in other words. Meanwhile, new technologies are giving rise to a new burst of time-space compression that results in it becoming harder to separate different geographical scales as “they constitute each other: the global the local, and vice versa” (Massey, 1994, p. 161). Hence, a place is an open and porous network of social relations (Massey, 1993) and it is constructed, and shaped, by social relations of power in a dynamic content (Massey, 1995; Peace, 2013; Wiles, 2005). This signifies that an individual’s geography of social relations can be unique or overlapping with others, and the person’s geography of social relations has an influence in the level of connectivity to place and the experience of ‘being in place’ (Massey, 1994; Peace, 2013). Being in place helps secure identity and facilitates an assumption of stability (Massey, 1994).

Overall, people transfer spaces into meaningful places by building layer upon layer of personal meanings in the space (Rowles & Bernard, 2013). In contrast, place has its own accumulated history as the product of layer upon layer of various linkages between the local and the wider world (Massey, 1994). Therefore, as Rowles & Bernard (2013) argue: “space matters, but place matters even more, because it captures the essence of meaning in life. To be placeless is to be alienated from the world and is a threat to identity” (p.20). Indeed, on the one hand, a sense of place influences the subjective view of stability and unproblematic identity whilst, on the other hand, time-space compression has effects of insecurity and is unsettling for people, triggering feelings of vulnerability (Laws, 1997; Massey, 1994). In addition to psychological well-being, geography matters to people’s health and overall well-being which are affected by a dynamic interplay between people (biologic and behavioural aspects) and the environment which unfolds throughout the life course (Maddox, 2000). Within this dynamic process, age plays an important role in shaping the context in which people function and, ultimately, affects health risks and resources (Satariano, 2006).
Within ageing societies, retaining a sense of ‘being in place’ is a challenge constructed of a complex process that encompasses multifaceted relations at various scales and is influenced by time-space compression. That is, time and space can affect older people’s geographical experience due to physical deterioration and social devaluation which can lead to decreasing involvement with spaces and meaningful places (La Gory et al., 1985).

To explain further, older people selectively intensify their psychological investments in local environments, such as neighbourhood and home, and they are therefore more likely to experience ‘vicarious engagement’ with past places and memorable locations through fantasy, such as by re-living past experiences with a place (Rowles, 1978). Rowles (1978) calls this phenomenon a ‘hypothesis of changing emphasis’ derived from four ‘modalities of geographical experience’, namely action (a movement in space), orientation (a mental template of the environment where action takes place), feeling (emotional reaction to the meaning of significant spaces), and fantasy (involvement in locales displaced by space and time). Feeling, fantasy, and to a lesser degree, orientation, are related to meaning and symbols which are at the core of social life (Rubinstein & Lawton, 1981).

These four ‘modalities of geographical experience’ provide ‘geographical lifespace’ but they fail to define the content of adjustment, such as competent behaviour or well-being (Rubinstein & Lawton, 1981), which is important because geographical experience and health are closely associated (Blackman, 2006). Nonetheless, “adjustment is the totality of the transaction” (Rubinstein & Lawton, 1981, p. 348), and this conceptual model stresses the importance of the transactional processes. These complex, dynamic processes provide a helpful theoretical framework in understanding the relationships between older people and their environment and establish an association between geographical experience and older people’s health in the social domain.

For older people, the continuance of ‘being in place’ contributes to, and associates with, the current policy of ‘ageing in place’ which is defined as “remaining living in the community, with some level of independence, rather than in residential care” (Davey et al., 2004, p. 133). This implies that ‘ageing in place’ aims to enable older people to remain in their homes and neighbourhoods, for as long as possible, whilst maintaining independence, autonomy and connection to social support. As such, geographical
experience matters to older people’s health and well-being, influenced by not only time-space compression, but, also, by its ‘power geometry’. The latter seems to disadvantage the ageing population, particularly those living with one or more long-term conditions. For example, people living with dementia are more likely to be on the receiving end of, or ‘imprisoned’ in, time-space compression due to the impacts of ageing and decreasing capabilities. In other words, people living with dementia have less, or no, power to influence the flows and the movements across space and to affect their multifaceted relations, the outcome of which is that they become passive recipients. In this sense, it might be fair to say that ‘action space’ increasingly shrinks, while ‘vicarious engagement’ with places can become more frequent and intensified for people living with dementia.

This shifting geographical experience constantly influences people’s health and well-being. As such, in dementia care, place-based care needs to be endorsed through strengthening a person-in-environment approach (McGovern, 2017). Meanwhile, the current shifting landscape of the social model of disability with human rights and social citizenship principles enhances the scope of dementia care and practice and gives a prominence to environmental factors (Mental Health Foundation, 2015; Taylor-Gooby, 2008). This entails a close look at the everyday experiences of people living with dementia in a context of lived places to investigate who they negotiate with and how they respond to environmental opportunities and challenges. Consequently, neighbourhood and home would be a primary focus in any study.

To provide clarity in the focus of this theme upon ‘neighbourhood’ rather than ‘community’, it is important to look at how ‘community’ is defined and understood within the literature. ‘Community’ refers to a social unit of individuals with diverse characteristics who are linked by social ties, share common interests, and engage in joint activities (MacQueen et al., 2001; McMillan & Chavis, 1986). This concept is relevant to the four core community elements, namely locus (a sense of place, locale, or boundaries), sharing (common interests and perspectives), joint action (a source of cohesion and identity), and social ties (interpersonal relationships that formed the foundation for community) (MacQueen et al., 2001). These four dimensions are in parallel with a sense of community which consists of four dimensions, namely
membership, influence, integration and fulfilment of needs, and shared emotional connection (McMillan & Chavis, 1986).

‘Community’ can be perceived as a practice of engaging with others for ‘building community’ or be considered as a theoretical concept, such as ‘connected community’ (Douglas, 2010). As such, the term ‘community’ can focus upon geographical aspect (a substitute term for locality) and/or social relationships (well beyond a geographical location) but no agreed definition exists (Douglas, 2010; Gusfield, 1975). The complexity of the idea of community is demonstrated in Hillery’s (1995) literature review of 94 definitions. He found that two thirds cited social interaction, geographic area, and common ties as core elements of community, and nearly three quarters cited area and social interaction. When Willis (1977) reviewed 60 definitions of community, he found an emphasis on common ties within a geographic area.

Nevertheless, community has emotional overtones, implies a degree of attachment and belonging, and offers beneficial contributions to establish a strong and vibrant society (Douglas, 2010). As such, the notion of community positively contributes to aspects of society and helps improve people’s well-being (Douglas, 2010) and health outcomes (Marmot, Bobak, & Smith, 1995). On the other hand, communities can have negative anti-social goals and aim to exclude those who do not conform to an expected behaviour or condition; this can be associated with class, race, gender, sexuality, or disability and are classed as ‘dark communities’ (Douglas, 2010). It is this comprehensive understanding of community and health that has led to increased interests for community collaboration as an important strategy for public health research and programmes (MacQueen et al., 2001). For ageing and dementia populations, this understanding has been taken forward and integrated within the concepts of ageing-friendly, and dementia-friendly, communities which will be detailed in section 1.6.2.

It is recognised that communities change over time. In modern societies, new forms of communities emerge where people’s interactions with that community are based upon virtual contact via the Internet rather than physical interactions, providing a sense of belonging and resulting in personal benefits (Douglas, 2010). As such, modern communities focus more upon social connections and highlight the variation in
establishing and facilitating such connections; this results in strengthening the development of alternate social connections and weakening traditional place-based communities (Douglas, 2010). Brock (2008) contends that contemporary communities are fragmented, leading to people living in their ‘own worlds’. As such, ‘community’ does not necessarily provide a geographical lens and cannot be used to explore the daily lived experience of the locality. However, ‘neighbourhood’ is more localised and geographically boundaried, and ‘neighbourhood’ supports a person-centred understanding of the relationship between people living with dementia and their environments.

1.5.2 Neighbourhood
A neighbourhood is an important multi-dimensional place where people live and interact with physical, social, and cultural factors resulting in the development of patterns of behaviours (La Gory et al., 1985). In this respect, the neighbourhood is a setting which helps explain the relationship between people and the environment (Baker, 1968). It is this recognition that facilitates an understanding of how the residents’ quality of life and associated community’s dynamics can be affected by the neighbourhood (La Gory, 1982; Michelson, 1976). Indeed, neighbourhood as a complex system derived from individual interactions with geographical and social variations, becomes a complex causal combination that can influence local population health. This is illustrated through Blackman’s book ‘Placing Health’ (2006) where he examines complex interrelationships within a neighbourhood. He states that the ‘neighbourhood’ is ‘a walkable zone of experience’ at the ‘smallest significant socio-spatial scale of the societies of which they are part’ (p.2) and that the ‘neighbourhood’ is a geographical space that holds physical and social attributes.

Certainly, neighbourhood and health are closely related through physical and social attributes within a geographical space. Person-environment relationships have been significantly studied over time and knowledge of the interrelationships between people, place, and health have been broadened. For example in discussing ageing societies, Gomez et al. (2010) illustrates that access to public spaces can increase the levels of connectivity and safety for older people and is associated with physical activity, especially increased walking patterns. Walking behaviours can also be improved through
interaction with other every day environmental attributes, such as walking for transport
(Owen et al., 2007). The outdoor environment is essential to generate activity in local
public areas. In addition, natural environments and nature-related activities improve
self-confidence and social interaction (Gibson et al., 2007). Therefore, it is this
understanding of the association between environment and health that enables
‘neighbourhood’ to be frequently used in policy, strategy, practice, and research, and
there has been a continuous focus on its geographical aspect and application to address
local issues such as health inequality and poverty (Keady et al., 2012).

As older people are at a risk of experiencing reduced competencies they can become
increasingly sensitive to psychical, social, and cultural variations, leading to a changing
emphasis on geographical experiences (Rowles, 1978). Ultimately, decreasing
competence may prevent older people from taking a more active role in manipulating
their environment and their behaviour becomes increasingly dependent upon the
characteristics of that environment (Lawton & Nahemow, 1973). As such, ageing plays
an important role in geographical experience and leads to a position where older people
can share a geographical neighbourhood, although they may not mentally occupy the
same place (La Gory et al., 1985). The changing geographical experience affects social
life (Rubinstein & Lawton, 1981) and, eventually, influences health in the social domain
for older people. Therefore, ‘neighbourhood’ is an important place to understand the
daily experiences of the locality where people live and how this external environment,
consisting of both social and physical aspects, impacts upon older people’s ‘social
health’. Here, ‘social health’ refers to older people’s capability to fulfil their potential
and obligations, their ability to manage their life with some degree of independence,
and their ability to participate in social activities (Huber et al., 2011). As such, health in
the social domain is affected by social and environmental opportunities and limitations
which change across the lifespan (Huber et al., 2011; Vernooij-Dassen & Jeon, 2016).

For people living with dementia, ‘neighbourhood’ becomes increasingly significant as the
onset and progression of the condition affects their capabilities in managing and
interacting with the environment in an everyday context, which in turn influences their
‘social health’ (Ward et al., 2017). This geographical place provides an important lens to
understand how people living with dementia deal with the environmental challenges
and utilise opportunities to manage their condition. In so doing, the lived experience of dementia can be better unpacked through person-environment relationality where people and environment influence one another (Conradson, 2005; Cutchin, 2003, 2004). It is this linkage between the lived neighbourhood and social health that has stimulated more interest in research to study the interconnections between people living with dementia, place, and health. For instance, meaningful social interactions are positively associated with people living with dementia’s well-being and quality of life at a neighbourhood level (Tranvåg, Petersen & Nåden, 2015; Wiersma & Denton, 2016). Additionally, getting ‘out and about’ and walking around the neighbourhood contribute to a sense of independence, self-respect, and social contact (Keady et al., 2012; Mitchell & Burton, 2010). This is affected by environmental design (e.g. pavement, lighting, location of bus stops) which can facilitate or hinder the freedom to go outdoors and to access spaces and amenities in the neighbourhood (Blackman et al., 2003). Therefore, the connection between people living with dementia, social health, and environmental factors draws attention to the significance of the lived neighbourhood and it is this association that seems to establish a connection between neighbourhood and recognisable community.

The concepts of ‘neighbourhood’ and ‘community’ are not exclusively distinct but mutually interweaving. ‘Community’ refers to social relationships and operates within certain boundaries tacitly or explicitly agreed by members (Douglas, 2010). Conversely, ‘neighbourhood’ is broadly related to geographical boundaries or multi-dimensional places where people live and develop meaningful interactions (La Gory et al., 1985; Ward et al., 2017). Therefore, ‘neighbourhood’ can be considered as a ‘lived place’ – a ‘lived neighbourhood’ - where people interact with physical and social attributes within a geographical boundary (Ward et al., 2017). It is this lived place that supports a person-centred understanding of person-environment relationships in an everyday context (Ward et al., 2017).

In dementia care, it is this geographical understanding through the daily lived experience of the locality that gives rise to the significance of ‘neighbourhood’ over ‘community’. That is, the lived place is a significant setting to explore the experience of living with dementia and to understand how this experience relates to the person’s social health
and affects their quality of life. As such, neighbourhood is a key factor in supporting place-based dementia care. More importantly, neighbourhood enables an understanding of how people living with dementia’s daily lives are facilitated and hindered by where they live, which aligns with the current emphasis of the social model of disability with human rights and social citizenship principles (Mental Health Foundation, 2015; Taylor-Gooby, 2008). Neighbourhood is also closely intertwined with, and can begin within, the home environment (Ward et al., 2017). This close association suggests that the changing experience of negotiations with neighbourhood enables people living with dementia to assign new meanings to the home (Ward et al., 2017). In this respect, the shifting meanings of home in turn affect the perception of neighbourhood. Before discussing the meanings of home, it is crucial to first understand the notion of ‘home’.

1.5.3 Home
The notion of ‘home’ and the experience of being at home is the most intense expression of being in place (Rowlew & Bernard, 2013). Two distinct concepts must be explained here, those of ‘house’ and ‘home’ to provide an understanding of the critical difference. A ‘house’ is conceptualised as a mere physical setting, an empty living space without meaning or attachment (Rapoport, 2005; Rowles, 2006), whereas the concept of ‘home’ encapsulates the idea of a filled living space where living becomes active and has both meaning and attachment for the person, as such this space can be seen as part of individual or group identity (Rowles & Bernard, 2013). Inhabitation facilitates the process of expressing the relationship between people and a meaningful place through ‘home’. Transferring a space to a ‘home’ and developing a sense of being at home engages with use, awareness, and the development of emotional attachments through ongoing processes of vicarious immersion – the close intertwining of person and location over time (Rowles, 1978). Consequently, a sense of familiarity, comfort, and safety with home is developed. That is, making a ‘house’ in to a ‘home’ applies a similar process of transferring space into a meaningful place.

Home is a territory and associated with a sense of ownership, so home is a place to exercise control over the space and to have the freedom of self-expression, eventually becoming a place of belonging (Rowles & Bernard, 2013) and a place with strong
sentimentality which closely ties to a sense of self (Bhabha 1994; Blunt & Varley, 2004; Brickell, 2012). Home is not merely associated with positive feelings, it can have negative experiences when a sense of self is challenged, such as by ageing and living with one or more conditions which lead to changes in home experience. Hence, home becomes “a space of belonging and alienation, intimacy and violence, desire and fear, the home is invested with meanings, emotions, experiences and relationships that lie at the heart of human life” (Blunt & Varley, 2004, p. 3).

Geographies of home can be both materialistic and symbolic at various scales, ranging from the domestic to broader spatial scales, such as one’s streets, the neighbourhood, the nation, and the global (Blunt & Varley, 2004, 2006). In this sense, Massey’s (1994) ‘a global sense of place’ also applies to ‘home’ which is a place where globalisation intersects with daily life. Accordingly, home is not a simply physical place, but also an imaginary one that is “not separated from public, political worlds but is constituted through them; the domestic is created through the extra-domestic and vice-versa” (Blunt & Dowling, 2006, p. 27). This idea provides an explanation to understand the interrelation between home and neighbourhood and why the change in one geographical experience would affect the meaning of the other.

The ageing population can attribute various meanings to the home environment and the sources of meanings are diverse, such as furniture, collections, rooms, and objects (Rubinstein, 1989). A significant question that needs be asked here is how older people assign specific meaning to the home and its objects. As Rubinstein (1989) claims, older people allocate meanings to their own home through three processes:

1. The social-centred process by ordering the home based upon an individual’s version of socio-cultural rules, such as making decisions on room function and furniture placement. Arranging home space expresses some basic cultural notions in relation to personhood and social life (Bourdieu, 1973). Through this process, a person interprets and then implements what is appropriate for them, and asserts what it means, for them, to be a person, or rather to be themselves. This process thereby makes a crucial link between people and place.
II. The person-centred process which refers to the representation of an individual’s life course through home objects which have meanings to the person through the life course, such as photographs and memorabilia. This person-centred process relates to Augé (1995) ‘anthropological place’ – a place containing life stories, identity, family history and connection. Conceptualising the home as a ‘anthropological place’ is significant in facilitating care relationships and in enhancing an understanding of the needs and desires of the cared-for (Milligan, 2012).

III. The body-centred process through the ongoing negotiation between the body and the surrounded home features. This process comprises of entexturing and environmental centralisation. The former is concerned with ‘body-awareness’ of the detail of the home and is relevant to Rowles’ (1983) ‘physical insideness’ and his (1993) ‘preconscious sense of the setting’. This component plays an important part in comfortably negotiating daily life without facing harm in the home environment. The component of ‘environmental centralisation’ refers to the living space as centralised over time to central zones so that increasing limitations of the body can be accommodated (Rowles, Oswald & Hunter, 2004; Rubinstein, 1989). This means that the ‘shrinking world’ phenomenon, defined by Duggan, Blackman, Martyr, and van Schalk (2008), applies not only to the external environment but also to the home environment for older people.

Rubinstein’s (1989) three processes provide a conceptual framework in understanding the intersections between older people and the home and how the meanings of home derive in everyday life. However, what is lacking here is how people living with dementia experience and assign meanings to the home as the onset and progression of the condition affects their physical capabilities and cognitive function. This leads to the reducing body-awareness, decreasing the person-centred process, being unable to negotiate with the home environment, and so on. As such, a sense of familiarity and ‘being at home’ can decrease over time. In this respect, Rubinstein’s meanings of home are challenged. The meanings of home can even be further contested due to ageing and the onset, and progression, of dementia which may necessitate transitions in living
environments through adaptations to the current home or through relocations to more supportive areas (Perry, Andersen, & Kaplan, 2013).

Adaptations to current residences is a result of the shifting landscape of care towards the home – the heart of the care network (Cutchin, 2003) – triggered by the association between the ability to age in place and well-being in later life (Milligan, 2009; Rowles, 1978; Rowles & Chaudhury, 2005). This care provision is often facilitated by (in)formal support from social networks or social services (Rowles & Bernard, 2013). The home then becomes a favoured place of care and support for older people and experiences change to accommodate care provision; this shift contests the boundary of a private place of personal meanings and caring relationships (Milligan, 2009, 2012). The caring relationships can sometimes conflict with the home being safe and secure and instead alter it to be a place of neglect, fear, abuse, and/or violence. That is, the care provision adds a new dimension in changing the personal meanings of home. Home is therefore a dynamic, negotiated, and contested space which is shaped by care recipients, caregivers, and the physical aspect of the home (Milligan, 2012), with the meanings of home being dynamic and shifting over time. The fluid meanings of home can be more impactful for people living with dementia due to their decreasing cognitive function in dealing with the physical aspect of the home and managing the new caring relationships, in addition to coping with the condition in their daily lives. Home as a site of care provision entails a certain degree of place-remaking which creates difficulties for people living with dementia and disrupts the meanings of home.

Thinking of home relating to care provision, when external physical or social support can no long meet the increasing needs of older people, will eventually lead to some people relocating for more support in order to sustain daily living (Oswald & Rowles, 2007). In this case, an individual’s functional changes and environmental stressors are push factors which lead to relocation (Perry et al., 2013). In other words, older people are compelled to move, even though relocation may lead to positive outcomes. Again, people’s sense of being at home can be disrupted and remaking a new form of being in place is necessary (Rowles & Barnard, 2013). This transitional process is not only stressful, but also requires skills, particularly in relation to reshaping old habits to fit the new home, engaging in new activities, making new friends, and becoming familiar with
new surroundings (Rowles & Barnard, 2013). In addition, experience is a key factor within the creation of a new mode of being in place and being at home which happens in parallel with the abandonment of a familiar home. As an effect, relocation seems to force older people to react to environments where the level of control and independence can be significantly reduced, accompanied by diminishing levels of autonomy and ability to remake place. Following this line of thinking, for people living with dementia, relocation can be more challenging due to their physical and cognitive changes affecting their capabilities in adapting to the new environment. When this new environment exerts demands beyond a person’s maximum competence, feelings of discomfort will then occur (Lawton & Nahemow, 1973). Consequently, tangible resources (social and physical supports) could be met theoretically after the relocation; however, what might be absent is the intangible resource, such as the current community and intrapsychic resources. Although both resources contribute to social health, the latter seems to be associated more with aspects of social health. Nevertheless, relocation necessitates place-remaking which is a complex, dynamic process that imposes a significant challenge for people living with dementia.

Place-remaking does not only occur during transitions in the living environment but also occurs when living with one or more conditions. Taking stroke as an example, it disrupts person-environment relations and the continuance of ‘normal’ life as experienced prior to the onset of the condition (Meijering, Lettinga, Nanninga & Milligan, 2017). Bury (1982) terms the latter as ‘biographical disruption.’ However, this concept cannot fully represent the complex picture of life experience of pre- and post-illness as the onset can also be perceived as part of the ongoing life narrative, described as ‘biographical flow’ by Faircloth, Boylstein, Rittman, Young and Gubrium (2004). That is, life experience is attached and fulfilled by different symbolic importance (Faircloth et al., 2004). Biographical disruption and flow draw attention to the significance of temporal dimensions. It is this important temporal lens that enables an understanding of constant changes in people’s geographical experience and in the meanings of places, such as home and neighbourhood. When reconsidering person-environment relations, it is inevitable to reflect biographical disruption and flow through geographical perspectives, called ‘bio-geographical disruption and bio-geographical flow’ (Meijering et al., 2017). The inclusion of a geographical aspect highlights “the extent to which relational
experiences of space/place are disrupted by changes in the life course arising from disability as well as on how taken for granted embodied states have to be renegotiated at any other place anew” (Meijering et al., 2017, p.7). Although bio-geographical disruption can be experienced after the onset, the final purpose is to regain a sense of bio-geographical flow or create a new version of this flow (Meijering et al., 2017).

Therefore, place-making and remaking occur throughout the life course with constant changing in the meanings of places and in a sense of being in place and being at home. What cannot be ignored here is that to be ‘out of place’ and ‘homeless’ is inevitable for many older people living with dementia. To delay, or reduce, the negative feelings of displacement, attention should be paid to how to apply the existing theories into care practice to transfer belongings and significance to symbolising places and home as well as associated meanings. Equally important is that consideration should be given to a greater environmental awareness and to endorsing place-based care for the ageing and dementia population, particularly the ‘lived neighbourhood’ (Ward et al., 2017). This requirement is compounded by the limited knowledge of the lived experience of dementia at a neighbourhood level within the geographical literature. The ‘lived neighbourhood’ plays an important role in understanding how people living with dementia and their carers respond to, and interact with, their environments in an everyday context. Hence, a more detailed discussion of the ‘neighbourhood’ theme follows.

1.6 The Neighbourhood Theme

The neighbourhood provides a setting for social cohesion (Dempsey, 2007) and as “a characteristic of society which depends on the accumulated social capital” (Dayton-Johnson, 2003). That is, social cohesion is the stock of individual’s investments in social contacts which provide individual and social benefits (Oxoby, 2009). When measuring social cohesion, seven dimensions need to be considered: social interaction, social networks covering its support, sense of community, level of participation in organised social activities, level of trust and reciprocity, feelings of safety, and extent of a sense of place attachment (Dempsey, 2007). Socially cohesive behaviour and attitudes are positively associated with a high quality of neighbourhoods (Office of the Deputy Prime Minister, 2002). The neighbourhood quality can be measured using 10 common
features: residential density, mixed land uses, accessibility, connectedness and permeability, legibility, attractiveness, inclusiveness, maintenance, natural surveillance, and character of a place (Dempsey, 2007). The built environment and social cohesion are relevant concepts in understanding the intersections between people and their social and physical neighbourhood. When considering this theoretical approach in dementia care and supporting accessible buildings, there is a need to first look at the multifaceted relationships between older people and their neighbourhood from environmental perspectives. This will be followed by discussing the enabling environments of age-friendly and dementia-friendly communities as the focuses of current policy to understand how such communities respond to the needs of the ageing and dementia population respectively and offer opportunities where they can contribute to their living places.

1.6.1 Environmental Perspectives
To understand the interactions between people living with dementia and their environments, an ecological approach can be a good point to start as it explains the relationships between older people and their surroundings (Hans-Werner & Gerald, 2003). The ecological model has a long history in various disciplines, including biological, behavioural, social, and health sciences, thereby different forms of the ecological model have appeared depending on the time and discipline (Satariano, 2006). Some forms of the model focus upon the associations amongst biological, behavioural, and social factors, whereas others draw attention to the context – the social and physical environments.

The term ‘ecological’ has also been applied in epidemiology to describe the association between a summary measure of a local population and the incidence or mortality rate of a specific health outcome within the population (Morgenstern, 1998). As an illustration, an ecological model has also been used in the Ottawa Charter on Health Promotion as a foundation for its recommendation and adopted to explain the effects of factors on both the causes and consequences of health conditions (Verbrugge & Jette, 1994). This example assumes an ecological model to illustrate that people’s health and well-being are influenced by the interplay amongst biological, behavioural, and environmental
factors, and such a dynamic interplay unfolds throughout people’s life course (Maddox, 2000).

In epidemiology, an ecological approach has received renewed attention (Satariano, 2006). One of the clearest connections between epidemiology and gerontology is through Lawton and colleagues’ work on the ecological model of ageing, particularly Lawton and Nahemow’s (1973) ‘Press-Competence Model’, exclusively emphasising behaviour and well-being (Lawton, 1986) rather than focusing upon various health and functional outcomes in epidemiology (Satariano, 2006). This model pays attention to two components: one is about personal competence, such as cognitive functioning decline and physical mobility loss, and the other refers to the characteristics of the objective environment, such as housing and neighbourhood conditions (Lawton & Nahemow, 1973). Lawton then moved the ecological theory further, and in the spirit of Lewin’s (1951) concept of the ‘life space’, \( B = f(P, E) \), that is, behaviour (B) is a function (f) of person (P) and environment (E), Lawton added an interactional aspect of person and environment, a \((P \times E)\) function. Such interactional function is reflected in Lawton’s (1980) ecological equation, that is, \( B = f(P, E, P \times E) \).

These two equations represent different views: Lewin’s equation concerns ‘person’ and ‘environment’ as an inseparable whole from a transactional standpoint (Parmelee, 1998), whereas Lawton claims that the interactional function represents the interface between ‘person’ and ‘environment’ which are two separate elements (Lawton, 1980). However, the tension between these two views is also reflected in Lawton’s own writing and thinking. Lawton initially started from an ‘interactional’ position and moved to a ‘transactional’ model of person-environment as interactional views could not explain the complexity of the total system between ‘person’ and ‘environment’. After that, Lawton (1998) then moved back to his original ‘interactional’ perspective: “although person and environment form a unified system where what is inside is philosophically inseparable from what is outside, for heuristic purposes, it is necessary to speak of, and attempt to measure, them separately” (p. 1).

Nevertheless, Lawton (1980) posits that person-environment interactions are affected by different types and levels of personal competence and characteristics of the objective
environment. Thus, an individual’s optimal level of functioning is determined by the combinations of the competence of the person and environmental characteristics (Lawton & Nahemow, 1973) and relies on subjective experiences as to personal meanings, cognitive, and affective dimensions (Wahl, Iwarsson & Oswald, 2012). This insight indicates that such combinations between older people and environment determine the person’s behaviour and influence well-being (Lawton, 1986).

Personal subjective feelings can be a vital source of satisfaction despite the objective measures (La Gory et al., 1985) and understanding such feelings has the potential to broaden the attitudinal and cognitive evaluation of the environment (Wahl & Oswald, 2010). Taking the neighbourhood as an example, La Gory et al. (1985) argue that the production of neighbourhood satisfaction for older persons is a complicated process, concerning objective qualities in the neighbourhood, the psychological and physical state of the older individual who evaluates the neighbourhood, and the person’s own definition of the neighbourhood. They further explain that when considering the level of competence of older people, the neighbourhood is a ‘neighbourhood of the mind’ for the low competence group whose satisfaction is affected by subjective perceptions of the neighbourhood. In contrast, the neighbourhood is an ‘action space’ for the high competence group because their satisfaction level is influenced by both subjective and objective views of the neighbourhood. Here, the mental portrait or perception of the neighbourhood is a more significant factor. This insight supports a combination of emotional, cognitive, and behavioural responses to the environment; that is, despite that a neighbourhood can be shared by many older people, they do not necessarily occupy the same environments (La Gory et al., 1985).

The theoretical source of considering personal feelings towards the environment can be traced back to Lawton’s ecology theory of ageing that measures subjective experience in affective and cognitive terms, personal meanings, and attachment to the physical environment. ‘Cognitive’ represents biographical bonding to the place and this type of bonding covers areas such as familiarity, whereas ‘affective’ includes emotions and feelings to the place. These aspects of subjective experience can be addressed via Rowles’ (1983) ‘insideness’, collecting rich memories of the environment to support an individual’s sense of identity and its process of adaptation.
Rowles’ (1983) ‘insideness’ consists of three components: i) ‘physical insideness’ which refers to familiarity of the physical environment; ii) ‘social insideness’ which relates to integration with social fabric of the community; and iii) ‘autobiographical insideness’ that represents historical dimensions and/or remembered places. These three complementary dimensions of attachment stemmed from a three-year intensive participant observational study of older residents of Colton, a rural Appalachian community, to understand how they established and created meanings with the environment. However, Rowles’ (1983) work primarily focused on older residents rather than people living with dementia. The sample was chosen from persons over 60 years-of-age in a specific community, a lack of cultural and economic differences within the study might be worth noting when applying his theory to a wider population. In addition, the community was a predefined environment, which held diverse meanings for people. More importantly, although Rowles’ (1983) ‘social insideness’ was identified, this component refers to becoming part of a multigenerational social order. Within this order, social credit was derived from contributions to family and the community made “over the span of each individual’s life” (Rowles, 1983, p.4). A critical message here is that there is a deficiency of a deeper description of how older people identified themselves with groups, and how they interacted with their social ties within the community to supplement this type of ‘insideness’.

In addition to Rowles’ (1983) description of ‘insideness’, Wahl and Oswald’s (2010) conceptual framework of person-environment relationships is also one approach to address the subjective experience of the environment in later life. This framework is centred by two processes: experience-driven belonging and behaviour-driven agency. These two key features help better understand how people interact with the environment emotionally and physically as they age. The outcomes of this model simultaneously consider autonomy, identity, and well-being. However, Wahl and Oswald’s (2010) person-environment interchange focuses primarily upon the physical environment; hence, transitions in the social environment are required. Moreover, to better understand the role of environment in ageing well, there is an urgent need to learn how technology influences ageing well in the ‘new’ environment, in addition to barrier-free environmental design (Lawton, 1998; Wahl et al., 2012).
Nonetheless, Lawton and colleagues made a remarkable contribution to the ecology of ageing in explaining the complexity of older persons and their environment. However, an observation here is that although the ‘environment’ element covers both the social and physical elements, how an individual responds to each element varies and gives an unique value to each element in and through time. It is worthwhile considering the separation of ‘environment’ into ‘physical’ and ‘social’ aspects to gain a more in-depth, multifaceted understanding of the person-environment relations, even though the dynamic relationship between these two aspects cannot be ignored. More significantly, an ageing population living with one or more impairments, such as dementia, is increasing (Barnett et al., 2012; World Health Organisation, 2012). This increases the role that ‘support’ plays in the interactions between an ageing population and their environment, especially given the current movement towards the social model of disability with a human rights-based approach for people living with dementia through equity, empowerment, and engagement (Mental Health Foundation, 2015; Eriksson & Lindstrom, 2008). Finally, attention needs to be paid to the distinctions between the general ageing population and the dementia population in terms of person-environment relations. Despite this critical analysis of Lawton’s ecological model of ageing, the model provides fundamental principles in understanding the ‘good life’ in old age (Lawton, 1983). This classic contribution focuses upon how old age, as a critical stage in the life span, is significantly influenced by the environment (Lawton, 1989; Lawton & Nahemow, 1973; Rowles, 1983; Rubinstein, 1989), and it also provides a conceptual framework for understanding how older people can age well in place.

‘Ageing in place’ in late life is one focus in the current ageing policy and seems to be the preference of older people who would like to be enabled to maintain autonomy and independence (Wiles et al., 2011; Frank, 2002). ‘Ageing in place’ is about being able to continue living in one’s own home and neighbourhood by adapting or changing needs and conditions to maintain certain levels of independence, autonomy, and connection to social support (Davey et al., 2004; Fänge et al., 2012; Lawler, 2001). This notion focuses not only on home, but also neighbourhoods, that are crucial factors in the field of environmental gerontology (Oswald, Jopp, Rott, & Wahl, 2010).
‘Ageing in place’ associates with a sense of security and familiarity for an ageing population. For example, older people can perceive ‘home’ as a refuge, providing a sense of security and emotional attachment, whereas ‘neighbourhood’ is an important resource for ageing well; this environment gives older people a safety net where community members look out for each other (Wiles et al., 2011). More importantly, ‘ageing in place’ is seen in relation to a sense of identity, independence, and autonomy for older people and also extends beyond the home environment to the wider neighbourhood (Wiles et al., 2011). Hence, the notion of ‘ageing in place’ further emphasises the ‘neighbourhood’ theme with considerations being given to recreational opportunities and social engagement. As such, the provision of adequate transportation and amenities is required, in addition to housing options from the perspective of environmental gerontology (Wiles et al., 2011).

1.6.2 Age-friendly and Dementia-friendly Communities
Creating age-friendly cities or communities is one major response to the rise in an ageing population to ease the challenges faced by this population. The World Health Organisation (2007) defines an age-friendly city or community as a place that:

“Encourages active ageing by optimising opportunities for health, participation and security in order to enhance quality of life as people age. In practical terms, an age-friendly city adapts its structures and services to be accessible to and inclusive of older people with varying needs and capacities.” (p.1)

The essential features of age-friendly cities, recommended by the World Health Organisation (2007), include: outdoor spaces and buildings, transport, housing, social participation, respect and social inclusion, civic participation and employment, information, and health and social care services. Such an enabling environment contributes towards the improvements to independence, participation, health and well-being for older people and ultimately reducing social and health inequalities (Kendig & Phillipson, 2014).

Age-friendly communities capture the wider domains of developing respect for, and social inclusion of, older adults who are more likely to live with various age-related
conditions (Turner & Morken, 2016). However, such communities do not pay specific attention to the dementia lens and there needs to be an emphasis on breaking down stigma and raising awareness of dementia (Alzheimer's Society British Columbia, 2014), given the fact that the increase in people living with dementia is one of the consequences of the population growth in older adults (Turner & Morken, 2016; World Health Organisation & Alzheimer’s Disease International, 2012). To support the well-being of people living with dementia and to ensure that they can live as independently as possible and to continue to be part of their community, developing dementia-friendly communities is essential at an operational level. However, the term ‘dementia-friendly’ has been challenged by Shakespeare, Zeilig and Mittler (2017) who felt this phrase referred to people without dementia being kind to, and welcoming, people living with dementia by tackling socially-imposed barriers and the implication of this phrase seemed to devalue valuing human rights. Accordingly, Swaffer coined ‘dementia enabling communities’ as appropriate language in response to dementia being a rights-based issue (Swaffer as cited in Shakespeare, Zeilig & Mittler, 2017).

Despite the criticism of ‘dementia-friendly’ being negatively constructed and its associated implication, dementia-friendly communities have the functions of empowerment and enablement for people living with dementia to contribute to and participate in society. According to the Alzheimer’s Society (2013), “a dementia-friendly community is one in which people living with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them” (p.6), thereby being viewed as valuable members of the community (Turner & Morken, 2016). Its core principle emphasises the social dimensions of dementia over the medical (Turner & Morken, 2016). A dementia-friendly community enables individuals living with dementia and their carers to find their way around and be safe, access familiar local facilities, and maintain their social networks so they feel they belong to the community (Milton, 2012). People living with dementia and their carers can, therefore, be respected, empowered, and engaged in this dementia-friendly community (Local Government Association, 2012).

Before explaining the progress of creating dementia-friendly communities in the UK, it is worthwhile understanding how this initiative has evolved. For over a decade, the role of
supportive communities in mitigating cognitive impairment has been recognised, resulting in developing initiatives to assist with such an approach in countries in Europe and beyond, such as Scotland and Japan (Kendig & Phillipson, 2014; Turner & Morken, 2016). Creating dementia-friendly communities aims to support the well-being of people living with dementia who live in their community as independently as possible. This initiative is well established in Australia, Germany, Canada, and the UK (Turner & Morken, 2016).

In the UK, the concept of ‘dementia-friendly communities’ originally came from the exploration of ‘dementia-capable communities’ which was derived from ‘innovations in dementia’ by a ‘Think Tank’ of experts, including people living with dementia and their family carers (Rahman, 2013). This ‘Think Tank’ of experts was assembled by the Department of Health in 2011 (Rahman, 2013). Creating dementia-friendly communities then became one of the three key areas in the dementia challenge, which was launched in March 2012 by the Prime Minister to tackle one of the most important issues faced by the ageing population (Department of Health, 2012). To date, 82 communities have engaged with developing dementia-friendly communities in England (Alzheimer’s Society, 2014; Department of Health, 2015).

Alzheimer’s Disease International (2016) identified six core principles to dementia-friendly communities: involvement of people living with dementia, social environment, physical environment, dementia-friendly organisations, access to appropriate health care, and partnerships across sectors. Whilst these six core principles guide the development of dementia-friendly communities, there are various approaches to dementia-friendly communities as ‘no one size fits all’ (Alzheimer’s Disease International, 2016). This variation is partly caused by the differentiations in local social construct and responses, so a ‘one size fits all’ solution does not guarantee success for every community (Alzheimer’s Disease International, 2016). This is where public health plays an important role in analysing the specific needs in the community, promoting the use of evidence-based practices, and bringing multiple providers to work collaboratively to raise awareness and establish support systems (Alzheimer’s Association, 2016). In so doing, dementia-friendly communities can be tailored to fit with the characteristic of a locality and be more supportive and empowering of individuals living with dementia.
(Alzheimer’s Association, 2016). Again, this reiterates that public health posits dementia as a priority at both a strategic and an operational level to protect and improve the health of the dementia population and to focus on what public health can contribute towards tackling the impact of this condition.

From a public health perspective on ageing and dementia to effectively respond to, and better meet the needs of, an ageing and dementia population, it is vital to understand the similarities and differences between the key features of age-friendly and dementia-friendly communities, as identified by the World Health Organisation (2007) and Alzheimer’s Disease International (2016). To reach this, I have compared these two initiatives as summarised in Table 1.

Table 1. Key Features for the Age-Friendly and Dementia Friendly Frameworks

<table>
<thead>
<tr>
<th>Age-friendly community</th>
<th>Dementia-friendly community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eight domains</td>
<td>Six key principles</td>
</tr>
</tbody>
</table>

1) **Social Participation**
Accessibility of leisure and cultural activities; opportunities for older residents to participate in social and civic engagement with their peers and younger people.

1) **Involvement of People Living with Dementia**
Involvement of people living with dementia, together with the input from their carers to meet their needs and give them a sense of respect, dignity and purpose they seek.

2) **Communication and Information**
The promotion and accessibility of technology to keep older residents connected to their community and social networks.

2) **Social Environment**
Tackle the stigma and social isolation through engage and include people living with dementia in community activities and ensure these activities are available and accessible for them, in line with suitable transport options, to help them remain in their homes and communities.

3) **Transportation**
Safe and affordable modes of public and private transportation.
<table>
<thead>
<tr>
<th>4) <strong>Respect and Social Inclusion</strong></th>
<th>3) <strong>Dementia-Friendly Organisation</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Promotion of ethnic and cultural diversity as well as multigenerational interaction and dialogue.</td>
<td>Businesses and organisations need to demonstrate awareness, respect and responsiveness of dementia.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5) <strong>Housing</strong></th>
<th>4) <strong>Physical Environment</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>A wide range of housing options for older residents; the ability to age in place; and other home modification programmes.</td>
<td>It needs to be accessible and easy to navigate, along with specific consideration as to pathways, signage and lighting.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6) <strong>Outdoor Spaces and Buildings</strong></th>
<th>5) <strong>Access to Appropriate Health Care</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability of safe and accessible recreational facilities.</td>
<td>The provision of timely diagnosis and early treatment so that the unique needs of people living with dementia can then be met at the right place at the right time.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7) <strong>Community and Health Services</strong></th>
<th>6) <strong>Partnerships</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility of homecare services, clinics, and promotion of wellness and active ageing.</td>
<td>A collaborative approach across sectors to support social action initiative and to achieve effect changes.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8) <strong>Civic Participation and Employment</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>The promotion of paid work and volunteer activities for older residents and opportunities to engage in formulation of policies relevant to their lives.</td>
<td></td>
</tr>
</tbody>
</table>

This comparison of the key features indicates that age-friendly and dementia-friendly communities share three fundamental objectivities: i) helping older people (with dementia) to remain living independently in the community through an enabling physical environment; ii) supporting their social inclusion and participation as active citizens in the community; and iii) engaging with multiple stakeholders across sectors to increase support and access to health services. Despite this, these two initiatives can only supplement and not replace one another. Age-friendly communities pay attention to the general needs of an ageing population, such as promoting multigenerational interactions, facilitating ageing in place, and encouraging ageing activities. Conversely,
the dementia-friendly communities’ focus upon meeting the specific needs of people living with dementia, such as tackling stigma and social isolation, demonstrate awareness, respect and responsiveness of dementia, and timely diagnosis and early treatment.

Through this comparison, it becomes clear that integrating these two approaches helps improve policy making in meeting the diverse needs of older people and the specific requirements of people living with dementia (Turner & Morken, 2016). The rhetorical aspiration of incorporating both age-friendly and dementia-friendly communities together aims to promote equal active citizenship for an ageing and dementia population. Again, these two types of enabling environments raise the profile of the neighbourhood theme in the daily living of older people/people living with dementia and provide opportunities for social participation.

Such understanding and knowledge will contribute to the enablement of people living with dementia and their carers to live well in later life in their neighbourhood and the preservation of their rights to social contributions. The progression of these goals requires careful consideration of a wider array of factors relating to social-spatial neighbourhood where people living with dementia and their carers inhabit and how these factors affect their everyday lives. This focus will form the substantive literature review that follows in the next chapter.

1.7 Summary
Dementia is a public health priority and requires an urgent need to coordinate a public health approach to reinforce and establish a holistic, integrated health and social care system to support a person-centred approach. Such an approach can also help tackle the issue of comorbidities, as people who have dementia are often living with other conditions. A public health approach to dementia aims to support people living with dementia in maintaining their autonomy and independence, enabling effective access to appropriate health services, and more importantly, promoting human rights-based initiatives to enshrine and secure the rights of people living with dementia as equal to others.
A public health approach to dementia has raised the profile of the neighbourhood theme in a variety of areas. A neighbourhood as a multi-dimensional 'lived place' supports a person-centred understanding of how people living with dementia and their environments affect one another in an everyday context. Neighbourhood is also closely associated with, and begins within, the home environment. As such, changing geographical experience within the home would affect the meanings of neighbourhood for people living with dementia. This draws attention to the importance of home and maintaining a sense of 'being at home' is the most intense expression of 'being in place' and being in the neighbourhood.

In addition, the importance of neighbourhood has resulted in some public health actions being taken at a neighbourhood level. This enables older people to live well with dementia and comorbidities and provides evidence that calls attention to the integrated approach of age-friendly and dementia-friendly communities. Given the predominant consideration of 'neighbourhood' in current dementia policy and practice, this suggests that greater attention needs to be paid to the multifaceted relations between neighbourhood and dementia in the existing literature.
CHAPTER 2
Neighbourhood and Dementia: A Thematic Review of the Literature

2.1 Introduction
This chapter describes the methods and results of a thematic review undertaken to understand the relationships between neighbourhood, people living with dementia, and their carers to provide a conceptual framework through which it becomes possible to view and explore the lived experience of dementia in a neighbourhood context. This chapter starts with presenting the aims, methods, quality appraisal techniques, and results of the review. A thematic synthesis of the literature then follows, which found the multiple relations of neighbourhood and dementia were illustrated through five major themes – ‘social integration’, ‘space, place and home’, ‘neighbourhood design’, ‘physical activity’, and ‘supportive resources’. This chapter will conclude with a summary of the key findings and identified gaps in the existing literature to set the scene for this primary study.

2.2 Aims
The thematic review aimed to understand the important aspects of neighbourhood and how these aspects impact upon people living with dementia and their carers within the available literature. This review helped develop a theoretical framework, which was then used to locate and inform the fieldwork of the primary study by exploring the lived experience of dementia in a neighbourhood context.

2.3 Methods
2.3.1 A Thematic Synthesis
A thematic review of the literature was applied by concentrating on the ‘theories’ that underpin the impact of neighbourhood on people living with dementia and their carers. A thematic synthesis method has been adopted to address the key aims of this thematic review relating to neighbourhood and dementia. The findings conducted through this synthesis can directly inform policy and practice (Booth et al., 2016; Thomas & Harden, 2008). Additionally, a thematic synthesis is considered more epistemology-neutral in its approach to synthesise the methods of the included studies, which are predominantly qualitative (Booth et al., 2016). A thematic synthesis was, therefore, an appropriate
method for synthesising the existing evidence of neighbourhoods and dementia to contextualise the impact of the social and physical environments on people living with dementia and their carers.

2.3.2 Search Strategy
The search terms adopted in this review were as follows:

(dementia OR Alzheimer) AND (neighbourhood OR environment OR community OR social network OR couplehood OR social ties OR family) AND (space OR housing OR home OR transport OR technology OR design OR safety OR “social support” OR "social model of disability" OR "quality of life" OR well-being OR identity OR autonomy OR "social capital" OR loneliness OR personhood OR citizenship OR "physical activity" OR attachment OR belonging)

This search strategy was used in the following electronic databases: AMED, BNI, CINAHL, EMBASE, HEB, HMIC, MEDLINE, PsycINFO, Cochrane Database Systematic Reviews, Social Policy and Practice, and Social Care Online. Academic papers were identified through: a) electronic searching of key databases; b) hand searching of key journals; and c) reference searching of key articles for further relevant sources. All searches were conducted before the field work took place between June 2011 and July 2012 and then updated and completed in December 2016.

2.3.3 Inclusion and Exclusion Criteria
Inclusion criteria were specified as follows:

- Papers published from 1990 to 2016 in a health and social care context.
- Literature only included where key words used in the search had a relationship with each other.
- International literature on neighbourhoods and dementia. Due to a lack of translational facilities, identified studies were limited to those published in English.
In all searches, studies were excluded that focused on the following aspects:

- Medical, genetic or neurological reasons and treatments for dementia.
- Clinical trials of medications for dementia.
- Mixed populations (such as stroke and dementia) without differentiations between the two in the results.
- End-of-life care.
- Treatments, clinical therapies, or the views of professional caregivers.

Where a single author had written one or more books or journal articles presenting an account of their experience, only the most recent book or article was included in the analysis to avoid that individual’s account being over-represented in the final analysis.

2.3.4 Data Extraction and Quality Assessment

Evidence accounted for in this literature review includes qualitative and quantitative methodologies, including those of mixed methods designs and longitudinal studies. The included evidence was critically appraised in terms of scientific rigour using the Critical Appraisal Skill Programme checklists to contribute to the synthesis. These checklists are designed to be used for quality appraisal of the evidence (Critical Appraisal Skills Programme, 2013). Quality assessment was done through using a standard data extraction sheet on Microsoft Excel in which the included papers were documented as to source, an explicit statement of aims, methodology, research design, recruitment strategy, data collection, data analysis, a clear statement of the findings, and how valuable the research study is, including contributions it made to the existing literature, how transferrable the findings can be, and recommendations for further research. These eight criteria were used to determine the quality of each study. Each criterion was given a score ‘1’ if it was fully met. In the case of partially meeting the criterion, the score was accordingly given from ‘0.1’ to ‘0.9’. A low quality study was defined if the total score was ‘6’ and above, but below ‘6.5’. The medium quality was determined if the total score was from ‘6.5’ to 7.5’. The high quality was identified when the total score was above ‘7.5’.
2.4 Results Neighbourhood and Dementia: Core Literature

2.4.1 Search Results

A total of 1470 search results were identified for initial screening based on title or keywords. After checking the results of an electronic search by assessing title and abstract, 161 articles were included for further screening. As Figure 1 reveals, the process of search, sorting and quality assessment led to the identification of 36 articles to inform this thematic review. The identified key studies that informed the core of this thematic review are shown in Appendix 1.

Figure 1. Flow Chart of Included Studies

![Flow Chart of Included Studies](image)

2.4.2 Quality Appraisal

This thematic review primarily focused upon the ‘theories’ to enable an understanding of how both social and physical aspects of neighbourhood affect the lives of people living with dementia and their carers. Of the 36 included studies, 21 articles focused on individuals living with dementia, six studies concentrated on the carers of people living with dementia, and nine studies emphasised both people living with dementia and caregivers. All the included papers presented a clear statement of aims and described an appropriate methodological approach. However, the quality, especially relating to recruitment, data collection and analysis, varied considerably. The levels of quality of the
included papers and associated themes are summarised in Table 2 and detailed information relating to each included study and its quality is presented in Appendix 1.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Included</th>
<th>High quality</th>
<th>Medium quality</th>
<th>Low quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social integration</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Space, place and home</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Neighbourhood design</td>
<td>4</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Physical activity</td>
<td>7</td>
<td>0</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Supportive resources</td>
<td>15</td>
<td>5</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td>9</td>
<td>18</td>
<td>9</td>
</tr>
</tbody>
</table>

A total of nine papers were classified as ‘high’ quality studies. Of these, two papers focused upon people living with dementia, two articles emphasised the carers of people diagnosed with dementia and five papers stressed both with a disproportion in number of participants. This means that although the sample included both people living with dementia and carers, they were not necessarily having joint lived experiences of dementia. As a result, of these five papers, only two studies concentrated on both people living with dementia and their family carers to provide a collaborative understanding of their experiences (Arntzen, Holthe & Jentoft, 2014; Gibson, Dickinson, Brittain & Robinson, 2015). Of nine high quality papers, only three studies adopted a longitudinal approach (Arntzen et al., 2014; Phinney, Kelson, Baumbusch, O’Conner & Purves, 2016; Wiersma et al., 2016). Amongst the included 36 papers, only two studies employed participatory methods (Hanson et al., 2007; Wiersma et al., 2016) but none of them adopted a participatory mapping method to visualise the meaning and construction of neighbourhood. This quality appraisal process indicates that there is a paucity of studies examining the lived experience of dementia as a couple in association with neighbourhood through a longitudinal, participatory design.

2.4.3 Thematic Analysis

The included papers were extracted into NVIVO 9 for further analysis. When neighbourhood relating to dementia was described in an article, it was coded in NVivo 9 inductively with constant comparison and the generated codes were organised into
‘descriptive’ themes and then further interpreted to gain ‘analytical’ themes (Thomas & Harden, 2008). This was followed by reviewing or testing against the relevant themes between publications to identify commonality of the themes to integrate the findings interpretively (Thomas & Harden, 2008). This process led to the generation of five major themes emphasising neighbourhood and dementia, consisting of ‘social integration’, ‘space, place and home’, ‘neighbourhood design’, ‘physical activity’, and ‘supportive resources’. However, whilst conceptually distinct the themes do have some overlapping content and this should be considered when reading through this next section.

Before detailing each theme, the concept of ‘neighbourhood’ must be revisited here. As discussed in chapter 1, a neighbourhood is an important multi-dimensional setting where residents interact with physical, social, and cultural properties (La Gory et al., 1985). It is constructed by residents’ activities and by events taking place at a larger geographical scale, such as national decisions concerning taxation and welfare (Conradson, 2005). In this sense, a neighbourhood is a geographical product emergent from socio-economic processes at several scales (Massey, 1994) and it affects residents’ actions and choices (La Gory et al., 1985). Therefore, the neighbourhood impacts on quality of life and a community’s dynamics (Blackman, 2006; La Gory, 1982; Michelson, 1976).

Theme 1: Social Integration

Social integration refers to a dynamic process where people engage with, and are part of, their social networks to maintain meaningful social relations. Connection to, and identification with, social networks are positively associated with psychological and social health at a neighbourhood level (Wiersma & Denton, 2016). Meaningful relational interactions have positive impacts upon a person with dementia’s dignity, sense of safety, and quality of life (Tranvåg et al., 2015; Wiersma & Denton, 2016). Social interactions and support are also beneficial for the carers of people living with dementia, reducing their emotional burden and improving their well-being and quality of life (Donnellan, Bennett & Soulsby, 2016; Stuckey, 1992; Wiersma & Denton, 2016).

When interacting with the family members, experiencing love and confirmation from a spouse and other family members is crucial to preserving dignity for people living with
dementia (Tranvåg et al., 2015). In addition, family members have an important role to play in supporting the well-being of the caregivers of people living with dementia (Gideon, 2007). Gideon (2007) claims that the higher levels of emotional support from family intend to reduce overall carers’ emotional burden. Conversely, Donnellan et al. (2016) argue that although family support is important and serves a range of functions, it is perceived as unhelpful if the carers need to relinquish their sense of independence and autonomy. This comparison indicates the significance of maintaining of the carers’ dignity, independence, and autonomy when family members provide support to them.

When interacting to non-familial members, dignity can be influenced as social inclusion and living an active life within a social fellowship are essential dignity-preserving factors for people living with dementia (Tranvåg et al., 2015). Additionally, people living with dementia can benefit from their local community network; Wiersma and Denton (2016) argue that when interacting with a local community, a feeling of ‘knowing everyone’ leads to a sense of safety within that community, promoting a culture of caring and looking out for each other. This leads to people living with dementia feeling that they are protected by the community and they perceive the social network within the community as a ‘safety net’. Although these findings are influenced by the culture of rural communities, social support plays an important role in the context of dementia.

Moreover, positive social exchange with non-familial members affects the carers of people living with dementia both emotionally and practically. Gideon (2007) states that emotional support from non-familial members intends to strengthen the optimistic outlook among caregivers, whereas Donnellan et al. (2016) argue that the support derived from friends is considered as helpful and neighbours are more likely to play an essential role in crisis management. The positive effect of the practical support is reiterated by Stuckey’s (1992) work that social ties directly affect the well-being of the carers of people living with dementia, but when under stress, social support plays a more effective role in the carer’s well-being and quality of life. Here, it is worth noting that the positive emotional support seems to stem from the shared experience between carers and their social ties and this shared experience facilitates recognition and acceptation of the situation when caring for people living with dementia (Donnellan et al., 2016).
The existing evidence provides valuable insight into the effects of social integration on people living with dementia and their carers and the central point to meaningful, positive social integration is to retain dignity, independence, and autonomy through understanding and accepting attitudes. However, there is a lack of knowledge as to how people living with dementia and their carers identified with, and assigned specific meanings to, their social networks, in order to better understand the impact of the social environment on their daily lived experience of dementia.

Theme 2: Space, Place and Home
In the literature, space consisted of inside and outside space, and it is closely associated with social and health benefits through maintaining autonomy and continuing functional activities (Blackman et al., 2003). For people living with dementia, space can be therapeutic and frightening; this is due to the progression of dementia causing cognitive impairment that may prevent recognition of familiar surroundings (Brittain et al., 2010). This means that a previously familiar environment can become unfamiliar, potentially reducing a person’s confidence to go outdoors, resulting in the individual feeling out of place in public spaces (Brittain et al., 2010). Additionally, social stigma and disorientation are more likely to keep people living with dementia at home; this draws a greater focus towards ‘indoor’ private space and the need to support independence and autonomy for a person within the home environment (Blackman et al., 2003).

In terms of inside space, this is mainly related to home or referred to as housing. Home is a place where a person can freely exert control over his or her life and is also a way of preserving, but not compromising, independence. The home environment significantly impacts on the quality of life of people living with dementia and their carers. Gitlin, Hodgson, Piersol, Hess and Hauck (2014) acknowledge that, when living at home, the self-rated quality of life of people living with dementia is associated with the number of health conditions and of unmet needs in conjunction with the assistive devices they used to navigate daily essential tasks. To enable individuals with dementia to live well at home, it is essential to address modifiable risk factors and tailor interventions to meet their needs and their caregivers’ requirements (Gitlin et al., 2014), this can be achieved using skilful occupational therapists working closely with the family (Gitlin, 2001).
Effective assessment and modification of the home environment can also help sustain participation in instrumental activities of daily living for people living with dementia that helps maintain their autonomy, reduces caregiver stress, and provides an overall effect of enhancing affective well-being (Gitlin, 2001).

Home is perceived as a ‘protected place’ where people living with dementia can find refuge, gain a sense of belonging and familiarity, and maintain control (Ward et al., 2017). However, it is important to recognise that home may not always be a safe space and can be associated with emotional and physical harm (Blunt & Varley, 2004, 2006; Milligan, 2012). The challenge to the idea of home as a private space is particularly associated with the changing landscape of care at home that seeks to maintain independent living (Milligan, 2009, 2012). By bringing external support and caregivers into this safe place, the ‘home’ might be best described as a ‘quasi private space’ (Brickell, 2012). While there is a change in how home space is viewed, domestic care can be seen positively as it is used to support independent living, unfortunately, some frail older people have negative experiences of being cared for. For example, Twigg (2000) identifies that some older people can be upset and disturbed by the care they receive from their caregivers. Significantly, some vulnerable older people experience physical and/or psychological abuse by family and professional carers (Milligan, 2012). This negative experience seems to be more pronounced for people living with dementia than those without as the condition increases frailty and dependence on others which places them in a continuously vulnerable position (Knight & Hester, 2016). Although the progression of dementia can result in ‘new’ behaviours, such as aggression, this change is often a reaction to the person’s unmet needs (Lowery & Warner, 2009). These behavioural challenges can also impact upon people living with dementia and those around them, leading to a negative effect on close relationships (Lowery & Warner, 2009). Therefore, when people living with dementia become vulnerable, the home may change from a place associated with positive experiences of ‘being at home’ into one where negative feelings of ‘imprisonment’ and eventually of being ‘homeless’ may dominate (Rowles, 1978; Rowles & Bernard, 2013), as highlighted in section 1.5.3.

Nevertheless, housing can also act as a connection to nature and access to the outdoors that are important and increase opportunities for people living with dementia to
participate in nature-related activities and social interaction (Gibson, Chalfont, Clarke, Torrington & Sixsmith, 2007). When living in their own home, people living with dementia seem to have more opportunities to access the outdoors and to enjoy nature than those living in residential care homes; however, these opportunities are often subject to their carers’ availability and willingness (Gibson et al., 2007). Interacting with nature supports people through multi-sensory stimulation which positively affects people’s mental, emotional and spiritual well-being (Gibson et al., 2007). Interactions within the outside space are also sources of identity and social inclusion for people living with dementia (Duggan et al., 2008). Housing, therefore, impacts on well-being and quality of life for people living with dementia, and a positive environment enhances their lived experience (Gibson et al., 2007).

In contrast to indoor space, the outdoor environment also plays a significant role in the health, independence, well-being and cognitive functioning of people living with dementia, as getting ‘out and about’ in the neighbourhood helps maintain a person’s sense of independence and self-respect (Keady et al., 2012). Duggan et al. (2008) examined the experience of using the outdoor environment by people living with dementia. They found for those in the early and moderate stages of dementia, people derived enjoyment in going out of the house, even though going shopping was the most common reason for being outdoors. When comparing being outdoors with staying indoors, carers noticed an improvement in the mood and quality of life of people living with dementia when they accessed the outdoors (Duggan et al., 2008).

Access to natural environments and participation in nature-related activities improves social interaction and self-confidence (Gibson et al., 2007). For example, walking can be an important means of coping with dementia as walking around the neighbourhood contributes to mental stimulation and social contact (Mitchell & Burton, 2010). Getting out into the local neighbourhood can increase the level of pleasure for individuals with dementia, and being able to take part in the outdoor space can provide a sense of freedom (Brittain et al., 2010).

The literature describes the impacts of the physical environment, ranging from home to a community, on people living with dementia, what the environmental challenges are,
and how to address these challenges to maintain their autonomy and independence. The literature also illustrates the reasons for valuing recreational activities in the outdoor environment. Nevertheless, there appears a lack of fruitful insights into the deep meaning of physical places and spaces for people living with dementia personally, with a lack of detailed description of their emotional and behavioural connections to their physical surroundings.

Theme 3: Neighbourhood Design
The freedom to go outdoors and access public spaces and amenities is an important component of environmental design for people living with dementia (Blackman et al., 2003). However, accessibility to the outdoors presents obstacles for older people, such as uneven or stepped pavements, poor lighting, and inaccessible bus stops; accordingly, the outdoors is not always seen as a desirable setting for people living with dementia (Blackman et al., 2003). When focusing upon urban areas, these places often do not meet the needs of people living with dementia and can lead to social exclusion and disengagement (Brittain et al., 2010). All these factors lead to a continual downward spiral in to isolation and diminishment of confidence, defined by Duggan et al. (2008) as a ‘shrinking world’. To avoid, or delay, the occurrence of a ‘shrinking world’ and meet the needs of people living with dementia, as they are the users of the environment, good environmental design for dementia-friendly communities or neighbourhoods is crucial. Such neighbourhoods enable people living with dementia to maintain a sense of independence and a good quality of life (Mitchell & Burton, 2010), and thereby, in theory at least, of delaying the need for intensive supportive interventions at home (Duggan et al., 2008).

Due to disorientation and confusion caused by dementia, external environments can be seen as particularly unfriendly for people living with dementia (Blackman et al., 2003). Successful orientation and wayfinding could be achieved by small street blocks with direct, connected routes, well-articulated environments, with orientation cues and directional information to create familiar, meaningful and stable environments where people living with dementia could be assisted to live in and use their neighbourhood (Blackman et al., 2003; Mitchell et al., 2003). Good neighbourhood design can enhance the quality of life of those living with dementia, as well as enable them to better cope
with the physical and mental effects of dementia by maintaining them in familiar surroundings (Mitchell & Burton, 2006).

Mitchell and Burton (2010) recommend six design principles for dementia-friendly neighbourhoods: familiarity, legibility, distinctiveness, accessibility, comfort, and safety. These principles make people living with dementia feel welcome and safe, while making the environment accessible and enjoyable. Living in such an environment, individuals with dementia can then access and use the local area and find their way around. This will enable people living with dementia to undertake the pleasurable and beneficial activity of just going for a walk and to go to their favourite places, such as the shops, post office, and park (Mitchell & Burton, 2010). Therefore, an engaging and dementia-friendly environment has a therapeutic effect on people living with dementia, with the environment identified as an important factor in influencing the psychological well-being, behaviour, independence, and functionality of people living with dementia (Day, Carreon & Stump, 2000). This enabling environment also supports the social model of disability which politicises dementia as a social issue about universal rights (Blackman et al, 2003).

Indeed, an enabling environment plays an important role in a daily context of people living with dementia. However, what is lacking is how they perceive and utilise such an environment. Equally importantly, the key factors that motivate people living with dementia to interact with their surroundings are also deficient.

Theme 4: Physical Activity
The literature states that physical activity is positively associated with health-related quality of life (Hirano et al., 2011) and can reduce the risk of developing dementia, namely Alzheimer’s disease (Kishimoto et al., 2016) and vascular dementia (Ravaglia et al., 2008). In parallel, leisure engagement could decrease the risk of developing dementia and Alzheimer’s disease, especially when engaging in more than one of the mental, physical, and social components, this is more likely to benefit the individual than engaging in just one type of activity (Karp et al., 2006). Physical activities influence the health status not only of people living with dementia but also their carers. Hirano et al. (2011) explored the inverse association between physical activities, especially leisure
activities, and the care burden. This finding provides practical implications and suggests that interventions related to physical activity have the potential to improve the health status and quality of life of carers.

In addition to the positive impact of physical activities and leisure participation on the reduction of risks of developing dementia, the association between physical activities, social interaction, and dementia has also been explored. Bowes, Dawson, Jepson and McCabe (2013) examined the potential effectiveness of physical activity for people living with dementia, and they identified that physical activities, such as exercise programmes, walking groups, and leisure club activities, and social interaction improved the experience of people living with dementia. They also discovered that unlocking memories was identified as an indirect benefit brought about through social interactions. Bowes et al. (2013) argued that some activities were considered meaningful for participants, such as gardening and dancing which provide a sense of enjoyment and feelings of well-being, the benefits of physical activities were also gained through these engagements. The benefits of meaningful activities are also identified by Ruthirakuhan et al. (2012) whose work suggests that frequent engagement in meaningful activities helps reduce the risk of incident dementia and these activities combined with an intellectual stimulation function are related to personal hobbies and interests, such as puzzles and games. These authors claim that such intellectually stimulating activities function as a cognitive reserve that is built upon personal cumulative life experiences and these experiences enhance skills to compensate for Alzheimer’s disease pathology (Ruthirakuhan et al., 2012). Hence, when planning physical activities and leisure participations, there should be a focus of whether people living with dementia will find the activity meaningful so that they can gain multiple benefits for these activities.

Furthermore, engagement in daily occupations is a primary intervention strategy in the care of people living with dementia and in line with the ability to be as active as possible, even though people with mild dementia may experience reduced functional ability relating to the performance of complex activities of daily living (Öhman & Nygård, 2005). More importantly, engagement in daily occupations will enable people living with dementia to show that they can look after themselves and this will help maintain their
autonomy; although they are aware of the increasing limitations they will experience as the disease progresses (Öhman & Nygård, 2005).

The evidence in this theme portrays a clear picture of the positive effects of physical activity on people living with dementia. However, it reiterates the knowledge gap in relation to the rationale for people living with dementia to engage with physical activities and how these activities are relevant and meaningful to each individual beyond physical and cognitive considerations.

Theme 5: Supportive Resources
Due to the progression of the dementia and the decline in performing daily tasks, the availability and accessibility of supportive resources, such as technology, transportation, and community-based support, are essential in the everyday lives of people living with dementia when connecting to, and negotiating with, their social and physical environments. This also promotes equal rights in line with other citizens, as seen in chapter 1.

Sub-theme: Technology
Technology creates new forms of social control to support people living with dementia to remain longer in their neighbourhood and assist with the notion of ‘ageing in place’ (Kenner, 2008). The benefits of using technology for people living with dementia can promote independence and autonomy while increasing safety through regaining some lost skills (Kenner, 2008). Technology can promote good communication and enable the voice of people living with dementia to be heard and understood, such as automatic night and day calendars, picture-telephones, automatic night-lights, gas cooker monitors, and item locators. Such technologies have a positive impact on people living with dementia and their carers which can also be used to gain an improved understanding of the experience of people living with dementia (Cahill, Begley, Topo, Saarikalle & Macijauskiene, 2004). Moreover, technology, such as telecare and telehealth, can be applied to aid the delivery of housing, health care, social care, and support services to maintain the independence of people living with dementia staying at their home (Gibson et al., 2015).
Technology can be used by people living with dementia both inside and outside their home space. Brittain et al. (2010) point out that technological devices, such as mobile phones, can be used in supporting people living with dementia in outside spaces, because they are likely to become lost as their illness progresses. Technological devices could make people living with dementia feel secure by mediating between the physical and social environment so that they gain a sense of reassurance and security and feel connected to the outdoors (Arntzen et al., 2014; Brittain et al., 2010). Technology not only supports people living with dementia to maintain autonomy in their daily life, but also enables stress reduction for their carers (Arntzen et al., 2014; Kenner, 2008). For example, telephone-based cognitive behavioural therapy (CBT) illustrates similar effects to face-to-face CBT in emotional and psychosocial functioning for carers (Glueckauf et al., 2012).

Despite these benefits, safety and security must be taken into consideration when using any technology to ensure that it provides enabling rather than disabling functions. To enable technologies to become beneficial in the daily life of younger people living with dementia and their family carers, Arntzen et al. (2014) identified the following five essential elements that should be taken into consideration when using technologies:

i. The assistive technologies can address practice, emotional, and relational challenges of the daily living experience.

ii. The assistive technologies need to fit well into habitual practice and establish family strategies in coping with dementia; this enables smooth manifestations in their attitudes and habits in their everyday practice.

iii. The assistive technologies need to generate positive emotions and act as a reliable and trustworthy tool so that the experienced usefulness of the technology outweighs the technology’s inconvenience and gives people a sense of being in control.

iv. The assistive technologies have to be user-friendly, adaptable, and manageable to meet people’s specific needs according to their cognitive functioning.

v. The assistive technologies are able to engage with the family carers to shift their attitude and increase their commitment to learn and follow the technologies; this is essential to enable the technologies to be useful and functional.
Gibson et al. (2015) argue that the access to and adaptation of technologies are driven by carers. It is essential to provide training and support for both people living with dementia and their carers, particularly when individuals with dementia are living alone and lack the support from relatives so that they can gain benefits from using such technologies (Brittain et al., 2010; Hanson, et al., 2007).

**Sub-theme: Transportation**

Driving is closely associated with independence and freedom, and it is increasingly regarded as an important form of transportation by older adults who consider driving as an important skill and perceive driving as essential or very important (Lloyd et al., 2001). However, a diagnosis of dementia will eventually result in driving cessation (Talbot, 2005) due to the cognitive decline in memory, judgement, and problem solving ability (Lloyd et al., 2001). Evidence shows that a car driver with dementia has a greater risk of an accident compared to older people without a cognitive impairment (Carr & Ott, 2010) and that dementia significantly impacts on driving safety (Talbot et al., 2005).

Although driving cessation is co-related to lower neuropsychological scores, Talbot et al. (2005) argue that a significant clinical challenge remains in identifying those with increased crash risk caused by dementia, because driving behaviour of people living with dementia is also associated with clinical, social, and demographic factors. Amongst all the factors, cognitive impairment retains its strongest position in influencing driving cessation (Talbot et al., 2005). However, Gilley et al. (1991) claim that people are capable of driving for a median duration of 28.6 months after onset of dementia, and people living with Alzheimer’s disease drive significantly longer in comparison to those with other types of dementia.

The decision to suspend the driving licence of people living with dementia can be complex and has a significant impact on personal independence and public health. There is a need for appropriate assessment of driving safety, focusing on visual perception, selective attention, judgement, insight, alcohol use, and medications (Carr & Ott, 2010). If the decision to suspend a driving license is made, it is necessary to assist individuals in finding alternative forms of transportation, where supportive assistance may need to be
utilised to enhance social connectedness and quality of life for people living with dementia (Croston, Meuser, Berg-Weger, Grant & Carr, 2009). The rationale for this is that the cessation of driving is related to poor social integration, less out-of-home activities, dependence, depressive and anxiety symptoms, decreased self-esteem, reduced quality of life, risk of nursing home placement, and lack of access to services (Carr & Ott, 2010; Talbot et al., 2005), particularly for those living in rural areas, lacking an adequate support network, or lacking access to alternative transportation (Lloyd et al., 2001).

Sub-theme: Community-based support

It is evident that tailored community-based interventions and support is beneficial for people living with dementia and their carers. Adult day programs and caregiver support groups affect the quality of life of carers of people living with Alzheimer’s disease (Bartfay & Bartfay, 2013). Carers of people living with Alzheimer’s disease who received more instrumental and affective support from others are more likely to report greater satisfaction with the support, a higher sense of caregiving self-efficacy, lower depression, and greater well-being (Beekman, 1999).

A citizenship-based model of dementia, such as ‘walking in the neighbourhood’, can be classified as a form of community-based support, and this model can be constructed and achieved in various ways. ‘Walking in the neighbourhood’ is a programme organised by an independent social recreation group for people with young onset dementia who are physically healthy (Phinney et al., 2016). The members often meet at 10am using a modern hotel as their meeting space and start the day with a group conversation about current events or reading newspapers. After that, the members can join in group-based activities, such as yoga, dance or other flexibility exercises. After lunch, the group go for an extended leisurely walk through their neighbourhood and back to the hotel by late afternoon.

Phinney et al. (2016) argue that such group-based activities provide an enjoyable experience for people with young onset dementia by offering a ‘non-medicalised atmosphere’ and focusing on ‘normal everyday activities’ to ‘keep the focus off dementia’. In addition, when walking around the neighbourhood, the group is flexible in
its structure so that they can freely form and shift conversational groups and can choose where to go. Such freedom to participate in simple exercise is important in meeting the needs of people with young onset dementia and promotes a sense of social belonging (Phinney et al., 2016). Moreover, walking in the neighbourhood everyday enables young people living with dementia to socialise with community members and engage with their community, thereby ‘claiming a place in the community’. The performance of everyday exercise of movement and mobility in the neighbourhood promotes awareness of dementia through their regular presence and provides opportunities for social interactions and co-construction of social belonging within a safe physical environment (Phinney et al., 2016). ‘Walking in the neighbourhood’ is centred around people living with dementia in line with the principles of compassion and empowerment to frame and articulate the complexity of their daily activities and actively contribute to social citizenship at a practical level (Phinney et al., 2016).

A social citizenship model supports the human-rights based approach by drawing attention to living well as a social citizen and fully exercising one’s rights in everyday living (Wiersma, et al., 2016). When emphasising the rights of people living with dementia, a citizenship lens explicitly posits the significance of the involvement of the family in affecting their experience of exercising full citizenship (Wiersma et al., 2016) as the family’s support is crucial to preserve dignity (Tranvåg et al., 2015). Additionally, self-management programmes have shown effectiveness in assisting people with chronic conditions to cope with the illness, and developing such programmes for individuals living with dementia is a logical step and grounded through a citizenship lens (Wiersma et al., 2016). When developing self-management programmes for people living with dementia, Wiersma et al. (2016) discovered four areas for consideration:

i. Creating safe spaces where people living with dementia feel comfortable and confident to express their thoughts and feelings.

ii. The voice of individuals with dementia being heard and valued by others to sustain their dignity.

iii. The significance of a balancing act, maintaining their relationship when people living with dementia speak on their own behalf while their care partners are part of the conversation.
iv. Participating in such programmes that provide a sense of solidarity – ‘you’re not alone’.

Wiersma et al. (2016) research highlights an important area for consideration; although the idea of the couple taking part in the programme is considered important, flexibility is needed as to whether the care partners should be part of the conversational group, this should be considered because one size does not fit all. This further posits the significance of flexibility in community-based service provision and delivery as well as the establishment of dementia-friendly communities in different locations.

This thematic review highlights the importance of neighbourhood in the daily experiences of people living with dementia and their carers illustrated through five major themes: ‘social integration’, ‘space, place and home’, ‘neighbourhood design’, ‘physical activity’, and ‘supportive resources’. However, there is a lack of longitudinal, participatory research involving people living with dementia and their carers to understand their lived experience of dementia in a context of neighbourhood. Additionally, there is no research that asked people living with dementia and their carers to define their neighbourhood and employed a participatory mapping method to enable them to visualise their self-defined neighbourhood. This highlights the scope for this empirical study to help build an evidence base for the meaning and construction of neighbourhood and the role that plays in the daily lives of people living with dementia and their carers. Furthermore, there is a scarcity of evidence as to how people living with dementia and their family caregivers interact and negotiate with their neighbourhood in a daily context through thick description. This knowledge gap raised a research question: “how do people living with dementia and their carers understand and interact with their neighbourhood?” to contextualise the requirement for this empirical study.

2.5 Summary

This review illustrates the significant impact of neighbourhood on people living with dementia and their caregivers from multiple dimensions. First and foremost, when people living with dementia are positively integrated within society, their social ties can help preserve a sense of dignity and safety, improve their quality of life, and maintain
their social identity. Secondly, the physical environment and neighbourhood design also influence health, independence, well-being, and cognitive functioning of people living with dementia, with going out and participating in nature-related activities being important for both physical and mental well-being. Thirdly, engaging in physical activities and daily occupations are beneficial for the health outcomes of people living with dementia and help maintain their identity and autonomy. However, this important factor becomes increasingly challenging to maintain due to the progression of their condition. Attention should be paid to ensure neighbourhood design is enabling and to promote access to supportive resources to compensate for the limitations people living with dementia experience, this helps retain independence and autonomy, and maintain their quality of life.

It is apparent from this review that neighbourhood impacts the health and well-being of people living with dementia from multiple aspects, including social, spatial, and experiential factors, and these aspects closely intertwine. However, the lack of insight into the multifaceted, dynamic relationships between people living with dementia, their carers, and their neighbourhood highlights the need for this study to examine the relationships and interactions between people and environment as both social and physical spaces through a longitudinal, participatory design. In so doing, this public health study on dementia will make a valuable contribution to a bottom-up approach to the development of a neighbourhood model based on the role that the environment plays in the lived experience of dementia.
CHAPTER 3
Study Methodology and Methods

3.1 Introduction
This chapter begins by setting out the aim and objectives of the study, followed by describing environmental gerontology which was employed to set up the research question and design. This chapter will then turn to describing narrative inquiry as a methodological frame and participatory methods for knowledge production to construct the lived experience of dementia through a neighbourhood lens. This is followed by discussing how the sample eligibility criteria were determined, and how the sample was recruited. The chapter will then present the methods of data collection used in the study, followed by a detailed explanation about how the data were managed and analysed. This chapter will then describe how rigour in this study was achieved, and close by explaining how I addressed the ethical issues in the research design, specifically focusing on the topic of process consent.

3.2 Aim and Objectives of Study
The main research question was: “how do people living with dementia and their carers understand and interact with their neighbourhood?” To answer this research question, the primary aim of this study was to explore the meaning, construction and place of ‘neighbourhood’ in the lives of people with mild dementia [hence forward referred to as ‘people living with dementia’ in the context of the study design and findings] and their carers living in one East Midlands county of England. The primary research aim was supported by the following objectives:

- To work collaboratively to understand people living with dementia and their carer’s self-defined neighbourhood.
- To map how people living with dementia and their carers interact with their self-constructed neighbourhood using a variety of approaches to document life activities.
- To identify the main factors that impact on how people living with dementia and their caregivers negotiate with, and assign meanings to, their self-defined neighbourhood.
• To develop creative methods of working and maintain researcher reflexivity during all research encounters.

From a public health perspective, environmental gerontology is a relevant field to explore the dynamic relations between older people and their environment, how and why older people attribute meanings to place, and how such relations affect their daily lived experience (Lawton, 1986; Satariano, 2006). One way of exploring these complex relations is through the medium of diagramming and storytelling (Hans-Werner & Gerald, 2003). It is therefore salient to adopt narrative inquiry as a methodological frame and employ participatory methods in a longitudinal design as an approach to research engagement and to operationalise the aim and objectives of this study. Each of these areas will be discussed in more detail in the following sections.

3.3 Environmental Gerontology
Environmental gerontology, a subfield in gerontological theory, research, and practice, was initially derived from behavioural and social gerontology in the 1930s. Environmental gerontology emphasises the “description, explanation, and modification or optimization of the relation between older people and their socio-spatial surroundings” (Hans-Werner & Gerald, 2003, p. 616). As with the progress of studies on the complex relationships between older people and their environment from multiple perspectives (Wahl & Weisman, 2003), the ‘sociophysical’ environment (Canter & Craik, 1981) has been used to address the complexity of the closely interwoven associations between physical, social, and cultural environments (Lawton, 1977). Hence, environmental gerontology is a suitable approach to establish the principle research question, exploring how people living with dementia and their carers understand and interact with their neighbourhood.

To disentangle person-environment relations in old age, Lawton’s (1989) differentiation between three basic functions of the ‘sociophysical’ environment is a fundamental conceptual framework at a meta-level. These three basic functions, namely, ‘maintenance’, ‘stimulation’, and ‘support’, are detailed here:
i. Maintenance function of the environment: ‘Maintenance’ comprises two features of the environment: constancy and predictability. This function in relation to places, such as the private home environment, would be how cognitive and affective feelings relate to the home ‘maintaining’ the self and continuity in later life (Hans-Werner & Gerald, 2003) through the everyday lived experience.

ii. Stimulation function of the environment: ‘Stimulation’ is defined as when something new and different happens to a person which has an effect on their behaviour. This means that, at either a symbolic or an explicit level, the person-environment interchange processes significantly impact on the behavioural and emotional functioning of older people in living a 'good life' (Hans-Werner & Gerald, 2003; Lawton, 1983).

iii. Support function of the environment: ‘Support’ refers to anything, both physical and social, which can compensate for reduced or lost competencies. In relation to the ecology theory of ageing (Lawton & Nahemow, 1973), the independent level in the behavioural competence of older people is strongly associated with physical and spatial characteristics. As such, to maintain or increase the level of independence of older people, support plays a significant role in recompensing the decreased competencies and in maintaining autonomy for older people.

Lawton’s (1989) three functions of the environment focus upon the profound influence of the environment on older people, with less consideration of how older people shape the environment. Due to the complexity of the person-environment interchanges, Lawton’s interactional stance was substantially reconsidered. Parmelee and Lawton (1990) claim that the people-environment relations cannot be explained through an interactional lens but instead should be understood through a transactional perspective to recognise their inseparable association. In this respect, there seems to be an acknowledgement of the impact of older people upon the environment.

Despite Lawton’s evolving theories, his approach to person-environment relations has been further challenged and critiqued by more contemporary scholars who place equal emphasis on a bidirectional relationship. Cutchin (2003, 2004) argues for a strong transactional perspective and demonstrates how people develop ‘place integration’
within the environment of their everyday life. ‘Place integration’ is the combination of place (the medium of human experience) and place experience (from an action-based perspective) (Cutchin, 2013). This concept calls attention to ongoing transactions that stress instability and change. In this sense, the continuity of the relational unity of person and place is paramount (Dewey, 1989, 1998).

When disentangling this transactional perspective, although it is salient to understand how the environment impacts upon older people, unpacking how they influence their environments is equally important. Buss (2009) identifies three methods in which people affect their environments, namely evocation, selection, and behavioural manipulation. The method of ‘evocation’ is concerned with an environment being simply altered by the presence of a person that unintentionally evokes others’ behaviours which, in turn, changes the situation of the person. The key feature of ‘evocation’ is that the person does not need to do anything to change the environment. The second method refers to ‘selection’, a person actively decides and selects a particular environment. This means that the match between the person and the environment is non-random (Kihlstrom, 2013). The third method is ‘manipulation’ which is defined as a way in which a person engages in overt behaviours to modify the characteristics of the environment. In doing so, the environment more closely matches the person’s desires and capabilities.

Building on Buss’ (2009) three non-random person-environment interactions, Kihlstrom (2013) adds a new dimension, defined as ‘cognitive transformation’. In this context, people can alter their mental presentations of the external environment and assign unique meanings to it. Here, attention should be given to the idea that this cognitive transformation changes the environment for that person only. These four dimensions recommended by Buss (2009) and Kihlstrom (2013) conceptualise how people shape their own environments. As Conradson (2005) concludes, “interactions between people and environment are complex and multifaceted, emerging out of particular embodied encounters but are also subject to later interpretation” (p. 2).

Building on the work discussed above in exploring the relationships between older people and their environment, it is important to emphasise the idea of relationality. This can be done by combining Lawton’s framework with Buss (2009) and Kihlstrom’s (2013)
theories and to focus upon bidirectional relationships between older people and their environment. This combined approach can reveal how the environment impacts upon the daily life of older people and uncovers how they deal with environmental opportunities, and limitations, providing a comprehensive picture of person-environment relationality.

Employing such a combined approach, the use of narrative is salient as it has been used in gerontology as a method to access data at more subjective aspects of a reality of ageing; conversely, the reality of ageing lies objectively behind the scenes. It is fair to say that “all theories of ageing are narratives” (Kenyon, Ruth & Mader, 1999, p. 41) as all knowledge is metaphorical, historical, and contextual and it is contained within a narrative structure (Bengtson & Schaie, 1999). Narrative contributes to the knowledge base of the meaning of the environment in old age within the field of environmental gerontology. For example, Rowles and Bernard (2013) adopted narratives to understand the meaning of home and the concept of environmental positioning for childless older women. In their study, participants were asked to tell their stories, including important aspects of their current lives and views on not having children, via a number of face-to-face interviews. Phillips (2013) also used oral narratives to gain knowledge on how older people without pre-existing diagnosis of cognitive impairment assigned meanings to key features in an unfamiliar town landscape compared with a familiar landscape. Phillips found that the attractiveness of the place and the ease of accessibility were the key features in developing a sense of place for an older population.

Therefore, to unpack the nuanced and multifaceted relationships of people living with dementia and their carers with their environment, it is appropriate to adopt narrative inquiry as a methodology to understand the experience of living with dementia in a daily context through a neighbourhood lens. Meanwhile, participatory methods within a longitudinal design were employed to raise the profile of people living with dementia and their carers during the research process and enable their voice to be heard and valued as they expounded the truth of their experience. Before discussing these approaches, there needs to be an understanding around the concept of ‘truth’ explored through both epistemological and ontological approaches.
3.4 Epistemological and Ontological Approaches to Narrative Inquiry

Epistemology is the way in which we understand and learn about the nature of knowledge and justify our beliefs, while ontology is the belief and understanding of the nature of being, the concept of reality as existing ‘out there’ (Lincoln & Guba, 2000). These two approaches deal with issues relating to the truth (Creswell, 1998; Snape & Spencer, 2003), which can be addressed by the naturalistic paradigm (Agostinho, 2005). This paradigm is driven by naturalistic inquiry to arrive at ‘scientific’ data.

Naturalistic inquiry is an approach enabling an understanding of the societal and cultural contexts in which the researcher observes, describes, and interprets the actions and experiences of specific people. Three common assumptions guide naturalistic inquiry at an operational level (Lincoln & Guba, 1985):

i. Naturalism: The belief that phenomena should be studied in the natural context where they occur; the idea that no phenomena can be observed independent of the context in which it occurs.

ii. Phenomenology: The belief that the object of interest can be examined without preconceived notions so that the data collected can be understood more fully and objectively.

iii. Interpretive nature: The belief that data can be analysed and interpreted by the researcher who sees the situation from the perspectives of those who are being studied and the self.

As will be demonstrated in the next section, narrative inquiry encompasses these assertions by paying particular attention to people’s genuine life experiences in a real-world setting via storytelling (Connelly & Clandinin, 2006). Storytelling can be conducted verbally and visually to form oral and visual narratives so that people’s own understanding of the daily experiences of living with dementia can be reflected (Riessman, 2008). To closely reflect on people’s real beliefs and experiences, one way of achieving this is through participatory methods which aim to empower participants to have control over their own stories and situation (Bergold & Thomas, 2012). These stories can make sense from the perspectives of both participants and the research, thereby narrative inquiry in a participatory context adheres to the necessary
epistemological and ontological approaches to generate authentic and collaborative research (Riessman, 2008).

3.4.1 Narrative Inquiry

Narrative is a common approach in contemporary social research and refers to various topics of study, methods of data collection and analysis, and theoretical orientations (Andrews, Squire & Tamboukou, 2013). Narrative is used as a device by people, enabling them to tell and shape their experience through personal interpretation so as to make sense of their lives and sits at the core of human experience (Connelly & Cladnin, 2006). Through storytelling, people can make sense of their past from their current perspective (Garro, 2000) and their experience can then be re-constructed and brought into the present and provide expectations of the future (Holloway & Freshwater, 2007).

Narrative inquiry evolved from the further development of qualitative research methods from the Chicago School of research in the early part of the twentieth century and focussed on collating life histories and documents to study the experiences of a range of groups (Bruner, 2004; Holloway & Freshwater, 2007). Narrative has been widely used in anthropology, ethnography, and life histories (Williams & Keady, 2008). In addition, the use of narrative in social research has become increasingly popular, especially in the field of nursing and health related research. This is due to the fact that narrative inquiry emphasises how the narrator makes sense of reality and identity in the social and cultural worlds in which the person lives and in which (s)he establishes personal identity (Andrews et al., 2013; Riessman, 2008).

Narrative inquiry seeks to study people’s experiences as stories, and provides a way of thinking about and understanding experience through collaboration between researcher and participants over time in real-world settings with social interaction (Connelly & Cladnin, 2006). Narrative inquiry places experience as the phenomenon under study and it asserts three primary facets: temporality, sociality, and place, all of which require simultaneous exploration (Connelly & Huber, 2016). In accordance with Connelly and Huber’s (2016) work, these facets are further detailed below:
i. Temporality: Events or experiences under investigation are in temporal transition. This highlights the significant importance of the past, present, and future of people, place, space, and events under investigation. People’s views of experiences and lives happen through the passage of time; they are continually formed in the present and used to shape a remembered past and predict future outcomes.

ii. Sociality: Narrative inquiry focuses on both personal and social conditions. Personal conditions consist of emotional experiences and feelings of the researcher and participations, whereas social conditions cover i) the conditions under which people’s experiences and events are explored; and ii) the inseparable relationship between the researcher’s and participants’ lives. This draws attention to the adaptation of participatory methods during the knowledge production process; this will be described in section 3.4.2.

iii. Place: People’s identities are strongly associated with their experiences that occurred in specific places and with the stories about their experiences told in particular places.

When studying the experience of people living with dementia and the changed meaning of personal life, narrative inquiry is pertinent for capturing and analysing meaning-making in situations where there is a difference between the ideal and the real (Riessman, 1993) as both ageing and dementia are considered issues that affect the ability to maintain a ‘good life’ (Lawton, 1983; Robertson, 2010). A meaningful life of a person living with dementia is influenced by past social status and relationships (Robertson, 2010). Hence, narrative inquiry is suitable for exploring the sense of the new role as an ‘ageing person with dementia’ in wider social and cultural worlds in which the continuity or disruption in the personal identity and life is constructed (Robertson, 2010).

However, despite the benefits of using narrative inquiry to explore the lived experience of dementia, considerations should be given to how the effect of the onset and progression of dementia on language and cognitive function influences the key features of narrativity. Baldwin (2006) claims that these features are comprised of narrative agency, narrative consistency and coherency, and emplotment. He further details each
feature and the challenges people living with dementia might encounter when constructing their own stories:

i. Narrative agency: This feature refers to the ability to express self in a narrative form and having the opportunity to present self narratively. For people living with dementia, they might face the difficulties in verbal communications and loss of memory, so they might be perceived as losing narrative agency and lacking in meaning by others. This, in turn, affects their control in their decision-making and limits their opportunities in expressing selves narratively.

ii. Narrative consistency and coherency: This feature aims to ensure the continuity of a successful narrative is maintained by holding together the events, characters, and context in an understandable entirety. In practice, it might not be possible for people living with dementia to present their story in such a consistent or coherent way but instead to appear confused or contradictory due to the decrease in cognitive functioning. As such, their stories might not be acknowledged in a narrative form.

iii. Emplotment: This feature formulates a narrative trajectory through time, so the story moves from one position to another through logical relationships between events, characters, and context. In addition to being confused by the story itself, the forgetfulness and losing a sense of time create more challenges for people living with dementia to emplot a story.

To ensure people living with dementia are not dispossessed, but rather facilitated, by narrative, Baldwin (2006) suggest ways in which they can conceptualise and operationalise narrative through reconfiguration:

i. Reconfiguring narrative agency: There are two aspects within this feature: first, seeking other means for expression of narrative other than language, such as photographs, diaries, and observations; and second, employing the joint authorship to share narratives by both people living with dementia and their carers or to co-construct narratives through a negotiative process between people living with dementia and others. This feature is associated with the principles of participatory methods, particularly the use of visual and co-
construtive narratives to empower people living with dementia to express self and identity. Participatory methods will be detailed in section 3.4.2.

ii. Reconfiguring narrative consistency and coherency: It might be a challenge for people living with dementia to make their stories consistent and coherent in chronology. However, this feature can be achieved by assembling related fragments of meanings, and narrative analysis under a holistic approach can focus upon the narrative account as a whole. This will be detailed in section 3.9.1.

iii. Reconfiguring emplotment: To express the self in a changing circumstances over time, emplotment can be reached by collecting ‘small stories’ (Bamberg, 2004) relating to one another to contribute to the performance of identity in daily interactions over a lengthy period of time. A holistic approach to narrative analysis can also help address this feature by linking relevant ‘small stories’ collected through a longitudinal period to the entire narrative account. Again, this will be detailed in section 3.9.1.

Evidently, narrative has begun to be used in dementia research in a variety of contexts and situations. As an illustration, Hydén (2009) used narrative to examine how people with Alzheimer’s disease engaged with various communicative resources to establish and negotiate their senses of self and identities. O’Connor, Phinney and Hulko (2010) also used narrative to explore the experience of living with dementia, daily activity and use of support services, and data were collated through audio- or video-taped in-depth interviews, observations, telephone conversations, and health and social records. The use of multiple methods in gathering narratives aimed to enhance narrative agency of persons living with dementia and was to truly ‘hear’ their voices.

In addition, collaborative storytelling was successfully used by Hydén (2011) to study the experiences of finding out about, and living with, the Alzheimer’s disease for couples where one spouse had the condition. Their stories were collected through audio- and video-recorded interviews with the couples. Although a person with advanced Alzheimer’s disease had both cognitive and linguistic issues, with the spousal carer’s assistance they both participated in actively telling their own life stories as a consequence of employing narrative collaboratively. The success of collaborative
narrative was because people living with dementia performed better in telling their stories if they were supported by their spousal carers who deeply understood the persons they cared for and might use interactional strategies to enhance the ability of people living with dementia in storytelling (Kemper, Lyons & Anagnopoulos, 1995).

Therefore, narrative methods can be used to gain insight into the personal experience of living with dementia and make sense of their experience in a specific setting in which their experience occurs (Lincoln & Guba, 2000). The meaning and construction of a specific place and the interactions between people living with dementia and the place can be explored through discourse to eventually unpack the person’s attachment and connection to their environment. However, the growing acknowledgement of truly hearing the voices of people living with dementia requires the recognition and application of a participatory approach with participatory methods.

3.4.2 Participatory Methods
To promote the opportunities for people living with dementia and their family during the research process and to enable their voices to be heard and valued, the application of participatory methods was one appropriate approach. Participatory methods refer to a number of research activities with a common feature of enabling participants to become active members in the research process to influence decisions which shape the outcomes of their stories (Institute of Development Studies, 2017). This means that participants can equally contribute to all aspects of the research process. A participatory approach aims to collect insights on the collaboration between participants and the researcher (Bergold & Thomas, 2012), and this is in line with the ‘sociality’ facet of narrative inquiry (Connelly & Clandinin, 2006). By raising the profile of participants in all aspects of research, they are empowered and have control in sharing their own experience and shaping their stories in order to provide insights into their own situation. In addition, their voice can be embedded in the research process and represented as ‘experts of experience’ (Swarbrick et al., 2016).

Although there are different features and traditions of participatory approaches, such as participatory learning and action, participatory rural appraisal, and rapid rural appraisal, the commonality of these approaches is to work towards equitable development and
social justice through the means of participation to collaboratively gain insights into everyday practices and experiences (Bergold & Thomas, 2012; Institute of Development Studies, 2017). However, a participatory approach can impose obstacles in engaging people living with dementia in taking an active role in the research process, particularly relating to their traditional role of being a ‘subject’ or ‘participant’ and to ethical issues (Harrison & Johnson, 2015). These obstacles prevent the rights of people living with dementia from equal active involvement and decision-making in research and from their full citizenship in society (McKeown, Clarke, Ingleton & Repper, 2010). There appears to be a need to shift this traditional view towards a participatory approach where people living with dementia can undertake an active role in research (Hellström, Nolan, Nordenfelt & Lundh, 2007). This movement encourages an ideological change based upon ‘us’ finding out about ‘them’ to ‘us’ learning from people living with dementia through partnerships (Institute of Development Studies, 2017).

A participatory approach can be facilitated via narrative which is a powerful approach for expressing lived experience (Hydén, 1997), and allows people living with dementia to impose their own order on the stories they tell and to make it complete from their perspective. In return, a participatory approach contributes to the production of successful narratives as narrative agency can be enhanced through the use of participatory methods. This means that people living with dementia can tell their stories via a variety of ways, consisting of verbal conversations, written documents, and visual presentation. Some of these are directly under participants’ control and shape their stories, such as diaries, photographs, and maps (Reissman, 2009). Additionally, the variation in storytelling needs to be sensitive to an individual’s capability and helps offset the disadvantages the person might have, thereby people living with dementia can be empowered to present their experiences and beliefs with optimal capacity, and their level of narrative agency is improved (Baldwin, 2006). As such, people living with dementia are perceived as experts, able to articulate their own views through storytelling which serves as a means of transferring the power of the researcher to participants during the knowledge production process. Undertaking an active and influential role in producing the knowledge empowers participants to feel a sense of ownership which in turn encourages further commitment. Moreover, narrative enables people living with dementia and their carers to better understand their own, and their
peers, situation as well as allowing the researcher to learn and appreciate the experience and knowledge from the perspective of the storytellers (Reissman, 2009).

The combined approach of narrative and participatory methods is consistent with both epistemological and ontological approaches, and helps pursue the unequivocal commitment from both parties (Nolan et al., 2003). Unequivocal commitment can be further reached via a significant time commitment in a longitudinal design (Nolan, Hanson, Magnusson & Andersson, 2003) where trust relationships between participants and the researcher are established to further elevate in-depth insights into daily experiences and beliefs. Knowledge gathered through a lengthy period of time helps increase the level of employment of narrativity (Baldwin, 2006). Hence, a participatory approach is the key in driving the understanding of the lived experience of dementia together with verbal and visual narratives.

The combination of narrative and participatory methods within a longitudinal design has been adopted in dementia research. To justify this choice further, Kindell (2015), for example, applied narrative alongside participatory methods, such as biographical interviews and life story work coupled with both video and audio recording of daily conversations, to explore the daily interactions of people with semantic dementia and their spouses at home during a period of ranging from seven to 18 months. A similar approach was employed by Roach (2010) who used narrative over a 12- to 15-month period to gather life stories along with co-constructive family biographies to understand the day-to-day experiences of people with young onset dementia in a family-centred context. These studies support the methodological approach I adopted in this study to gain in-depth insights into the experience of living with dementia. The next section will move onto describe how narrative inquiry and participatory methods were employed in practice to co-construct the lived experience of dementia.

3.5 Co-constructing the Lived Experience of Dementia

3.5.1 Narrative Inquiry in Practice

To validate the claim that using narrative inquiry is suitable for this study, I will explore how three concepts, those of ‘temporality’, ‘sociality’, and ‘place’ (Clandinin & Huber, 2016) were the foundations of this study and how narrative inquiry was well placed to
help explore the importance of these concepts to the construction of neighbourhood. To explore the lived experience of people living with dementia and their carers in a neighbourhood context, this study initially focused upon the definition of the ‘place’. This was done by exploring the ‘place’ itself to gain personal meanings from the participant’s points of view. This was followed by further studying the concept of ‘place’ through i) uncovering the interactions of people living with dementia and their carers with their home and neighbourhood and documented their activity patterns; ii) exploring how they dealt with the environmental challenges, such as accessibility within home and public places; and iii) unpacking how their experiences and feelings of these activities associated with their identities.

Secondly, to gain in-depth insights into participants’ stories about the experiences of living with dementia, a crucial element was to consider and explore ‘sociality’. This consists of the emotional experience and the social context under which their stories made sense from the perspectives of both participants and the researcher. These emotional experiences and feelings were explored through focusing on participants’ emotional and behavioural correspondences to their neighbourhood and the impact of these correspondences on their daily life. To gain these comprehensive insights, an iterative approach within a longitudinal design of one year was applied to build a good rapport over time and helped increase the emplotment feature of narrative.

Thirdly, the study sought to explore ‘temporality’ by asking participants to tell their stories about the experiences of living with dementia in their defined neighbourhood. These told stories were the views of past experience, and a potential prediction of their future, shared at the present time. The employment of ‘temporality’ unpacked how participants located their historical and memorable places into their current neighbourhood, which then influenced the way in which they predicted their future. In addition, ‘temporality’ helped uncover how participants interacted and constructed their social networks over time. Moreover, ‘temporality’ had an important role to play in the impact of neighbourhood on the continuity of self over the life course. The attention to ‘temporality’ was further facilitated using a longitudinal approach to gain an in-depth understanding of this phenomenon over time. Therefore, the use of narrative inquiry
fitted well with the aim and objectives of this study by allowing simultaneous exploration of the three primary facets of ‘temporality’, ‘sociality’, and ‘place’.

The knowledge of these experiences closely relates to participants’ identities and their attachment and connection to their surroundings. These stories were told in the participant’s home where they felt comfortable and provided a context-specific setting enabling the process of storytelling to be informal and relaxed. These told stories were supplemented by the visual narratives to enhance narrative agency. These visual narratives included photographs taken by participants and the neighbourhood maps constructed collaboratively between participants and the researcher. This collaborative approach actively mapped the participants’ own stories, situation and the lived experience of dementia. The construction of multiple narratives through collaborative participation will be further discussed in section 3.5.2. Furthermore, narrative consistency and coherency that people living with dementia might face were elevated and strengthened through both a holistic approach to analysis (detailed in section 3.9) and case studies presentation (Yin, 2009).

3.5.2 Participatory Methods Through Narrative in Practice

The application of participatory methods through narrative is one way of gaining an in-depth understanding of the lived experience of dementia in a neighbourhood context. In light of naturalistic inquiry and the three features of narrativity, some fundamental principles and distinctive features of participatory methodology, according to Bergold and Thomas (2012), were applied in this study.

During the design stage, to ensure the data collection methods were appropriate to the participants and their capabilities and to increase their level of narrative agency, multiple methods were employed to capture both verbal and visual data as I was aware that conversations might become increasingly difficult as the participant’s condition progressed. The inclusion of both people living with dementia and their carers to storytelling contributed to the construction of successful narratives as the persons living with dementia received assistance from their carers in telling their stories and experiences of living with dementia (Hydén, 2011).
During the field work, the need for a ‘safe space’ was adopted to facilitate sufficient openness and help build confidence and trust with participants expressing a willingness to take part in the study. Throughout data collection, participants had control in their storytelling and how to share their stories both verbally and visually. By so doing, the power of the researcher in controlling the knowledge production was shifted towards the participants to balance the power relations. Meanwhile, constant negotiation was engaged to ensure that people living with dementia and their carers could trust the researcher and could voice their views openly, describing experiences and everyday knowledge on the subject under study.

The ability to establish rapport and build trusting relationships, leading to the development of tacit knowledge, was facilitated by a longitudinal design. Tacit knowledge was derived from the interactions between the participants and the researcher at an intuitive level (Lincoln & Guba, 1985). Such knowledge helped elaborate participant’s versions of reality and belief, without any prior expectations. The incrementally established trust relationship enabled me to further adapt participatory and qualitative methods to explore deeper thoughts and feelings behind their beliefs via truthful communications, and provided me with the opportunity to be part of their storytelling process. During this stage, the issues under study were explored using multiple methods, which will be detailed in section 3.8. Self-reflection as a researcher was documented during the knowledge production process to indicate the situation, research process, personal thoughts, and observations, Borg, Karlsson, Kim & McCormack (2012) identify the importance of being fully aware of the self as a research instrument which can hold and critique the meaning of various interactions.

During the reporting stage, the living experience of dementia via a neighbourhood lens was illustrated via case studies (Yin, 2009). A key acknowledgement here is that each case study represents the perspective of participating couples who were recruited into this study, and as such is their truth. The study excludes alternative versions of this truth such as from the perspectives of family members and/or friends who were not engaged in the data. When presenting the findings via case studies (Yin, 2009), visual forms of representation were included in the case studies, such as co-produced neighbourhood maps and photographs (detailed in section 3.8). The presentation of the neighbourhood
maps and photographs not only demonstrates participants’ contributions to the research but also allows for easier understanding of the findings as “human memory is extremely sensitive to the symbolic modality of presentation of event information” (Madigan, 2014, p. 65). In other words, the impact of symbolic modality (verbal versus pictorial) on memory is reliable, and pictorial representations of material can have relatively powerful effects on learning and memory (Madigan, 2014). In conclusion, this longitudinal participatory study supported a person-centred approach by investing a one-year commitment between the researcher and the individuals with dementia in research, and the participatory element provided participants with choices and control within the study.

3.6 Sample Eligibility Criteria

Johansson (2003) suggests that a purposive selection of a case is an effective selection process and would potentially lead to an analytical generalisation of the research findings. Purposive sampling is a form of non-probability sampling by selecting samples in a deliberative and non-random method based on a variety of criteria (Oliver, 2006). Purposive sampling is unlike random or probability sampling and not free from bias. However, this sampling method can gain internal validity when a sample is measured correctly and external validity when a sample is representative (Dolores & Tongco, 2007). In this study, I particularly focused upon the first factor to achieve internal validity using a range of data collection methods so that the in-depth insights into the lived experience of dementia were gained. To some degree, I also addressed the second factor by choosing two distinctive areas with regard to the prevalence of dementia and economic status of the participants to represent the population of these two areas.

Participants were purposively selected, specifically drawn from two Community Mental Health Teams for older people with the function of memory assessment clinics, covering two district areas within a county in the East Midlands region of England [where the author was based at the time of data collection]. Participants were sought from these contrasting areas as service provision and social networks differed within these areas, and previous research has identified how important localities are in people’s lives (Emmel & Clark, 2009). Studying a sample based on demographic characteristics enabled
me to refine and expand the analysis, making for a deeper exploration within and across cases.

Area A has the highest number of people living with dementia aged 65 and over, and of people with early onset dementia. The prevalence of dementia in area A equals to 33 per cent of the total number of people living with dementia in the county in 2015. This largest concentration of people living with dementia may be partly due to a higher number of care homes being located in this area. In terms of the local population, according to Official for National Statistics (2016), area A has a population of over 222,500. Of this population, the number of people aged 65 and above is 78,900 (35.5 per cent of the total local population). Within area A, 84.5 per cent of the local population is White British. With regard to qualifications, the number of people having NVQ4 and above is 50,500 (35.3 per cent). The number of people being in employment is 119,800 (82 per cent) and the gross weekly earnings for full-time workers is £505.1. Area A is the second most deprived district within the county.

In contrast to area A, area B has the lower number of people living with dementia, the prevalence of dementia is about nine per cent of the total dementia population within the county in 2015. In general, according to Official for National Statistics (2016), area B is the largest district in the county but has the second smallest population of over 81,300; of this, the number of people aged 65 and above is 31,300 (38.5 per cent of the total local population). Area B is largely White British (96.5 per cent at the previous census) with little ethnic diversity. The number of people having NVQ4 and above is 14,300 (29.8 per cent) within the area. In terms of employment, 41,900 people are in employment (82.3 per cent), and the gross weekly earnings for full-time workers is £531.1. Area B is the most affluent area with features rich in history and its residents have the longest life expectancy within the county at 79 years old.

In addition to these two distinctive locations, this study set out to recruit people with mild dementia who had the capacity to consent. This was done to reduce the risk of the person with dementia losing the capacity to consent over the course of the (up to) one-year engagement. Participants were recruited from clinical areas and the recruitment was informed by the results of a neuropsychological battery of tests to establish the
diagnosis of dementia, including the Mini-mental State Examination (MMSE) to indicate the stages of dementia (Folstein, Folstein & McHugh, 1975). These tests were part of the clinical service provision rather than being carried out purely for this study. In the literature, a MMSE score of 20 or above (up to a maximum score of 30) is indicative of early or mild dementia (Pezzotti, Scalmana, Mastromattei & Lallo, 2008). Moreover, the MMSE has been recommended by the National Institute for Health and Care Excellence (2006) and the British Psychological Society (2015) for the purpose of measuring cognitive functioning, even though the MMSE may be inappropriate for people with intellectual disabilities and insensitive to the mild dementia and affected by various factors, such as educational level (National Institute for Health and Care Excellence, 2006).

3.6.1 Inclusion Criteria
People living with dementia were eligible for inclusion if they had been diagnosed with a dementia of any type within the last 12 months, excluding alcohol related brain damage; having a score of 20 or above on the MMSE (Folstein et al., 1975) as administered by their clinician to ensure that the degree of impairment is mild and that the person living with dementia can give informed consent without access to a proxy; currently in the care of an NHS professional at one of the Community Mental Health Teams for older people; living with somebody (who normally, but not necessarily, is the primary carer); mobile; and speaking and understanding English. Due to the longitudinal, qualitative nature of the study and resource constraints, study participants were limited to those that can speak and understand English.

People cohabiting with the person with dementia (such as the primary carer) were eligible for inclusion if they were living with the person with dementia at the time of approach; aware of the diagnosis; and nominated as a carer by the person with dementia. The final inclusion criterion was to ensure that people living with dementia maintained control over participation in the study especially when sensitive areas might be discussed over the length of the planned one-year engagement.
3.6.2 Exclusion Criteria

Individuals with dementia were excluded if they had a MMSE (Folstein et al., 1975) score below 20 at the commencement of this study; had alcohol related brain damage; were living alone; did not speak and understand English; and had a severe physical illness alongside their diagnosis of dementia.

Research ethics committee approval was obtained on the 23rd February 2011 from the Nottingham Research Ethics Committee (REC) 1 that approves research proposals involving adults lacking capacity. It was necessary to put this application through a NHS capacity REC as there was a risk that the person living with dementia might lose capacity during the course of the planned one-year engagement. The NHS REC reference number for the study is 10/H0403/100. Approval from the appropriate NHS Trust Research and Development where the study was to be undertaken was gained on the 20th March 2011 in line with the research governance procedures that were live at the time. The NHS Trust Research and Development reference number is R.113.11. The necessary approval letters and the approved research protocol for the study are shown in Appendix items 2 and 3 respectively.

3.7 Recruitment

Recruitment was initiated in May 2011 after a meeting with the clinicians who managed the Community Mental Health Teams for older people at their workplace. I provided these clinicians with the information packs containing information sheets (Appendix 4) and consent forms (Appendix 5). I then built a positive working relationship by maintaining frequent contact with the clinicians via telephone conversations, email, and face-to-face visits. This positive working relationship looked to overcome a number of barriers to the recruitment process, which included the time required from the clinicians to identify potential participants who would meet the inclusion criteria, and the confounding issue that the clinicians were already engaged in recruitment for other dementia-related studies in the area. These challenges meant that the recruitment of participants took over one year, from May 2011 to June 2012.

During the recruitment, if people living with dementia met the study inclusion criteria, the clinicians then briefly explained the study to potential participants and handed out
the information packs and my contact details. Concurrently, the clinicians obtained initial verbal consent from the potential participants to share their contact details with me. If the potential participants expressed an interest in participating, I then made initial contact by telephone before arranging a home visit to discuss the study in more detail. As a result, a total of seven couples expressed an initial interest in taking part in the study, but of this total only five couples gave final consent. The two couples who initially expressed a verbal interest declined to take part after the study was explained in greater detail via a telephone conversation with the researcher and due to complexities within their family circumstances.

These five couples, where one partner had a dementia, were recruited from two distinct areas within an East Midlands county in England (as outlined a little earlier in the chapter as area A and area B) by two Community Mental Health Teams for older people as each team covered each area. In this thesis, ‘couple’ refers to the couple where one partner has dementia, and pseudonyms are used in the thesis in line with the study protocol. Two couples were from recruitment area A, which is the second most deprived district within the county, and three from recruitment area B, the most affluent area within the county. In terms of the MMSE (Folstein et al., 1975) score, three out of five individuals with dementia had a score of 20, one with 29, and one with 19 at commencement of the study. The rationale for recruiting Emily with a MMSE score of 19 as part of the study was based on discussion with my supervisors around Emily’s particular condition and current capacity at the time. It was agreed that she would be a suitable participant for this study as she indicated a willingness to take part and had capacity to consent at the first meeting when we discussed the project.

As the next chapter will show, Emily performed well throughout the study, even though she had a score of 19 at the commencement of this study. In contrast, Patricia had a score of 20 at the time of recruitment, but her cognitive functioning decreased throughout the study and her score was down to 17 towards the end of my engagement. The impact of this was that she struggled to recognise her own home at times and additional care was needed to ensure consent was properly obtained. Jonathan’s MMSE score was 20, interestingly, he was the only person with dementia who drew the neighbourhood map himself and kept a diary using his computer. For the other couples,
the maps were mainly drawn by the carers in collaboration with the persons with dementia. This variation indicates that a challenge in a longitudinal study is that initial (one-off) MMSE scores are not an accurate predictor of the progression of a person’s dementia. This means that flexibility should be built into the selection criteria to allow for the inclusion of potentially suitable participants who initially fall slightly outside of the inclusion criteria. A summary of the families that participated is presented in Table 3.

A detailed description of the main activities that took place on each visit with each couple is shown in Appendices 6 to 10.

As the study was qualitative in design, and specifically focussed on narrative and participatory engagement, the quality and depth of the data was instrumental to such insights and lived experiences being brought to the surface. In such circumstances, the literature suggests that a small sample is consistent with a longitudinal qualitative approach (Holloway & Freshwater, 2007; Moore & Hollett, 2003) and this is common when studying the lived experience of dementia (Cotrell & Schulz, 1993; Kindell, 2015; Roach, 2010). This design enables a focus on an in-depth, rich description of lived experience. A sample size of five couples had provided a rich source of data in previous dementia research utilising a longitudinal approach. This enabled the refinement and expansion of narrative analysis, making for a deeper exploration of each case. This sample size also enabled me, as an individual researcher, to manage the longitudinal data collection via multiple visits, and maintained an important continuity as I undertook each interview. Appendices 6 to 10 summary the main activities and the time spent during multiple visits.

3.7.1 Sample Characteristics
At the time of recruitment, the mean age of people living with dementia was 76 years of age, with the mean age at diagnosis being 74 years. The sample of people living with dementia comprised one man and four women. Four couples lived in their owned properties and one in a rented home. The mean length of stay in the properties was 20 years with a range between five and 53 years. The levels of education consisted of one participant having an undergraduate degree, with the other participants educated to O-Level or equivalent qualifications (gained at age 16). The mean score of the MMSE was 21.6 at the commencement of the study. In respect to the participating family carers,
the mean age was 77 years of age at entry into the study. Amongst all the participating couples, four couples were married and one lived together as a partnership. All participants identified their ethnicity as ‘White British’ (n=10) and had heterosexual relationships.

Table 3: Participant Demographics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Sex</th>
<th>Diagnosis</th>
<th>MMSE</th>
<th>Relations</th>
<th>Housing tenure</th>
<th>Length of stay</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mary</td>
<td>86</td>
<td>F</td>
<td>Alzheimer</td>
<td>20</td>
<td>Owned</td>
<td>53 years</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Steve</td>
<td>86</td>
<td>M</td>
<td>Husband</td>
<td></td>
<td></td>
<td></td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Family 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patricia</td>
<td>74</td>
<td>F</td>
<td>Mixed type of dementia</td>
<td>20</td>
<td>Owned</td>
<td>5 years</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Brian</td>
<td>77</td>
<td>M</td>
<td>Husband</td>
<td></td>
<td></td>
<td></td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Family 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diane</td>
<td>76</td>
<td>F</td>
<td>Alzheimer</td>
<td>29</td>
<td>Owned</td>
<td>7 years</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Dave</td>
<td>76</td>
<td>M</td>
<td>Husband</td>
<td></td>
<td></td>
<td></td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Family 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jonathan</td>
<td>66</td>
<td>M</td>
<td>Alzheimer</td>
<td>20</td>
<td>Owned</td>
<td>22 years</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Jackie</td>
<td>66</td>
<td>F</td>
<td>Partner</td>
<td></td>
<td></td>
<td></td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Family 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emily</td>
<td>76</td>
<td>F</td>
<td>Alzheimer</td>
<td>19</td>
<td>Rented</td>
<td>11 years</td>
<td>White British</td>
<td></td>
</tr>
<tr>
<td>Tim</td>
<td>79</td>
<td>M</td>
<td>Husband</td>
<td></td>
<td></td>
<td></td>
<td>White British</td>
<td></td>
</tr>
</tbody>
</table>
Throughout my involvement with the five couples, we spent most of our time in face-to-face interviews and in co-constructing the neighbourhood maps which recorded the significant places and social ties in their lives to illustrate their neighbourhood landmarks. My engagement was well received by the five couples; the diary keeping and construction of each neighbourhood map was perceived as helpful, particularly by the fourth couple in stimulating Jonathan’s (the person living with dementia) cognitive functioning.

3.8 Data Collection

To ensure the robustness of methodological quality, a variety of participatory and qualitative methods were used over three study phases (Figure 2). For the first four participating couples (see Table 3), each phase lasted approximately four months with a face-to-face meeting each month, while the last couple recruited preferred a shorter duration for the study, meeting on a weekly basis over a period of two months. Due to the experience gained interviewing the first four participating couples, I was able to bring that experience to bear on the reduced timeframe of the final couple and ensure the data collected maintained trustworthiness. During all three phases, creative methods of working were developed and researcher reflexivity was maintained. A summary of the aim and data collection methods of each phase is shown in Figure 2 and each will be developed further.

3.8.1 Mixed-interviews

Mixed-interviews have been increasingly used in social research to study the living experience of people with early to moderate dementia. For instance, Duggan et al. (2008) interviewed 22 people with early to moderate dementia and their carers to explore the use of the outdoor environment. In their study, a mixed-interviews approach was adopted, consisting of face-to-face interviews, diary interviews, and biographical interviews; these mixed-interviews took place in the homes of people living with dementia.
It seemed logical to extend this method as the basis of this study, to move from the understanding of the use of the outdoor environment, to exploring how people living with dementia define, interact, and make meaning of their neighbourhood. The core structure of the interview for exploring each topic was divided into two steps (Zinn, 2004) as follows:

i. Free narration: Participants were asked an open-ended question, for instance, “how would you define your neighbourhood?” to provide a full narration of the definition of neighbourhood from their own standpoint and to give space to emphasise what is important to them. This technique has been used to collect individual and collective biographies (Keady, Ashcroft-Simpton, Halligan & Williams, 2007; Garwick, Detzner & Boss, 1994; Gubrium, 1993). The aim of free narration is to avoid restrictions on the participants (Riessman, 1993) so that narrations are connected by plots and characters to illustrate how and why meanings are assigned to the events in question (Holloway & Freshwater, 2007;
Riessman, 1993). This narration was encouraged by means of non-verbal and paralinguistic expressions of interest and attention, but prevented uncontrollable effects on the process of self-presentation as the storytelling normally takes little prompting (Holloway & Freshwater, 2007).

ii. Further questioning: The advantage of in-depth interviews is that they allow further exploration of how people make and attach meaning to events in their lives by following ‘guided’ conversation in a natural setting (Johnson, 2001). At this stage, participants were initiated with narrative questions to explain the topics previously mentioned and to answer other questions which had not been addressed (Rosenthal, 1993). It is worth noting the ethical implications of ‘probing’ which should be in a sensitive and thoughtful manner so that participants feel comfortable to provide further information (Johnson, 2001).

Interviews took place as soon as possible after initial contact was made and began with developing a relationship with the families and obtaining their background information, including their demographics, their health conditions, and their family members. These conversations contributed towards building trust and good rapport with people living with dementia and their carers, which was as crucial when conducting interviews as it was when interacting clinically (Nygård, 2006). This background information helped build a richer picture of each participating family and contributed to the production of their family genogram. Genograms were adopted as a visual representation of family composition and structure and it served as a means of telling family stories (Rempel, Neufeld & Kushner, 2007). Genograms also helped explore the family relationships and elicited stories generated in narrative inquiry to obtain rich contextual data (Rempel et al., 2007) and thick descriptions of how the family members responded to people living with dementia and whether there were any changes in family dynamics.

Sensory experience was accommodated into the interviews by participants spending time at home and walking through their garden with me. This supports a person-centred research approach aiming to put the value and best interests of the individual with dementia at the centre of the study. The person-centred method was further supported by a participatory approach (Nolan et al., 2003) to this study by balancing the power
dimensions between people living with dementia, their carers, and the researcher, and by valuing the opinions of people living with dementia and their carers.

During the interviews, there were times when the participants took the lead. For example, participants were trying to ‘educate’ me about what constructed their current neighbourhood and what had changed in both the social and physical surroundings over time. On a few occasions, participants took me to their gardens and then gave detailed accounts about these spaces by taking charge of the conversations. At various times, when the carer was dominating the telling of a story about a particular event, I encouraged the person living with dementia to express his or her opinions about this phenomenon and emphasised the importance of the person living with dementia’s perspective, while appreciating the carer’s thoughts. The same principle remained when, due to the progression of dementia, the carer responded more quickly to my question than did the person living with dementia. My role in these situations was to facilitate equal opportunities for both the person living with dementia and their carer through a negotiation process, and to balance their contributions towards their joint narratives.

Taken together, this indicates how I attempted to ensure equal participation and equality of power was adhered to in the interview context. Enabling each couple to maintain a central role throughout this study was also established through diary-keeping, photograph-taking, and participatory-mapping. These methods will be discussed in detail in the next sections.

At the end of each interview, the date for the next interview was made. However, participants could contact me to rearrange the next visit, discuss any matters arising, or have any questions answered between visits if they needed to. All the interviews were audio recorded and transcribed verbatim by myself.

3.8.2 Participatory Mapping
Participatory mapping as a tool for empowerment was utilised with the aim of enabling and presenting people’s sense of place and identity and their knowledge of their local community (Gessa, 2008; Pathways through participation, 2010). Participatory mapping is part of participatory learning and action which consists of various participatory
methodologies and approaches (Gessa, 2008). Participatory mapping has gathered increasing interest and there has been a greater focus on its development since the late 1980s, as mapping can be traced back from different sources, such as social anthropology and participatory action research (Chambers, 2008). Maps are a powerful tool as “maps are more than pieces of paper. They are stories, conversations, lives and songs lived out in a place and are inseparable from the political and cultural contexts in which they are used” (Warren as cited in Rambaldi, 2005, p.5). Drawing maps as a participatory exercise helps explore people’s knowledge, perceptions, and experience of their social and physical environments (Pathways through participation, 2010). This participatory exercise is often facilitated by ‘outsiders’ for knowledge creation (Chambers, 2006).

Participatory mapping has been widely used across many disciplines from community mapping to social network mapping (Gessa, 2008). For example, community mapping was carried out in Bassac to explore the issues of a Phnom Penh’s (capital of Cambodia) large, troubled, informal settlement where most of its 2,300 families lived without daily living essentials, such as water supply and electricity (WaterAid, 2005). This participatory exercise was led by a group of local leaders – Solidarity for the Urban Poor Federation – and was in line with the principles of community development to empower residents to have control over their land (WaterAid, 2005). The outcomes of drawing community maps by residents in 13 communities were used to negotiate with municipal officials and to identify solutions which could be beneficial for both local people and the wider city (WaterAid, 2005). This example illustrates that community mapping is not an end in itself, but a simple participatory mapping process which can inform and create valuable projects that bring benefits to people and places. In addition, a participatory mapping method was used in Emmel and Clark’s (2009) study to map participant’s social networks, neighbourhoods and communities. This approach enabled participants to move from a description of spatial practices in to elaboration and theorisation. The rationale of using the mapping method was to rapidly gain knowledge of a locality and map people’s movement around the local neighbourhood, which could demonstrate the relationship of mobility to interaction levels and reveal isolation levels. Moreover, Ward, Clark and Hargreaves (2012) used this method to explore the meaning of neighbourhood for carers of people living with dementia to gain further insights into the relations
between carers of people living with dementia and their neighbourhood for improving local support.

This PhD study adapted a participatory mapping approach, but distinctively, it was a co-constructive mapping process between participating families and myself to map out the physical construction of their defined neighbourhood and the activities they engaged with within their neighbourhood. This approach not only enhanced narrative agency for the person living with dementia, but also provided an opportunity to understand the interactions between participating families and places and if there was any effect on these over time. Mapping participants’ activities helped illustrate aspects of their life stories within, and their perceptions of, their neighbourhood. Mapping the activities of people living with dementia also demonstrated the current utilisation of community services and resources which would assist policy makers in proactively planning service provision through appropriate allocation of resources in the community. These activities were associated with the places and/or social ties. In effect, the co-constructed neighbourhood maps were graphic portrayals of the neighbourhood physical construction and/or social relationships. The visual representation of social networks are called ecomaps (Wright & Leahey, 2005).

Ecomapping is a valuable research method in eliciting social relationships and the nature of the emotional bonds within the networks (Rempel et al., 2007). In this study, ecomaps provided rich contextualised data in understanding how people responded to and approached people living with dementia and how each family assigned meanings to those who offered practical and/or emotional support to them. This indicates that the collaborative participatory diagramming process led to in-depth conversation and further disclosure of participants’ interactional experiences with their social networks. As a result, ecomaps illustrated participants’ supportive social networks both emotionally and practically over time and represented their lived experiences of dementia within their defined neighbourhood.

To begin the mapping process, participants were asked to plan a map before the interview. At the commencement of the drawing process, if participants were unsure about how to start the map, I encouraged them to think about drawing what they
thought constituted their neighbourhood and reassured them that there was no ‘right or wrong way’ of doing this, following the example of the mapping exercise used by Emmel and Clark (2009). To further assist the mapping process, I provided the couple with a blank piece of A1 paper, some coloured pens, and stickers; of course, the couple were free to add to, or not use, these items as they created their map. It was crucial that participants could choose the way in which they would like to produce the neighbourhood map so that it made sense to them and was shaped by their lived experiences of dementia, so capturing the meaning and place of their neighbourhood.

During the drawing process, four carers and one person with dementia took the lead role amongst the five couples, and I answered any questions they had on how to represent the information on the map. To ensure the equality and ‘fairness’ for people living with dementia in the participatory mapping context, I constantly encouraged the persons living with dementia to talk about the elements on the maps while the carers were drawing, this was to ensure these maps accurately reflected the neighbourhoods from the perspectives of the individuals living with dementia. By doing so, both the persons living with dementia and their carers had a say in controlling and shaping the neighbourhood maps during this co-production process.

Once the map had been co-constructed, interviews facilitated further discussion to elicit information on what was important on the neighbourhood map and why (Emmel, 2008). The co-constructed neighbourhood maps served as a catalyst for in-depth conversations. This co-created participatory mapping exercise illustrated the collaborative potential and the adaptation of the ecomap tool in recording each family social (support) networks over their life span. More importantly, the neighbourhood maps represented emotional bonds to the defined neighbourhood and helped uncover data that might not otherwise had been evident without using this participatory mapping method. The co-produced neighbourhood maps were then analysed in line with other qualitative data collected in this study, alongside the researcher’s reflections, to gain a strong sense of the participants’ activities and life stories and to understand their perceptions and experiences of living with dementia in a context of neighbourhood.
3.8.3 Diaries
The diary is considered as a means of elaboration and corroboration (Emmel & Clark, 2009) of everyday life of individuals with dementia. This method can produce a structured account of daily activity accompanied by interviews to generate discussion around sensitive issues (Emmel & Clark, 2009) and to capture rich insights into personal feelings and beliefs over a period of time (Bartlett & Milligan, 2015). Hence, the diary is an appropriate method to gain knowledge of how participants interact with their neighbourhood and engage in their networks and communities. The use of diaries, alongside interviews, is increasingly being labelled as biographical research and takes a holistic approach to studying personal life rather than a traditional one-to-one life story elicitation (Roberts, 2002). Diaries are seen as a form of ‘accessories’ to life, prominently supplementing the elicitation of the narration about people’s lives (Plummer, 2001) and they reveal significant insights into the lived experience of dementia. Within the new ‘technology’ arena, a diary can be kept through the use of digital devices, such as a computer or electronic tablet, like an iPad (Bartlett & Milligan, 2015).

In this study, the application of the diary method helped enhance the level of narrative agency for people living with dementia as it provided an additional means to structure the conversation, allowing for a more in-depth exploration of their experience. While I developed a diary template (Appendix 11) and provided it to participants to record daily activities, a flexible approach was adopted to allow participants to document their activities in the way they preferred, such as using the fixed template or free text format. This flexible approach provided options about how the participating families would like to record activities, and by whom. As a result, four couples - Mary and Steve, Patricia and Brian, Diane and Dave, and Jonathan and Jackie - kept diaries started after each couple’s first interview and it was completed before the last visit, whilst Emily and Tim’s preferred approach was to verbally describe their important activities from their second interview to the final one. Of these four couples, two kept their diary electronically: Jonathan used a computer and Brian used an iPad. The recorded activities were then collected and discussed further during the interviews with participating families. Data collected from diaries were incorporated into interview transcriptions and used in analysis. These discussions aimed to record as much data as possible about the life
stories and experiences of people living with dementia and to make sense of those activities from description through elaboration to theorisation (Dyck et al., 2010).

### 3.8.4 Photographs

Photographs are also seen as a form of ‘accessories’ to life and support the person-centred approach; photographs can be used to communicate meaning throughout the life course and enable others to see and feel as the participant does (Riessman, 2008). The use of images provides ways of collecting social sciences data to create a visual narrative and increases narrative agency for people living with dementia (Baldwin, 2006).

The use of images is historically grounded in sociology and anthropological research, especially ethnography (Banks, 2007). The applications of images were moved from following the principle of realist epistemologies as illustrations to being integrated into interpretation. This calls attention to “how and why the images were produced and read by different audiences” (Riessman, 2008, p. 142). Consequently, when telling a story, images are often used alongside spoken and written text and of course have particular benefits when working with people living with dementia by using visual narratives to supplement the traditional oral storytelling. For instance, photographs were used to provide partial accounts of the place, alongside walking interviews, to explore the complexities of living in networks, neighbourhoods, and communities in an inner city area with local residents (Emmel & Clark, 2009). Equally, photographs were previously used successfully to contextualise and map carer’s experiences of caring for a person living with dementia (Keady, Page & Hope, 2009), and photographs allowed for analysis of embodied participant’s behaviour and not just description on the views of the neighbourhood. For example, Diane and Dave (family 3) used photographs of a games afternoon, an event organised by the local village, to illustrate what they did, how they interacted with one another, and where the event took place.

The participating couples were asked to take pictures of the physical buildings and to demonstrate what was important to them in their neighbourhood. They were provided with disposable cameras or they could use their own digital camera if they wished. Photographs were selected by the couples to represent their neighbourhood. The
rationale for choosing those photographs and their specific meaning were then
discussed further. Having the power to take and choose photographs enabled
participants to retain control over their own stories, shaping the end narratives, and
making sense of their experience. By combining photographs with other methods,
participants’ narratives of their lives in and beyond the neighbourhood were presented
and produced (Clark & Emmel, 2010).

3.8.5 Demographic Information
Demographic data were collected from people living with dementia and their carers to
provide sensitising and descriptive data of each case. This data included age, sex,
diagnosis, time since diagnosis, ethnicity, education, employment, length of time in the
property, and housing tenure. This information was collected on a proforma data
collection sheet (Appendix 12) for each individual. The ‘16+1’ ethnicity categories, used
by the Office of National Statistics and the Department of Health for accessing diversity
and identity (Office of National Statistics, 2005), were adopted in this study to facilitate
comparisons across cases.

3.9 Data Analysis
Multiple sources of data increase the credibility of the research findings (Shenton, 2004)
and provide a deeper understanding of the lived experience of people living with
dementia and their carers in the context of neighbourhood (Bromley, 1986). This allows
an insightful appreciation of each case based on each couple’s real-world experience and
potentially results in new knowledge about their interactive activities with their
neighbourhood and associated meanings (Yin, 2012). However, the management and
analysis of the amount and variety of data gathered was one of the most challenging
aspects of this study. Yin (2012) recommends creating a formal case study database to
present multiple sources of evidence for each studied case, case files were then created
to keep records for each couple in both electronic and paper formats. All qualitative data
collected through this study were entered into NVivo 9 for sorting and storing, and I
used it to analyse data and explore recurring themes and linkages in the different
strands of data within and across cases. This helped me efficiently analyse and
triangulate the data at a more in-depth level for further interpretation. These multiple
sources of evidence are as follows:
- Audio recorded interviews and associated transcriptions.
- Diaries documented by the participants.
- Photographs taken by the participants.
- Co-constructed neighbourhood maps.
- DEMQOL questionnaire results.
- Field notes containing observations and reflections.

Narrative analysis is case-centred and pays attention to sequences of action (Andrews et al., 2013; Riessman, 2008). This analysis allows the stories to be seen from the perspective of both the researcher and participant to make sense of the person’s experience and claim their identity by telling, interpreting, and writing their story (Riessman, 2008). Narrative analysis is therefore the most appropriate method and used to reveal truths and make meaning of participant’s experience (Riessman, 2008).

A broad approach to analysing the narrative data was adopted in this study, consisting of narrative analysis within each case and in cross-case analysis. Within this approach, Patron’s four types of triangulation (1999) were employed to enhance the quality and credibility of data analysis and synthesis:

- Analysis within each case: ‘Methods triangulation’ and ‘triangulation of qualitative data sources’ were applied.
- Cross-case analysis: ‘Theory triangulation’ and ‘triangulation through multiple analysts’ were adopted.

3.9.1 Narrative Analysis within Each Case
A two-stage process was adopted when analysing data within each case. Firstly, thematic analysis was used when transcribing and analysing each transcript. This aimed to uncover themes within and between interviews to gain knowledge relating to the personal meaning of the neighbourhood and what each couple perceived as important to their experience of living with dementia. At this stage, a certain level of categorical content and categorical form analysis was applied by breaking the text into relatively
small units of content to learn, and create meaning, from the content itself (Williams & Keady, 2008).

Secondly, thematic analysis was used under a holistic approach to focus upon the narrative account as a whole and an individual’s storyline to establish its entirety about personal experience of living with dementia and how this affected the plot and direction of their identity and interactions with their neighbourhood. This incorporated a degree of holistic content and holistic-form analysis (Williams & Keady, 2008). This holistic approach helped enhance narrative consistency and coherency through assembling fragments, and improve narrative emplotment through accumulating relevant ‘small stories’ across space and time. These were associated with the person’s identity and interactions with the neighbourhood as a whole to understand and make sense of the person’s life story as a ‘big story’ (Baynham & Georgakopoulou, 2006).

Although the narrative analysis of textual data can be applied to the general analysis of content and presentation, visual data need to be analysed alongside the textual data; this analysis can be assisted by utilising a set of methods recommended by Riessman (2008, p. 144):

- The production of an image: Who the creator and subjects of the image are and where it was made.
- The content of the image: What the image includes and suggests in the context of the whole storyline.
- The reaction of the audience to the image: Responses and subsequent responses of initial and later viewers, how stories interweave with the image.

It is essential to implement a flexible approach to narrative analysis when accommodating the diversity of data sources, especially when more than one independent source points to the same accounts, stories, or interpretations, as this is where the most desired convergence occurs (Riessman, 2008; Yin, 2012). The analysis was performed through repeatedly viewing the visual data alongside other qualitative data collated in this study to evolve relevant concepts inductively and then to identify a sequence of relevant events to contextualise and explain the meanings of the visual data.
(Riessman, 2008). Take Jonathan and Jackie as an exemplar, they photographed a local park as a visual representation of their neighbourhood landmarks, while the diaries and interview data further explained how often and why they went to the park, with whom, and what it meant to them within their life experience.

Analysis of an individual case was performed through repeated listening to the interviews, reading the transcripts, viewing the visual data, and then deconstructing the narratives into stories that created ‘the whole’ (Riessman, 2008). In parallel, notes (or memos) were written down about each emerging storyline and themes through the use of NVivo 9. Here, it is worth noting that all the diary data were merged into the interview transcriptions as the main activities recorded in diaries were explored further during face-to-face interviews. That is, the analysis and presentation of interviews data covered diary data which were therefore not described separately in chapter 4 and 5.

The Dementia Quality of Life Measure (DEMQOL) consists of two questionnaires: one is DEMQOL, a 28-item interviewer-administered questionnaire for people living with dementia, and the other is DEMQOL-Proxy, a 31-item interviewer-administered questionnaire for their carers (Smith et al., 2005). Both DEMQOL and DEMQOL-Proxy include comparable psychometric properties to the best available dementia-specific measures and are appropriate to use for the individuals living with dementia with MMSE ≥ 10 (a mild to moderate dementia) in a UK context (Smith et al., 2005). However, this tool restricts dementia-specific measures to a limited timeframe (a week before the measure taking place) and encompasses the psychometric challenges of self-report in dementia. In addition, this tool is recommended for people living with mild or moderate dementia, so it is possible to say that this tool might not fully reflect the challenges faced by, and not be appropriate for, people living with severe dementia.

Despite these limitations, this tool was developed using gold standard psychometric techniques and has been tested and validated to rigorously measure health-related quality of life in dementia (Smith et al., 2005). So, to gain complementary views of quality of life in mild to moderate dementia relating to feelings, memory, and daily life, Smith et al. (2005) recommend that both measures are used together. In practice, DEMQOL and DEMQOL-Proxy have been widely applied in dementia research to
evaluate the effectiveness of an intervention. For example, Camic, Williams and Meeten (2013) used both measures to examine the effects of ‘Singing Together Group’ on the quality of life for people living with dementia at pre, post and 10-week follow-up of the intervention. Additionally, Orgeta et al. (2015) applied both measures to test the effectiveness of individual cognitive stimulation therapy for dementia at baseline, 13- and 26-week follow-up.

Therefore, it was appropriate to adopt DEMQOL in this study to descriptively compare the impact of neighbourhood on the participants’ quality of life and to explore potential changes in the quality of life of people living with dementia between the first and the last visits by focusing on issues beyond cognition (Smith et al., 2005). The results were combined with the qualitative data, the key factors that affect quality of life in dementia were then identified and understood. When obtaining the self-reported quality of life data, the DEMQOL and DEMQOL-Proxy questionnaires were administered by myself and completed by the persons with dementia and their carers respectively. However, when analysing the results of DEMQOL and its carer proxy version in the study, it is important to highlight that the outcomes did not highlight any differences between the two instruments. However, to enhance the lived experience of participants in this study, it was decided during PhD supervision to integrate these outcomes narratively into the Findings chapter of the thesis rather than reporting on them separately.

Once each dataset within each case was analysed, data analysis moved towards triangulation to synthesise multiple data and to increase the credibility of the findings within each case study. At this stage, Patton’s (1999) guidance on ‘methods triangulation’ and ‘triangulation of qualitative data sources’ was applied as follows:

- **Triangulation of qualitative data sources:** This applies to triangulating multiple sources of qualitative data by comparing and cross-checking of data gained at different times using a number of qualitative methods. In practice, for example, I compared the neighbourhood map with photographs and interview data, and I then checked the interview data for the consistency as each couple talked about their neighbourhood over time to draw thematic connections as well as
comparing the different points of views between the person with dementia and the carer.

- **Methods triangulation:** This refers to the comparison of qualitative and quantitative data: that is, a form of ‘comparative analysis’. This type of triangulation aims to provide a single, richer picture of the phenomenon. For instance, the use of DEMQOL and its carer proxy version was to measure the quality of life of people living with dementia. By comparing this kind of quantitative data with multiple source of qualitative data collected in the study helped clarify what was important for the person and how that impacted on their quality of life. This approach helped to illustrate the implications of, and rationale for, such categorisation. By following this process, a well-integrated picture of the lived experience of dementia could be provided.

3.9.2 Cross-case Analysis

Once the analysis of each dataset within each case was complete, cross-case analysis was applied to uncover recurring themes and to identify common, unique, or contradicting themes. Cross-case analysis helped gain an understanding of the differentiations and similarities between cases and how each meaning relates to a specific experience or event. These themes were then imported into Excel to compare the differences between cases and “to generate inductively a set of stable concepts that can be used to theorise across cases” (Riessman, 2008, p. 74). This process was guided by Yin’s (2009) recommendation that the data from each case can be displayed in a thematic framework for cross-case analysis in case studies. The objective of this process was to identify the main storylines and meta-messages across cases and contribute to the development of a theoretical model of people living with dementia and their carers interacting with their neighbourhood.

To ensure that an account is comprehensive and well-developed, once analysis of each case was completed and compared, work moved towards encompassing all the narrative data to triangulate across all the datasets across the five cases by further discovery of common and distinctive themes. Again, to increase the credibility of the results generated from cross-case analysis, Patton’s (1999) guidance on ‘theory triangulation’ and ‘triangulation through multiple analysts’ was utilised, as follows:
• Theory triangulation: This implies the use of different theoretical perspectives to review the data. The implementation of this type of triangulation in the study allowed me to look at the data from the perspectives of narrative, participatory, and environmental gerontology to understand not only the lived experience of each couple, but also the multiple dimensional relations between each couple and their environment. It also enabled me to balance the interpretation of the data from different perspectives, based upon my involvement with each couple and my experience of working with commissioners and policy-makers in the past: i) a researcher’s perspective to generate new knowledge to understand the phenomenon; ii) the standpoint of the person with dementia to understand the lived experience of dementia and what it meant to them; iii) the point of view of the carer to examine the experience of caring for a person with dementia and how it affected on the carer’s daily life; and iv) what the findings meant to policy-makers for actions.

• Triangulation through multiple analysts: Although the data collection and analysis was solely done by me as a PhD student, regular discussions and frequent reviews of case studies with my supervisors, provided a vital important check on the overall quality of data analysis and synthesis to increase the credibility of the thesis.

3.10 Rigour
It is significantly important to consider how the validity of this study can be achieved, and how the credibility and dependability of the data can be ensured in this research involving people living with dementia. To achieve this, Lincoln and Guba (1985) suggest that it is important to increase the amount of data, to increase time spent with participants, and then to triangulate all the data sources. These three elements were achieved in this study as follows:

• Multiple interviews: To gain sufficient data, the number of interviews with each couple ranges from nine to 13. The duration of the interviews lasted between 60 and 90 minutes, this ensured adequate time was given to the participants to explore each topic.
• Multiple data sources: The application of multiple data collection methods supported the narrative inquiry, and enabled interview data to be developed further and more meaningfully (Riessman, 2008). Hence, the use of a number of methods in data collection compensates for the limitation of each dataset and exploits their potential benefits to increase the credibility of the research (Shenton, 2004), which leads to the provision of a more complete picture of the lived experience of dementia.

• Prolonged contact: The long-term contact enabled me to build good rapport and trusting relationships with these families and to develop an in-depth understanding of their lives. This prolonged contact contributed to the credibility of the findings (Erlandson, Harris, Skipper & Allen, 1993; Lincoln & Guba, 1985).

• Cross-case analysis: By using multiple readings and triangulation of all the data sources, I gained a comprehensive picture of the meaning and construction of the neighbourhood for each family and their neighbourhood-interacting behaviour (Moore & Hollett, 2003; Morris & Field, 1995). Triangulation of multiple datasets can increase the reliability and credibility of the data (Shenton, 2004; Tellis, 1997).

• Further exploration of the data with my supervisors: Regular supervision sessions provided me with an opportunity to explore and discuss the data with my supervisors to further refine the key themes within and across cases.

3.11 Ethical Considerations

3.11.1 Capacity to Consent and Use of Data
Participants entered into the research of their own free will after being fully informed of its nature, process, and any potential benefits and risks. Written, informed consent was obtained prior to participation in the study. The method of process consent (Dewing, 2007), consisting of five elements detailed in Figure 3, was applied throughout the study with the participating people living with dementia. In addition to the method of process consent (Dewing, 2007), the Mental Capacity Act 2005 was adhered to in order protect the participant’s right to autonomy.

All participants consented to the use and inclusion of all the data collected in this study. Data confidentiality was assured and storage of data followed the guidelines set by the
Data Protection Act 1998 and the Freedom of Information Act 2005. All data collected as part of the study were stored and transferred securely in accordance with the research protocol and audio recording and transcriptions were stored in separate, password protected files on a secure computer. All data were encrypted. Identifiers were held in a separate database and linked through a case number. All data could only be accessed by me and my supervisors; this was to ensure the confidentiality of the obtained data.

Figure 3. The Detailed Process of Gaining (Ongoing) Informed, Written Consent

1. **Preparation and background: Gain permission to access people living with dementia**
   - Identified clinicians as ‘gatekeepers’.
   - Provided clinicians with information sheets and consent forms and explained the study and inclusion and exclusion criteria.

2. **Establishing basis for consent**
   - Contacted and met with participants to discuss the study and their participation, once initial interest was expressed.
   - Answered any questions they might have.

3. **Initial consent**
   - Gained informed, written consent from people living with dementia and their carers.
   - Reinforced the right to withdraw from the study at any point.

4. **Ongoing consent monitoring: Continually assess the choice of people living with dementia**
   - Obtained informed, written consent from people living with dementia at each visit to ensure they had the capacity to continue in the study.

5. **Feedback and support: Maintain an audit trail to explain what decisions were made**
   - Kept the copies of the signed consent forms as the evidence.
   - Wrote field notes to illustrate how the decisions were made.
3.11.2 Participants and Researcher Safety

Although participant’s comfort and safety was considered in the research design, it was possible that the topics addressed in the interviews could potentially be upsetting to participants. The study protocol outlined that if participants became upset or showed signs of distress, they were treated sensitively at the time and asked if they would like to stop the interview for that day and reschedule for another day. Participants could also be supported by their clinicians, and any participant distress would have been reported back to them. However, no interviews had to be terminated due to distress and all participants were willing and able to continue for the full duration of the study. In retrospect, the interviews were well received by all the participating couples and appeared to help build their well-being and confidence, and no unexpected ethical dilemmas were encountered.

During my involvement with the five couples, it was possible that I might have found some of the conversations or situations distressing. To address this, specific times were scheduled with my supervisors to allow me to discuss any aspects of the study that were distressing to me, whilst maintaining participant confidentiality. To take an example of maintaining professional boundaries, good rapport was established with the participants to gain in-depth insights into their lives. This meant that after the data collection was completed some participants desired to maintain frequent contact with me. However, as this was a professional relationship it was important to remind participants of this aspect of the relationship; so, I was unable to view this as a friendship. Maintaining this boundary when the study ended was emotionally difficult for me and I observed that it was difficult for some of the couples too. To maintain this professional boundary whilst recognising that there had been an emotional connection between us, I gave each family a ‘thank you’ card and a bunch of flowers as a way of saying ‘thank you’ and closing the relationship.

Lone field working also contained risks; so, I strictly adhered to the School of Health Sciences’ lone fieldworker policy. I also took into consideration other factors, such as limiting interviews to times where I could get home reasonably safely after dark and making colleagues and/or relatives aware of what time I would be expected to return.
3.12 Summary

Narrative inquiry was adopted as a methodological frame to study how the factors of temporality, sociality, and place related to the living experience of people living with dementia and their carers. In addition, participatory methods conducted longitudinally as an approach to research engagement was employed to enable the voice of people living with dementia and their caregivers to be valued and heard. This combined approach was consistent with the epistemological and ontological approaches.

The use of multiple data collection methods was innovative and co-constructive, it allowed for an in-depth understanding of the lived experience of dementia via the lens of neighbourhood, and provided participants the opportunity to maintain control over their stories. The combination of the holistic and categorical approaches to narrative analysis allowed for the examination of narrative accounts for each participating couple and resulted in an accumulation of detail that was assembled into a ‘fuller’ picture of the daily life of people living with dementia in the context of neighbourhood. This was then followed by triangulation to synthesise multiple data and to increase the credibility of the findings within and across each case study, and ultimately contributing to developing a theoretical model of people living with dementia and their carers interacting with their neighbourhood.
Chapter 4
Findings: Co-constructing Neighbourhood Maps with Five Families

4.1 Introduction
This chapter will start by presenting the five case studies in greater depth and will describe this following an iterative and sequential manner starting with the first family recruited into the study and ending with the last recruited family. Each couple’s story is presented in a similar format using the same headings - ‘background’, ‘family and relational dynamics’, ‘mapping the neighbourhood’, ‘explaining the neighbourhood’, ‘initial impressions of the neighbourhood’, and ‘summary’ - but, of course, the details under each heading are different due to the variation in each couple’s approach to co-constructing and representing their neighbourhood map. At the end of the chapter, a summary will be presented in preparation for a cross-case analysis.

4.2 Presentation of Case Studies
For the purpose of consistency, each case study is presented under the same headings, emphasising the past, present, and future storylines of living with dementia via a neighbourhood lens, and each case was analysed using thematic narrative analysis, in line with triangulation detailed in section 3.9.1. This approach to presentation and analysis allows for subsequent cross-case analysis. Each case emphasis in the writing is placed on the creation and pictorial representation of the neighbourhood maps with data collection led by the persons living with dementia and/or their carer. Each case study will first describe the family and rational dynamics that influenced how each couple understood and defined their neighbourhood. This is followed by presenting the personal meanings of the neighbourhood and its visual representation within a temporal perspective, before moving on to demonstrate how each couple interacted with, and attached to, their neighbourhood in the specific social context. This is followed by illustrating the initial impressions of the neighbourhood for each case and moving from a descriptive to an analytical level of understanding the dynamic, multi-layered relations between participants and their neighbourhood by linking theory to each presented case. The couple-based case will then conclude with a summary of its key storyline to prepare for a cross-case analysis. The five case studies are presented in one chapter to demonstrate continuity and development.
The five case studies are written in the first person as the neighbourhood maps were co-constructed by the participating couples with my support, as described in section 3.8.2. Whilst my general guidance on the mapping processes and provision of materials for drawing the maps remained the same, it was not prescriptive. In other words, co-constructive neighbourhood mapping was a creative process and it allowed flexibility to empower the couples to remain in control during the knowledge production process. These co-constructed neighbourhood maps were supplemented by photographs which were taken and chosen by participants to illustrate what was important to them. The production and selection of photographs also enabled participants to make choices and to have control over their own stories. This whole innovative, participatory exercise empowered participants to visualise their neighbourhood and to make sense of their own life stories, and more importantly, to take an active role in knowledge creation.

The language used by the couples has led to an interpretation of ‘belonging’ through the use of words that represent their feelings of close bonds to their neighbourhoods. For example, the use of ‘my’ and ‘our’ denote personal identification and ownership, i.e. “this is my neighbourhood”, “it’s mainly these sort of three streets, three or four streets really. I’d call my neighbourhood”, and “it [the garden] is important to our bit of life”.

In line with the study protocol and the Data Protection Act 1998, all names have been anonymised by using pseudonyms. The case studies are organised into a time sequence in the order that each couple was recruited into the study; each case is presented separately to maintain the integrity of each couple. This approach provides an opportunity for the researcher to reflect and comment on preceding case(s) and to build analysis within and across the five cases.

4.3 Case Study 1 – Mary and Steve

Main Storyline: Home Matters

4.3.1 Background

Mary and Steve were the first couple recruited for this study, and I visited them at their home 12 times during a one-year period between June 2011 and May 2012, and a total of 13 hours and 41 minutes was spent collecting data with them for this study. A
detailed description of the main activities undertaken with Mary and Steve on each visit is shown in Appendix 6.

At the time of recruitment, Mary was 86 years of age and lived with her 86-year-old husband, Steve. They married in a village church in 1944 and had been living in their current owned, semi-detached bungalow since 1958. The couple’s property was located in recruitment area A, which was an urban area and about four miles away from a main town centre. One third of the local population where the couple lived were retired (Office for National Statistics, 2011). Mary and Steve described the area as: “it’s nearly all older people [who live here], nearly all widows actually”, because “they are bungalows” (transcript: 03/06/2011).

After living in the bungalow for 54 years, Mary and Steve described their property as: “...the best thing we have done in our life” (transcript: 03/06/2011). One key reason for their positive perception was because of the greater impact of the arthritis on Mary’s mobility, and Steve described her mobility in the following way: “she has a job to get from room to room [so] what would she be [like] living in a house?” (transcript: 03/06/2011). Living in the bungalow, and therefore without stairs to negotiate, enabled Mary to move around their home with the assistance of a walking stick. This support aided her mobility and helped maintain as much independence as possible at home. Mary’s arthritis caused her considerable and constant pain, and she described her experience of the pain in one of her fingers as: “it’s in pain all the while, even in the night if I wake up it’s still in pain and I very often will sit down and I hold that finger and then I have a little go with it to try and keep it” (transcript: 24/06/2011). This constant pain had a knock-on effect on her daily quality of life. Mary’s decreased mobility was also compounded by her late-onset Alzheimer’s disease. In addition to the Alzheimer’s disease and arthritis, Mary also had cataracts and a heart condition; the latter required her to wear a pacemaker. Overall, Mary’s physical health was, perhaps, best described as frail.

4.3.2 Family and Relational Dynamics
Mary’s declined mobility was primarily caused by her arthritis and further compounded by her Alzheimer’s disease which was diagnosed in 2010. The diagnosis of Alzheimer’s
disease was well accepted by the couple as they had both noticed some early symptoms with Mary prior to the diagnosis. Irrespective of what the literature may say, Mary and Steve also felt that it was ‘normal’ to have dementia at their age. However, despite all the physical and cognitive difficulties Mary endured, there was a degree of personal fulfilment in her life, as she shared: “I can walk down there [the hall], I’ve got a pusher [a lightweight four-wheeled walking frame], I’ve got the sticks so I’ve got everything I need in that respect” (transcript: 03/06/2011). To further exercise her autonomy, Mary tried to keep as active as possible around the home, such as doing all the washing-up and walking around the bungalow and/or the garden every hour or so. Walking around the garden and physically engaging in this outside space was particularly enjoyable for Mary.

In terms of the family structure and its dynamics, Mary and Steve had one child, a daughter named Whitney, who usually came to see them once a week and helped Mary set her hair. If Whitney was away, Steve’s niece, who was his brother’s eldest daughter and Mary’s goddaughter, came and helped Mary with her hair. Steve’s brother looked after three girls and one boy on his own after his wife had died when she was fifty. From Mary and Steve’s standpoint, children were a strong focus in a family: “… as long as the children have turned out all right, they’ve not been in trouble they are all happily married” (transcript: 03/06/2011), this view seemed to help compensate for the loss of a family member. Although Mary and Steve perceived their daughter as significantly important to them, they did not have as close a relationship with Whitney as they would have liked. For instance, the couple described that they were recently not invited to Whitney’s birthday party, even though they had offered to take a taxi the short distance to their daughter’s home. In contrast, the parents of Whitney’s husband had been invited and that upset Mary and Steve further. This family conflict had a significant emotional effect on the couple who described their feelings as: “we were upset all day long and never slept at night … as we were so gutted … nearly in tears” (transcript: 20/04/2012).

While there was a degree of non-inclusion from Whitney towards her parents, Mary and Steve appreciated Whitney’s help and support with their essential requirements of daily living, such as helping them with the weekly grocery shopping, even though there were concerns in that she did not buy what the couple wanted; spent more money on items
than they used to; and just dropped the shopping off without stopping to spend time and chat to them. As Mary and Steve’s only means of income was a state pension, this was a challenging situation for the family. My personal observation and reflections about the family’s relationships were recorded in my reflective notebook on the 20\textsuperscript{th} April 2012:

“Steve was a very positive person and always kept and expressed his sense of humour, even with unwelcome situations. However, his disappointment and unhappiness with their only daughter was obvious. This was partially because that they felt that they had done a lot for her, but the return seemed very little from their perspective. Such view further reveals their preference of seeking and receiving support from the family.”

This underscores a sense of loss and sadness, and such feeling was also extended to their granddaughter and her family when they moved to America for work as Mary and Steve were particularly attached to their great granddaughter who was only three-years-old at the time of the move abroad. The couple missed them a great deal and Mary spoke of their hope at seeing them at Christmas:

“You see the granddaughter, she is working a bit further away, passed New York like, and so of course you can’t expect her to phone much or to come, she promised she said coming home for Christmas. She keeps saying that so we are praying.” (transcript: 24/06/2011)

Despite the existing family dynamic, at the end of my third visit on the 22\textsuperscript{nd} July 2011, through detailed discussions, I produced the couple’s family genogram as shown in Figure 4.

When discussing the family structure, Mary and Steve reiterated how their life had been centred around their family in the past and the enormous changes they had experienced in being ‘pushed away’ from their family since Mary had become less mobile. Overall, Mary and Steve felt that they were segregated from their family, particularly from their only daughter, Whitney.
Figure 4. Structure of the Family of Mary and Steve
Receiving less support from the family and being a main carer, Steve felt that it was hard and stressful to look after Mary all the time. Steve strongly believed that there was a general lack of understanding about what it was like when living with someone with dementia. He indicated his main struggle with Mary was caused by her short-term memory loss, even though he understood the rationale for her behaviour, expressing his feeling of guilt and empathy in the following way: “she just can’t help it, but it drives me mad. She forgets things in five minutes” (transcript: 03/06/2011). When discussing how Mary felt when Steve became upset because of her lost short-term memory, Mary gave a matter-of-fact response: “I don’t take any notice really” (transcript: 03/06/2011).

As well as taking on the main caring role, Steve also took up new responsibilities, whilst Mary had given up certain roles in their relationship structure. Steve became responsible for the couple’s finances, managing all the bills, and doing most of the domestic chores, such as washing the clothes, hoovering, and cleaning. Despite that, Steve appeared quite stoic in performing these tasks, even though he struggled at times because of his own advanced age and health needs; for instance, due to breathing difficulties and pain in his knee joints, Steve had to sit down and rest after vacuuming half of the bungalow. The motivation for him to undertake these tasks for as long as possible was his belief: “it was good exercise” (transcript: 24/06/2011). Meanwhile, Mary tried to help him as and when she could, such as preparing the vegetables for dinner. Through it all, Mary and Steve had altered the degree of reciprocity and bonded through the experience of living with dementia as Steve repeatedly mentioning: “I’m the best husband she’s ever had.” After 67 years of marriage, that was a moving and humorous testimony.

4.3.3 Mapping the Neighbourhood
4.3.3.1 Personal Meanings
After expressing satisfaction with their home, Mary and Steve were happy to engage in a conversation about their neighbourhood and what it meant to them. This conversation commenced from my second visit onwards and the couple presented a very neat and coherent understanding of a neighbourhood: “surely a neighbourhood is what’s near you?” (transcript: 24/06/2011) and, further, “how far you would go to know people” (transcript: 25/11/2011).
This understanding emphasised two important elements: spaces and/or places within a close geographical distance of their bungalow and people they knew. On this basis, Mary and Steve felt that their neighbourhood was a restricted and defined part of the street in which their property was located, comprising a few neighbours who lived nearby, a school opposite their garden, and a local shop. This neighbourhood understanding was also informed by the couple’s long association in the street in which they lived as they had seen many changes to neighbours and architecture and felt that “the local residents did not engage with each other as it used to be many years ago” (transcript: 25/11/2011). Mary and Steve thought that this lack of community interactions, when comparing to their remembered community, was caused by two main factors: first, the demands of employment which took people away from their homes during the day; and second, the rise in car ownership which made residents much more mobile and meant that neighbours could find opportunities to socialise outside of their immediate surroundings. These factors limited the number of people the couple knew and reduced the opportunities for them to interact with others. Mary and Steve cohesively summarised their nostalgia by reminiscing about the past as follows:

“Everybody should be friendly but it’s changed, it used to be like that years ago ... people didn’t have cars so they probably had to walk up the street to get a bus and that’s when you used to talk to your neighbours... It’s entirely different to like it used to be.” (transcript: 25/11/2011)

Apart from these perceived changes, the couple’s personal factors, multiple chronic conditions, and old age, influenced their daily life and choices enormously and meant that they were no longer as visible in their neighbourhood as much as they had been previously. In effect, their neighbourhood had shrunk to such an extent that the bungalow had become the main focus of Mary and Steve’s neighbourhood.

Despite the couple’s compact neighbourhood, they were happy with where they lived: “we are very lucky because the street is quiet and it’s quiet out the back, so we are quite lucky how we are situated” (transcript: 23/03/2012). The couple gave a detailed account about why it was quiet ‘out the back’, which referred to their garden, as:
“The only thing we say which is nice to think you look out to a field instead of a load of houses ... It could be people who live at the bottom of your garden and they might be unruly, they might be noise or anything. We’ve got none of that trouble. We’re lucky because it’s so peaceful here.” (transcript: 20/04/2012)

The word ‘quiet’ referred to a sense of being away from ‘noise’, which the couple perceived as ‘trouble’. This ‘quiet’ neighbourhood enabled a sense of tranquillity where they were better able to enjoy their garden.

4.3.3.2 Visual Presentation

After discussing Mary and Steve’s understanding of neighbourhood and its personal meanings for them, we started to co-construct a map of their neighbourhood for visual representation of their everyday experience. This process started on my sixth visit, and the couple followed my general guidance and used the materials I provided as detailed in chapter 3. Steve took the lead role in constructing the neighbourhood map, whilst I encouraged Mary to express her thoughts to ensure that the map was also representative of her view and experience. The map was put together on a small table in Mary and Steve’s sitting room where the three of us sat together around the table.

Initially, and mirroring our earlier discussions, Steve drew their own property and a few neighbourhood houses where their close neighbours lived and associated house numbers. Steve also drew a school on the neighbourhood map as they both agreed that the school was part of their neighbourhood. When the weather was nice, they both enjoyed sitting in the garden and watching children playing football on the playing field in the school. In addition, as Figure 5 indicates, the neighbourhood map included a local shop which was two streets away from Mary and Steve’s home. Whilst Mary was unable to get to the shop on her own, she felt that the local shop was ‘useful’ and ‘not far from their bungalow’. Furthermore, as Figure 5 reveals, Steve also drew a church on the map although this church was not near their home.
Figure 5. Mary and Steve’s Neighbourhood Map
Getting to the church meant they had to use a door-to-door bus service, but this was where the ‘Friendship Club’ took place, and the couple attended this club every Friday to meet other members. Since my third visit, Steve had stopped driving caused by his advanced glaucoma, so travelling to the church was the only social event in which the couple participated.

In Figure 5, Mary and Steve included the place where their best friend lived, named as ‘Friend A’ on the neighbourhood map, regardless of the location being much further away from their property. This signifies the importance of the strong social ties in their lives. Interestingly, the couple did not include their daughter as part of the neighbourhood even though Whitney’s house was close to the church. This omission could be explained by the conflicted family dynamics and demonstrates the importance in understanding what is not included on the map as much as what is present.

It was a deliberate decision by the couple that the drawing did not represent the actually physical dimensions and distances of the neighbourhood, and was, instead, a collected representation of people and the places that were important to them. On the neighbourhood map, the names of the couple’s neighbours have been redacted for the purpose of anonymity, and Mary and Steve’s location is labelled for easy, visual identification.

4.3.4 Explaining the Neighbourhood

After co-constructing the neighbourhood map, Mary and Steve felt that it was crucial to further explain how they connected to the places and people which were important in their daily life. Based on our early conversations, the couple spent most of their time staying at home, and Mary placed a major emphasis on the window of the sitting room, facing the main street, mentioning: “I spend hours looking out that window there [Mary points to the window in the sitting room], what else can you do?” (transcript: 25/11/2011). ‘Home’, as a context, featured in Mary and Steve’s feeling of being lonely and lack of social engagement, in spite of their satisfaction with ‘home’ as an object. This descriptive narrative is also presented in the photograph taken by the couple, and shown in Figure 6 that represents their neighbourhood. Steve further explained the
internal descriptive narrative of the photograph of their front room with these words: “that’s to let you know that we’re imprisoned. You see that’s the cage all-round the prison” (transcript: 25/05/2012).

Figure 6. Front Room

The couple had come to view their home as a prison and it was their declining health that had locked them indoors. This loss over the years was framed around decreasing friendships, mobility and neighbourhood engagement. Specifically, Steve shared that a primary reason for them no longer going out as frequently as before was his inability to drive: “people don’t realise how convenient it is to have your own vehicle, and once you lose it, it’s like losing your right arm, especially when you’ve been driving over 60 years” (transcript: 16/08/2011). This further attributed to their lack of social integration. While Steve spoke of a ‘cage’ at this point, he was specifically referring to the photograph of their living room (Figure 6) which hinted at the oppressive way they viewed the progression of their conditions.

Although Steve expressed his feeling of being restricted by likening their front room to being as a ‘prison’, the couple were still able to gain a sense of enjoyment by staying in
their garden. In this respect, the couple shared with me a long story about their garden, which was situated at the back of their bungalow and provided them with a pleasant outlook. Steve took me to their garden and showed me their summerhouse, as shown in Figure 7.

Figure 7. Summer House

This summerhouse held a key position in the couple’s daily life and captured specific meaning particularly for Steve who had built it 50 years ago, so he was very proud of it. In addition to the summerhouse, Steve’s role of being actively making their own places was also extended to the whole garden as he shared, when he walked me around their garden, saying: “I’ve always kept the garden nice, always. It is the first time I’ve had somebody to help me this year” (transcript: 03/06/2011). In this text, he used ‘always’ twice to illustrate his passion about, and how much effort he had made for, the garden. Unfortunately, due to his declining health, and for the first time in his adult life, Steve had to hand over some of his independence and employ a gardener to help him out. Speaking to Steve, it was clear to see and hear his feeling of disappointment about this situation. In other words, his decreased health was restricting him from doing what he used to do, and this change challenged the maintenance of autonomy, and continuity of biographical interest, of someone who “always kept the garden nice, always”.

However, this challenge did not diminish the enjoyment and pleasure the couple gained simply from being in their garden. From Mary’s perspective, she felt that sitting out
there was ‘so peaceful’ and reminded her that they had “worked hard to get all this” (transcript: 24/06/2011). As shown in Figure 8, by being in the garden the local secondary school can clearly be seen, and this environment gave Mary and Steve a sense of enjoyment and was also the place to which they felt emotionally connected.

Figure 8. The View of the Local Secondary School

Mary and Steve enjoyed seeing the school and the view of a field: “we were very lucky when we were able to get this place” (transcript: 20/04/2012). The couple further shared that they gained a great deal of pleasure from watching the school children playing football on the field as a way of connecting to their neighbourhood. It was apparent that the garden and outside spaces played a crucial role in the couple’s life and illustrated how they were attached to this place all year around, even in the winter as shown in Figure 9. Mary expressed her feeling of seeing the snow and the reason the couple captured such a scene: “I can’t believe we had snow... that’s a nice one ...” (transcript: 25/05/2012). Mary’s emotional connection to this specific feature of the garden also brought her pleasure in winter, when it might be thought that the garden was of less value given the lack of flowers and colder temperature that might preclude them using the garden.
4.4.4.1 Interaction with the neighbourhood

Although Mary and Steve stayed at home for the majority of their time, after living in the area for a long period, they had established close relationships with a few neighbours who lived nearby. One neighbour who lived in number 91 was Fiona, and she was a widow and had two dogs who helped keep her company. Fiona came to visit Mary and Steve once a week, and the couple believed that she was the closest neighbour for them. They looked out for one another; for example, if the couple had not seen Fiona for a few days, Steve would call at her home and ask her to come over, or vice versa. When people come to visit the couple, as Steve mentioned: “she [Mary]’s a different person, she’s happy, she’ll talk and joke and everything, but when they’ve gone or before they come then she’s so miserable at times” (transcript: 25/05/2012). This clearly illustrates how important meeting and talking to people was for the couple, particularly for Mary, and its positive impact on her.

Mary and Steve also kept regular contact with other neighbours who supported them in a number of ways. For instance, another close neighbour, Ben, was living with his wife in number 95, on the opposite side of the road from Mary and Steve’s property. Ben sometimes helped them with any plumbing issues, such as fixing the bathroom taps. The third neighbour was Tom who was living in number 114 and helped Steve to take the ‘wheelie bin’ up the slope every week as Steve had issues with his breathing. Tom also offered to do grocery shopping for the couple. They felt that the neighbours were very helpful and provided them with essential support in their day-to-day life. This reveals the
crucial role of the small neighbourhood support in meeting the couple’s daily needs. This also perhaps highlights for the couple the difference between the support, emotionally and practically, they received from their neighbours and from their daughter, Whitney.

The last neighbour included in the neighbourhood map was Sue who was a widow and living in Number 118. Sue sometimes had a chat with Mary and Steve over the fence. The couple described how Sue went out nearly everyday, such as going to visit friends, and they believed that Sue disliked being at home on her own, and this perhaps was a projection of their own feelings. The feeling of loneliness and being at home on their own had become more apparent since Steve was no longer able to drive, and this led to even less social participation. Mary and Steve were more aware of Sue going out regularly because they were no longer able to. It was clear that being able to access alternative transport was crucial for the couple to exercise their agency in regard to socialisation. In fact, they could not use local public transport close by as the bus stop was located on the top of the street, which also meant at the top of the hill, and it was impossible for Steve to push Mary in the wheelchair to get there. For Mary and Steve, an even pavement and flat ground were vital for them to access and use local services. Fortunately, there was a local door-to-door bus service that acted as a means of enabling them to engage with some social activities, such as attending the Friendship Club.

Mary and Steve’s attendance of the Friendship Club, which was held at a church every Friday, was the only routine social participation for them. As explained earlier, this location was identified as part of the couple’s neighbourhood, even though it was approximately four miles away from their bungalow. The couple went to the church to have a dinner and talk to the members of the club for a few hours. This club not only provided opportunities for older people to meet, but also organised various entertainments or events, such as having a choir, giving members the ability to share their own stories, taking the members for a ride out in the country, and going to the pantomime at the local theatre at Christmas. The club was socially structured by age, and this age construction seemed to be a positive aspect when Steve recalled the moment of listening to music at the club, he described the music as: “it’s our sort of music not the pub music, everybody loved it” (transcript: 12/01/2012). This age
constructed interest entailed a detailed and thoughtful planning by the club’s organiser(s). From Mary and Steve’s perspective, people who joined the club were similar to them who “hate the evenings [of being] shut away from everybody” (transcript: 03/06/2011). By attending the club, it not only provided opportunities for Mary and Steve to socialise with people, but also enhanced chances to make friends and break the sense of loneliness they felt. Socialisation and friend-making formed their social interactions and gave them a sense of purpose, enjoyment, and biographical continuity.

The significance of socialisation and friendship for Mary and Steve was further illustrated by the inclusion of their best friend, Catherine, as part of their neighbourhood. Steve used to work with Catherine who moved to Majorca in Spain years ago, but she came back to the UK to visit her family a few times each year. While in the UK, she often stayed in her son’s house which was near the church. The couple kept in regular contact with Catherine, and on my second visit, which was Mary and Steve’s wedding anniversary, Catherine telephoned them to give them her congratulations. The couple felt so excited about this and told me that: “she’s just phoning up and she remembered our anniversary, wasn’t that marvellous?” (transcript: 24/06/2011). This excitement was derived from ‘being remembered’, which gave them a sense of social belonging.

Apparently, not long after this telephone conversation, the doorbell rang and Catherine was standing there after coming straight from the airport; she had planned the whole thing and the telephone call was part of the ruse to hide the fact that she was going to be visiting. She even knew that Mary and Steve would often sit and watch people walk past their drive, so Catherine took care to approach the house so that she would not be seen. A few days later, Catherine called on the couple again and took them to the town centre to have a dinner, somewhere they had not been for six months. This triggered Mary and Steve to reflect on the relationship they had with their daughter and felt that Whitney should be doing this for them rather than their friend. For Mary and Steve, the family relationship was not as close as they expected and this could be one reason for why they did not include the family as part of their neighbourhood, though the physical distance could be another attribute.
4.3.5 Initial Impressions of the Neighbourhood

Mary and Steve’s daily lived experience seemed to be mainly focused on their home although they maintained close relationships with a few neighbours. These near neighbours helped the couple as and when they could and became a small support network for meeting some of their daily needs. This enabled the couple to feel part of their neighbourhood social network and improved their living experience as they aged. It was worth noting that the support, which stemmed from their neighbourhood community, could not replace the expectation of support from their family, especially their daughter. For the couple, it was as if their emotional needs appeared to have been neglected by their closest family and were being partially met by their neighbours. Emotionally, the couple desired to be close to the family, practically, the adjacent neighbours were closer. This reality conflicted with the couple’s traditional view of family being the first source of help and challenged their preference of seeking and receiving support. Nevertheless, the support that Mary and Steve received from their family and neighbours played a significant role in enabling them to live independently at home for as long as possible.

Due to multiple physical conditions, the couple’s chances of going out and about were severely restricted; this further limited their social participation. In other words, Mary and Steve spent the majority of their time at home. Thus, their neighbourhood was very much centralised around their home, with Mary spending most of her time sitting in the room and watching the world through the window, as she shared: “I never thought sitting here I could see somebody coming, I could if I thought… I see somebody coming down the drive and I used to say to him [Steve] the doorbell will ring soon somebody’s coming down the drive” (transcript: 24/06/2011).

The window in the couple’s front room seemed to be the main channel for Mary to connect and re-connect to the outside world, and indeed, when I came to visit them, she could see me walking towards them down the drive and Steve would open the door for me. This signified the importance of meeting with people for the couple given they had to spend so much time in the home. The process of interaction for the couple did not occur when the person arrived at the home but began as soon as (s)he was seen approaching up the drive. Staying at home most of the time and being unable to do what
they used to do or visit places they used to go to were clear challenges to their autonomy and their biographical continuity. Such discontinued biographical activities affected their lived experience and increased the level of loneliness.

However, the limited social participation did not mean no social engagement at all. They did undertake a regular social activity by going to a local church on Fridays to attend the Friendship Club. Regularly going to the church and meeting with others enabled them to engage with people and the place both physically and emotionally. Attending the club held a sense of purpose for getting ‘out and about’ and facilitated their social interaction from which they both gained a great deal of enjoyment. Such positive interaction and frequency of usage increased their level of appreciation and encouraged their commitment to re-connect to the place and so form emotional place bonds. These bonds further shaped Mary and Steve’s interchange with their defined, self-constructed neighbourhood. More importantly, the club organised group-based activities for older people with or without dementia to have shared and collective experience and promoted their social participation to construct important aspects of social citizenship.

Further to the functional declines, the decreasing social engagement of Mary and Steve was also caused by the death of same aged peers, as Steve said: “the trouble now is that we’ve lost all our friends, they’ve all passed away” (transcript: 03/06/2011). The term ‘trouble’ was used by Steve to express his feeling about their current situation regarding their loss of friends and how their future would mean becoming even more lonely. For the couple, having friends was of great importance for them, and would explain why they included their best friend as part of the neighbourhood, though this friend lived a great deal further away from their home than the other places included in their neighbourhood.

In conclusion, the couple’s perception of their neighbourhood was focused upon ‘what’s near’ to them. This can be interpreted from two perspectives, geographically and emotionally. A few close neighbours, a school, and a local shop were the demonstration of the first perspective, whereas the church that hosted the Friendship Club, and their best friend were the second. More importantly, due to the significant decrease in their
social participation over the years, ‘home’ had become an increasing focal point of the couple’s neighbourhood.

4.3.6 Summary
Over the year of my engagement with Mary and Steve, their defined, self-constructed neighbourhood referred to a neat social network, and the places – a school and a church – where the couple’s emotional bonds were established and strengthened. Interactions with the neighbourhood social network played a major role in the couple’s daily life and enabled them to feel part of their neighbourhood, whereas negotiations with the neighbourhood places developed a sense of familiarity and emotional bonds over time. These feelings gave Mary and Steve a sense of purpose and belonging. These important feelings influenced how the couple constructed their neighbourhood in time and their experiences of interactions with their defined neighbourhood contributed to, and shaped, their personal biographies over time.

‘Home’ gave Mary and Steve a strong sense of belonging which derived from the rich collection of memories over their life span, but ‘home’ was also perceived as a ‘prison’, constructed by their declining chronic health conditions. This metaphor indicates the oppressive feeling of being restricted at home and their loss of liberty. Therefore, Mary and Steve’s self-defined neighbourhood was a complex construction: on one hand, the couple were still happy with having the bungalow itself; on the other hand, they also had the desire to continue their biographical recreation by being out of their home, participating in activities, and going to places. This complex construction was shaped by their closeness towards people and the places at both emotional and geographical levels, and by the support gained from their social network within the neighbourhood. In fact, the couple’s neighbourhood boundary had shrunk, and would continue to shrink, caused by various factors. However, the level of support they gained from their family and neighbourhood community would continue to impact upon their neighbourhood construction, the greater the support the wider the neighbourhood construct.
4.4 Case Study 2 – Patricia and Brian

Main Storyline: Friendly but Fairly Remote

4.4.1 Background

Patricia and Brian were the second couple recruited in this study, and I visited their home 13 times during the period from August 2011 to July 2012, a total of 15 hours and 44 minutes. During these 13 visits, I interviewed the couple together four times (such as co-constructive participatory mapping process), for all the other interviews, Patricia and Brian elected to be interviewed separately. The detailed information on the main activities during each visit is presented in Appendix 7.

At the time of recruitment, Patricia was 74 years of age and lived with her husband, Brian, aged 77. They were married in 1957 and had been living in their current home, a detached house, since September 2006. The main reason for Patricia and Brian to relocate was due to their increasing age, so it was important to live in a smaller, more manageable property in an area with more support. Their present property was located in the constituency of recruitment area B. Within this area, there were over 6,000 residents, and one fifth of the local population were retired (Office for National Statistics, 2011). The couple’s house was half a mile west of a market town, so it was easy for them to access local amenities and get daily essentials.

However, once they had moved into this property in 2006, Brian had been diagnosed with cancer and Patricia with a mixed type of dementia. Although Brian’s condition was under control, Patricia’s dementia was steadily progressing. For Patricia, moving into the present house was associated with sad memories, apart from the relocation, which is often a challenge for older adults, especially for people living with dementia due to the decline in cognitive functioning. In addition to dementia, Patricia also lived with arthritis, which affected her spine and upper section of her neck and caused her permanent pain and difficulties in walking, as she shared: “I can’t ... walk ... my knees were going underneath me, so I daren’t walk down to the shops or anything at the moment” (transcript: 28/08/2011). In effect, Patricia could not walk without a walking stick, but she could walk for a few miles on good days. Patricia was a talented musician and loved to play the piano, this had always given her a sense of self and enjoyment and it was a source of pride for Brian, unfortunately her arthritis severely limited this ability. Apart
from the mixed type of dementia and arthritis, Patricia also had issues with her eyes, experiences of living with depression at several occasions throughout her life, and towards the end of my involvement with them in 2012 Patricia developed a new condition where she saw hallucinations. Overall, Patricia had significant health needs.

4.4.2 Family and Relational Dynamics
Patricia and Brian’s immediate family comprised of their son Adam, and daughter, Heather. Adam lived 45 miles away from Patricia and Brian’s home, whereas Heather lived only a two-mile distance away. Heather visited the couple at least once a week, helping wash Patricia’s hair and then taking her out for half a day. This gave Brian some time for either resting or doing what he needed or enjoyed. In addition to the planned visits, Heather came and helped her parents as and when they needed and she was available.

While Heather lived close by, all of the rest of Patricia and Brian’s relatives lived a significant distance away. The couple used to visit their wider family four times a year, and sometimes went on holidays together. But now, due to the decline of Patricia’s cognitive functioning, her capability in engaging socially with others, and coping with unfamiliar places, Patricia and Brian’s involvement with their wider family had gradually reduced, and they only took part in activities when it was either a major family event or that Patricia’s health needs could be managed. In addition, the couple felt that there was no longer the need for them to visit family members as their grandchildren were now adults and either at, or planning to go to, university. This situation had resulted in a change in the family’s structure: the couple had become passive recipients by giving up the role of proactively visiting the family, whereas the family had taken up new responsibilities of taking care of, and visiting, the couple as and when the family members were available. When the family visited the couple, Patricia and Brian retained aspects of their autonomy and established a new of sense of themselves by hosting the family interactions and taking their children and grandchildren out for dinner. The altered family structure did not appear to impact on the quality of time and enjoyable experience when they all spent time together. At the end of my third visit on the 25th September 2011, through discussing the couple’s family tree, I created their family genogram as shown in Figure 10.
Figure 10. Structure of the Family of Patricia and Brian
As Brian was aware of Patricia’s remaining ability, to support her memory, Brian independently created a family album using an iPad. Indeed, this album prompted her memories of the family members and she was able to remember them and their names when looking at the photographs. This album was a useful resource and helped Patricia to hold on to the remaining self, the person whom she used to be.

Initially, the progress of dementia had been a “very gradual process” and both Patricia and Brian had accepted the fact of living with dementia while changing the structure as a couple. Brian had slowly become accustomed to his role as a carer: “it may not have been easy … it’s not been a shock or anything like that … you can develop or grow with it” (transcript: 28/08/2011). For example, Brian had to forge a routine that worked for his wife. This meant that Brian had to get up on time so he could get the day started and ready for her. Fortunately, Brian did not need to do all the domestic chores as the couple had hired a cleaner, Emma, who came one day a week. Even with support, looking after Patricia restricted the opportunities for Brian to continue with his hobbies. For example, Brian had not indulged in collecting and repairing antique clocks that he used to work on, and was passion about, for a while. Despite the fact that Brian could not to continue with his biographical interest, he illustrated his commitment and togetherness to the new structure as a couple living with dementia: “I haven’t … much time because you need quite a few hours and it tends to get a bit difficult leaving Patricia alone for that length of time but … I think not doing it is more me … than having to look after her” (transcript: 28/08/2011).

Brian’s gradual acceptance of his new role and taking up new responsibilities and his commitment did not make the reality of being a full-time carer any less challenging, and one of the most difficult situations was when he was unwell and could not properly look after Patricia. At that time, he felt that Patricia was “very confused and panicky” (transcript: 28/08/2011), so he had to calm her down while dealing with his own condition. Although their daughter, Heather, often came over to help, she did work and this meant that she was not available all the time.

Furthermore, the dementia manifested itself as short-term memory loss, and Patricia repeatedly mentioned: “I can’t remember... my memory is getting worse, very much
worse” (transcript: 25/09/2011) and “I’ve got a terrible memory” (transcript: 19/10/2011). Despite that, Patricia was still able to easily engage with conversation for the first two-thirds of my visits. After that, due to the rapid deterioration of dementia it became harder for her to engage, Brian gave a matter-of-fact description of its impact on Patricia: “the memory is non-existent, really isn’t existent now, and we’re talking seconds” (transcript: 25/03/2012). This had a significant impact on the couple’s daily life and it was particularly challenging for Brian being the main carer and constantly reminding and/or persuading Patricia to take her prescribed medications at various times of the day. Patricia’s diagnosis of dementia also notably affected other aspects of her cognitive functioning, such as thinking and reasoning. I captured my thoughts on this process in my reflective notebook on the 29th April 2012 in the following way:

“Patricia’s dementia had rapidly declined within the last five months of my engagement with the couple. During that period, the deterioration in her cognitive functioning was noticeable for each of my visits. It was getting harder for conversations to be fluent, and the process of gaining consent at each visit was increasingly challenging as I need to be sure she does understand.”

With this decline in capacity I had to be certain that she still retained the capacity to consent, it was my considered opinion that she did in fact retain that capacity as documented through the use of the consent form.

4.4.3 Mapping the Neighbourhood

4.4.3.1 Personal Meanings

After discussing the impact of dementia on Patricia and Brian’s lives, their family and relational dynamics, it raised an opportunity for them to talk about their neighbourhood and what it meant to them personally. This discussion started from my fourth visit onwards, Patricia initially described her neighbourhood as: “absolutely nothing” and “this is just one road” (transcript: 19/10/2011). She then gave me a detailed account of not identifying herself with the neighbours:

“Just flat, they’re just people who keep themselves to themselves ... they’re nice people but I mean we only ever say ‘hello’, ‘goodbye’ ... there is not friendly
invitation ... I’m not prepared to push myself on people ... the rules ...” (transcript: 19/10/2011)

Patricia then explained how the existence of friendships compensated for her lack of connection both visually and emotionally to the present social surroundings:

“You can’t see people on the other side. They’re over there [Patricia points to the bedroom window] ... I don’t know half a dozen if that, it doesn’t worry me, coz fortunately a lot of our friends [two friends] are living here so that’s even better really as they are old friends and you haven’t got to go through making new ones.” (transcript: 19/10/2011)

When Patricia shared these words, we were in her bedroom, located on the first floor of the couple’s house. Patricia was in bed and I sat on a little bedside chair next to her. We were facing a window through which we could only see a number of house roofs. Patricia continued her account of not ageing in the current neighbourhood: “I don’t think that’s a lovely side out there [she pointed outside the bedroom window] for instance, that’s sort of raggedy... that’s just nothing to me...I can’t see any beauty of that... I don’t think we’ve got our life here” (transcript: 14/08/2011). Patricia used this storyline to further project her lack of emotional connection and belonging to the outside world. By way of contrast, in the first case study, Mary found that the sitting room window had a more engaging view enabling her to see the outside world, and she was able to observe her neighbours and other people coming and going to gain a sense of belonging and connection.

Patricia’s view of the present neighbourhood as ‘absolutely nothing’ became clearer when she compared it to the positive aspects of the locality they lived previously; at the extreme western end of a village with poor local facilitates within recruitment area B, and almost out in the countryside. These differences appeared less to do with the physical location and seemed more about the couple’s social integration or remembered social interactions with her friends and neighbours. Here, Patricia drew comparisons between the couple’s past and present neighbourhood to emphasise the importance of social ties and relationships and how these influenced the way she perceived the
physical environment. Patricia’s perception and experience of interacting with her present neighbourhood had an impact on her personal biography. For Patricia, the lack of connection and belonging to the present neighbourhood challenged her biographical continuity.

From Brian’s perspective, he defined their neighbourhood as: “the physical, just this little cul-de-sac” (transcript: 19/10/2011), and he expressed his feeling about the physical area as: “very quiet and almost a countryside which was lovely” (transcript: 14/08/2011) and about the social environment as: “friendly but fairly remote, we’re on Christian name terms and we talk when we meet when we pass ... but that’s it” (transcript: 19/10/2011). The discrepancy occurred as to the views of the relationships with neighbours between the couple. Brian seemed more familiar with the neighbours than Patricia did, and that might be due to the decreasing cognitive functioning caused by dementia and her decreased mobility. Despite that, the couple had a cohesive view of their social environment, ‘friendly but fairly remote’, which held more meaning in shaping the perception of the physical environment for Patricia than for Brian. He explained how gender and age influenced social relationships in the following way: “the old age and gender as men do not make friends easily” (transcript: 14/08/2011).

In terms of identifying the geographical boundary of her neighbourhood, she said: “I’m not quite sure” (transcript: 19/10/2011). This might be owing to her failure of connecting self to neighbours and the physical surroundings, even though she tried hard to retain such connections. Brian felt that the boundary of their neighbourhood could be the area that “covers closer friends [who] live within about half a mile and our daughter who lives two miles away ... so that’s the people we see the most” (transcript: 16/10/2011). Brian believed that dementia had tremendously reduced the geographic boundaries of their current neighbourhood when compared to their past one, they tended to view everything they had done together in the past as part of their neighbourhood. Brian also mentioned that keeping the diaries, as part of this study to capture Patricia’s activities, enabled him to realise the current limitations of their activities and how their neighbourhood had shrunk.
4.4.3.2 Visual presentation

Once we had discussed Patricia and Brian’s definition of a neighbourhood and its personal meanings for them both, we began to co-construct a map of their neighbourhood. This mapping process commenced on my sixth visit and followed the process described in chapter 3. Although Patricia and Brian were unsure about how to start the map, especially Brian who said: “I hate drawing maps” (transcript: 04/12/2011), they engaged well with the process. Indeed, by the end of the process, Brian felt that the map had helped them see what their current neighbourhood looked like and how dementia had affected their lives.

Brian decided to access his computer and print a local map of the area: “it might be easier if I print a map” (transcript: 04/12/2011) to start with. Once Brian had printed a coloured local map, he took the main role in highlighting their neighbourhood using the printed map as a basis for the construction, whilst I constantly checked with Patricia to make sure that her understandings were also present. Working together, the three of us discussed each place on the printed map in more detail, whilst Brian was illustrating and marking this discussion on the printed map. This conversation helped Patricia remember the places she had visited, including how often and with whom. Without this type of conversation, it was a challenge, or perhaps impossible, for Patricia to connect herself to the places on her own. This neighbourhood mapping process was done on the dining table in the lounge of the couple’s house, and Brian highlighted how their neighbourhood was constituted (Figure 11) using the following schema:

- The couple’s current house, marked as ‘H’.
- The couple’s friends to whom Patricia and Brian saw regularly, marked as ‘F1’ and ‘F2’, and then wrote down ‘[1/week]’ to illustrate, on average, that they saw each of their friends on a weekly basis.
- The Conservative Club where Patricia went to have a lunch weekly, marked as ‘CON CLUB’.
- A local shopping village, ‘S’ on the map, where Patricia went on a regular basis.
- The daughter’s house, marked as ‘Daughter’ and used ‘*’ to highlight this place.
- Their neighbours, ‘N’.
• A Flower Club, ‘FC’, which was situated in a community centre. Patricia often went to the Flower Club once a month.

At this point, the couple felt that their previous location should be part of their neighbourhood, but not covered by the coloured map, so Brian went to print another one which detailed a larger geographical area. On the second black and white map, Brian repeated the earlier process and included two more places, as shown in Figure 12:

• The couple’s previous house, which was three or four miles away from their current home, and Patricia described it as: “that’s a nice area” (transcript: 04/12/2011).

• The location of the couple’s general practice, marked as ‘DR’.

At the end of the mapping process, the couple felt that both maps represented their neighbourhood, and Brian said: “we don’t travel further than that these days,” and “anything else would be too extreme” (transcript: 04/12/2011). By including the past house as part of the present neighbourhood, it gave the couple a sense of continuity when bonding through the experience of living with dementia.

4.4.4 Explaining the Neighbourhood

Once we had co-constructed the neighbourhood maps, Patricia and Brian further reflected upon the contents and how they interacted with their neighbourhood when living with dementia. Based upon our early conversations, Patricia and Brian both included their previous home as part of their present neighbourhood, and each of them gave a detailed account of their former house.

The couple had lived in their previous house for 27 years. When Patricia and Brian started living in the village they rapidly established friendships with their immediate neighbours, so an interesting and close knit community had been formed and the extremely friendly atmosphere had lasted for the first 15 years. Brian perceived the village as: “it’s much more influential and important than the general community” (transcript: 19/10/2011). Meanwhile, Patricia shared her memory about the village as:
Figure 11. Patricia and Brian’s Neighbourhood Map 1

Figure 12. Patricia and Brian’s Neighbourhood Map 2
“Lovely ... it was just perfect really because they weren’t noisy neighbours but you could go over and knock on the door and say, ‘can you help me out?’ We didn’t have to really go to each other’s houses regularly ... because we met up in different places...where you all gather for concerts and things... a town hall sort of thing.” (transcript: 19/10/2011)

Patricia gave this testimony to illustrate the importance of social support networks and social integration to her life. Social engagement gave her a sense of belonging to the group and connection to the places where she could meet up with others, which in turn influenced her social participation and shaped her biography. Patricia made an even clearer comparison between the two neighbourhoods as to the social and physical aspects in the past and present, as: “I don’t think the place [the current home address] is a community, whereas our village is a community and the one we had was perfect” (transcript: 19/10/2011). When Patricia spoke about ‘community’ it was with a sense of nostalgia and realisation that her current neighbourhood did not provide the same sense of community. She related ‘community’ to the specific aspects of social support and integration and drew attention to a sense of belonging and participation, whereas the ‘place’ focuses on the physical environment that could only hold meaning through social engagement.

Patricia’s memory about the village was based on the first 15 years of the experience of living there. After that period, Brian described: “it became very much imprisoning for her” (transcript: 19/10/2011) in the village as the people around them drifted away and there was nobody close by, except for Patricia’s best friend who lived at the other end of the village, and Patricia stopped driving due to her ‘mental disorder’. Despite that, Patricia constantly connected herself to the first 15-year lived experience in the village demonstrating that belonging and social participations were of importance to her. These two factors shaped Patricia’s emotional connection to the present neighbourhood, so ‘friendly but fairly remote’ relationships with the current neighbours led to her lack of attachment to the environment which re-shaped her biography.
Nevertheless, the couple kept contact with two of their friends who lived about half a mile away from their present house, and they had longstanding relationships with these friends who had lived in the same village before. Keeping regularly contact with these two friends enabled Patricia and Brian to bring their past lives into the present as Brian shared: “we almost moved with our old acquaintances” (transcript: 14/08/2011). The continuity of the past into the present enabled Patricia to maintain part of her biography and compensated for her feeling of being segregated from the current neighbours. However, the progression of dementia affected the quality of Patricia’s interactions with her social ties, weakened her emotional bonds to them, as well as reducing her ability to recognise the places where she often visited.

4.4.4.1 Interaction with the Neighbourhood

Brian understood the importance of belonging and participation for Patricia, in order to promote her ‘personhood’, he worked hard to help her establish friendships and fulfil a caring purpose by utilising proximate relationships and then, based upon a person-centred approach, found tasks that Patricia would be interested in and gave her a sense of satisfaction. To do this, Brian described that, initially, Emma was the person who, for one day each week, helped the couple with cleaning their house, Brian asked her if she could try to become Patricia’s friend and take her out for half a day. Once the friendship had been built up, in addition to going out with Patricia half a day per week, Emma also came to accompany Patricia and to do some tasks with her for another half a day, such as helping Patricia make decoupage (a process of cutting out pictures, gluing them to an object and then varnishing the item), which Patricia could not make on her own due to the impact of dementia. For Patricia, she thought that this was a nice process as she enjoyed making decoupage, she also liked the companionship Emma provided. As a result, Patricia proudly showed me a beautiful decoupage she had made with Emma. At a deeper level, this friendship-based approach, with the aim of carrying out activities that were sensible to Patricia’s capability and were meaningful to her biography, contributed towards the continuity of her biographical interests.

Brian was fully aware of Patricia’s ability and supported her to maintain her remaining abilities by scheduling regular activities for her, and these activities took place within a five-mile radius from their home. Brian also photographed the places where Patricia
(regularly) visited as representative of their neighbourhood landmarks. One photograph Brian took was the local Conservative Club (Figure 13) where Patricia regularly went out with her friend Emma, who was also the paid cleaner as described previously, for lunch and met with other members of the club. In November 2011, Brian went to the Conservative Club with Patricia to attend a party, with approximately 60 members. Brian felt that Patricia thoroughly enjoyed this event as she could meet with their friends from their previous neighbourhood, which gave a sense of continuity of her social relationships and participations. Social integration was important for Patricia, going to the club each week enabled her to meet other members and she enjoyed this type of interaction.

Figure 13. Conservative Club

After having lunch with Emma in the club, Patricia enjoyed going to a local garden centre, as shown in Figure 14. When showing me this photograph, Brian reminisced, mentioning:

“Patricia used to enjoy doing things in the green house, such as putting things in the pots and moving them into the garden, but now ... when my sister was here and doing things in the green house, but she [Patricia] only did a few minutes and then went away.” (transcript: 26/05/2012)
Brian felt that for the majority of the time Patricia was a totally different person and rarely saw her as being herself, this was a glimpse into his life and demonstrated a sense of loss of his partner caused by the dementia.

Figure 14. Local Garden Centre

Despite that, on Patricia’s good days, she continued to pursue her passion about flowers. Patricia went to a local Flower Club each month with her friend, Matilda, who was one of the couple’s two main friends. At the Flower Club, there were presentations by experts on how to arrange and grow flowers. This was a social evening and took place on a Thursday between 7.30pm and 9.30pm. Matilda took care of Patricia, and she often collected Patricia so they could go to the club together and then brought her back home afterwards. Patricia gained a sense of enjoyment by attending the Flower Club, and she had been a member ever since she had lived in the village. This also enabled her to continue her biographical interest and maintain a sense of self that had been of importance. Patricia explained that getting out and meeting with her friends, as well as doing things she enjoyed, gave her great pleasure and enjoyment. In respect to this, Patricia said: “feeling causes action” (transcript: 06/11/2011), showing how social participation and belonging had such a positive impact on her well-being, enabled her to remain active, and maintained a sense of self. The Flower Club served as a means for Patricia to connect to the neighbourhood, and of expressing her self.
As Patricia’s dementia rapidly deteriorated, so too did her cognitive functioning, and this further impacted on her ability to recognise and connect to the surroundings, which in turn led to increased difficulties for Patricia to face and accept the disruption of her biographical continuity. Brian encapsulated this when he said: “she is still... very intelligent and bright, but the ability to store or to recall thoughts is virtually gone” (transcript: 16/10/2011). The support from the family was crucial to the couple’s experience of living and coping with dementia. The daughter, Heather, always tried to persuade Patricia to go out, even on her good days, however, there was an increasing tendency on her part to make excuses not go. Once Patricia was out on the trip, she invariably enjoyed herself; Brian provided an example to demonstrate his point: on the 27th August 2011, Patricia went out with her daughter; they left home at 11.30am and came back at 5pm, Brian said: “nobody was complaining, nobody said she had to stop so obviously she’s managed to walk around and do everything” (transcript: 28/08/2011). This highlighted how dementia affected Patricia’s confidence, which might have a greater impact on her social interactions than the deteriorative impact of her physical capabilities.

This encouraged Brian to seek support from more skilful people in caring for Patricia via a person-centred approach. For Brian, this was borne out when Patricia’s sister, Silvia, came and stayed with them for a few days. With Silvia’s input, Patricia had an active few days talking and undertaking activities that Patricia enjoyed, this kind of activity gave her a sense of pleasure and enabled her to continue her biographical interests. While Brian felt that it was good for Patricia to undertake activities with others, he still noticed a difference between being encouraged to participate with someone and actively carrying out an activity by herself because she enjoyed it: “it really took somebody to come and sit with her all the time, and do something and get her to copy it... it would be nice to find something she’d like to do on her own” (transcript: 25/03/2012).

To promote Patricia’s sense of independence, Brian had engaged the support of a shop keeper of a local store, shown in Figure 15, this creative thinking by Brian meant that Patricia was able to go to the local store on her own, the shop keeper would then help her in the store, and, when she left to go back home, he pointed her in the right direction to ensure that she could get back home. Without this level of support, there
was a high risk of her getting lost. This type of support helped Patricia to exercise a degree of agency and autonomy, which were seen by Brian as important factors to be maintained.

Figure 15. Local Store

Unfortunately, as the dementia rapidly progressed, Brian’s sense of loss of his partner continued. Towards the end of my involvement he felt that the dementia had not only impacted Patricia’s cognitive functioning but also changed her attitude and behaviour towards people who were close to her, she had slowly become unfriendly, while Brian tried to keep the peace:

“Our [the couple] interaction is abrasive at times … the better thing for me to do is to be quiet and shut up, walk away … now and again with daughter … but I can see it’s slowly getting more fractured with Emma.” (transcript: 25/03/2012)

At this point, a decision was made to seek a professional care agency, as Brian shared:

“I hope professional carers got the training in this experience [dealing with people living with dementia] and they know some tricks, some ways to get deeper, to find out what’s really needed, what she [Patricia] wanted. We are still a bit experimental.” (transcript: 25/03/2012)
4.4.5 Initial Impressions of the neighbourhood

The progression of the dementia had significantly affected Patricia and Brian’s daily lived experiences and social activities. Given that the couple’s lives were so closely intertwined, the experience of dementia was a shared experience, as well as an individual condition for Patricia, and this had implications for them both. For Patricia, the declining cognitive functioning affected her ability to recognise the connection to the social and physical environments, and shaped the meaning of the current neighbourhood. Her memory about the past neighbourhood was brought into the present as a means of continuity of her biography. Interestingly, the continued neighbourhood was also the case for Brian. Consequently, as a couple, they both included their previous neighbourhood as part of the present one. This continuity of neighbourhood was also illustrated through the relocation of their two friends from the village to the present location where the couple currently lived. The comparison between the past and present neighbourhood highlighted the significant importance of belonging and group identification for Patricia, and how these two factors affected her social participations and her perceptions of both social and physical environments. Although the neighbours were ‘friendly’, and ‘on Christian name terms’ when talking to each other, for Patricia, the present neighbourhood was ‘friendly but fairly remote’ emotionally.

Familiar surroundings played a significant role in Patricia’s quality of life and as such Brian believed that their home was the best place for Patricia to be as home provided her with a sense of familiarity, belonging, and control. Being away from home meant that Patricia had to encounter the challenges of unfamiliar surroundings where the demands would potentially increase for her, giving rise to anxiety and fear, because her capabilities in dealing with new, and even familiar places continually decreased. Unfortunately, on my final visit to the couple, Brian described how Patricia could not even recognise that where she was living was her home at times, so her senses of ‘belonging’ and ‘security’ had decreased tremendously.

Patricia’s case seemed to highlight the delicate balance between the perceived need for better access to local amenities, a main stated reason for them moving to their current home, and the perceived importance of longstanding social connections and friendships
in personal biographical continuity. Patricia’s identification to her social group was lessened as she was unable to emotionally connect to her current neighbourhood. This lack of emotional connection was influenced by her past experience and further reduced opportunities for her social participation with others. Although Patricia went out with her daughter and friends on a regular basis, the decreased cognitive functioning as a result of her dementia led to less meaningful interactions, which in turn reduced the quality of social participation and shaped her biography. At a deeper level, these less meaningful interactions might be because the activities that Patricia carried out were not suitable for her capacities and/or relevant to her biography as time passed.

Patricia seemed to be closely connected to her two cats and gained a sense of belonging, as she described her feeling towards them in the following way: “they’re lovely, him and his brother, they’re gorgeous ... [they’re] my best friend ... they are great company” (transcript: 28/08/2011) and “I’m crazy about the cats ... Sometimes you have a lovely cuddle with them and they get comfortable and go onto sleep. Yeah, they’re lovely” (transcript: 25/09/2011). From Brian’s point of view, he felt that the two cats were very important to Patricia who had emotional ties to them.

Nevertheless, the progression of Patricia’s dementia not only reduced the boundary of the couple’s neighbourhood at a geographical aspect, but also affected the quality of Patricia’s interactions with her social and physical surroundings at an individual level. As a main carer, Brian sought to help Patricia to maintain a sense of autonomy and biographical continuity by utilising proximate relationships to fulfil the caring purpose as their social world shrunk.

Despite the significance of informal support from their family and friends, with the rapid progression of dementia such informal support became quickly overwhelmed, Brian described this as a “cliff edge phenomenon” (transcript: 19/02/2012), for the couple it became crucial to seek formal support services. Brian mentioned that he had found formal caregivers and registered with a local service which provides emergency cover for up to three days to look after Patricia when he felt unwell. However, Brian found that the quality of this service was of concern, he illustrated this by recounting on one occasion that one of the formal carers had lost Patricia on an outing. The carer had taken
Patricia out and left her in the car to deliver a letter, Patricia then got out of the car, wandered off and became lost; it took two and a half hours to find Patricia. This low quality of service had led to negative outcomes for both Patricia and Brian and had clearly shaken Brian’s confidence in allowing others to care for Patricia. In addition, Brian emphasised that the local healthcare service was poor in general, citing issues such as limited appointments for Patricia to see the psychologist and a long waiting time for an adult social care assessment.

4.4.6 Summary

Over the year of my engagement, the couple’s past neighbourhood was a feature that continued through to the present via the sustained relationships and interactions with the two long-term friends. The couple’s self-constructed neighbourhood and its boundary were shaped by Patricia’s social activities, and Brian’s life was consumed by his caring role. Patricia’s interactions with the neighbourhood were made up of the family and friends who she had frequent contact with and the places she visited on a regular basis. Patricia’s experiences of these interactions influenced her biography and affected her neighbourhood perceptions. To maintain Patricia’s autonomy and to continue her biographical interests, the informal support network, which was made up of the family, friends, and local shopkeeper, had made a significant contribution. As the dementia progressed, although the couple were able to seek both formal and informal support, the ability to engage with and utilise such support remained a significant challenge for Patricia. The declining cognitive functioning also affected the meaningfulness and purpose of social interactions for Patricia, and the qualities of such participations had been, and would continually be, lessened. Arguably, it might be partially due to the support and activities that she engaged with not being sensitive to her capacities and/or relevant to her biography.

4.5 Case Study 3 – Diane and Dave

Main Storyline: The Neighbourhood Hub

4.5.1 Background

Diane and Dave were the third couple recruited in this study, and I visited their home 11 times during a period of one year between August 2011 and July 2012, and a total of 11 hours and 43 minutes was spent collecting data with them for this study. A detailed
description of the main activities undertaken with Diane and Dave on each visit is shown in Appendix 8.

At the time of recruitment into the study in August 2011, Diane was at age 76 and lived with her 76-year-old husband, Dave. They had been married for over 50 years. For the majority of this time they had lived in an affluent and well-established village within recruitment area B. The village had around 1,200 residents and was about four miles west of a main town centre. The average age of the population of the village as a whole was older than the national average (Office for National Statistics, 2011). Initially, the couple lived in a two-storey, four-bedroomed house in the village. However, due to Diane’s arthritis which severely impacted upon her mobility, in 2004, the couple moved into a terraced bungalow just cross the road from their previous home. The couple shared that this was a fortunate decision as they could not have predicted that Diane was going to have a stroke so soon after moving into the bungalow. Living in the bungalow allowed Diane easy access around the property, the lack of stairs was particularly helpful for post-stroke rehabilitation, her reduced mobility following the deterioration of the arthritis, and the onset of Alzheimer’s disease in 2009. Diane also lived with Parkinson’s disease, glaucoma, and hearing problems; physically, she was not a well woman.

4.5.2 Family and Relational Dynamics
Diane’s decreased mobility was primarily caused by her arthritis, which for the past few years had inflicted considerable back pain and discomfort in her everyday life. Diane was unable to stand “for more than a couple of minutes” (transcript: 17/10/2011), so she was using a wheelchair to aid her mobility and to maintain as much independence as possible. When attempting to be mobile, Diane required the assistance of a walking frame; however, this was not without its problems as Diane was unable to walk outside her home due to the unevenness of the ground. This mobility restriction had a knock-on effect in the sense that Diane was unable to walk to the garden unaided and indulge in her passion for gardening at a time of her choosing. In conversation, Diane was extremely frustrated by the situation and her pronounced lack of independence. Although the garden was small, it held significant meaning to the couple. Throughout our time together I was struck by the couple’s attachment to this outside space, as
recorded in my reflective notebook on the 22nd June 2012: “during this interview, they [Diane and Dave] were sometimes distracted by birds or flowers in their garden and were always keen to talk more about the garden. This had happened throughout my visits.”

In terms of family structure and its dynamics, Diane and Dave had a daughter named Lisa, and a son named Phil. Although Lisa and Phil both had full-time jobs, the couple saw them at least once a week as they all lived nearby. Normally, Lisa or Phil brought their children with them when visiting Diane and Dave so that the whole family could be together. In addition, Diane and Dave “talk[ed] to them on the phone quite a bit” (transcript: 17/10/2011), particularly when either Phil or Lisa knew that Dave was not at home and that their mother was ‘home alone’. If Diane wanted to go out but Dave was unable to take her, Lisa or Phil would usually come and drive her to wherever she wanted to go to support her remaining autonomy.

This caring bond was also expanded to the couple and their grandchildren. For example, when talking about their grandson who was 17-years-old, Diane and Dave were very emotional and concerned about his next steps: “when our grandson goes [to the university] ... it will be next year...as long as he gets his exam results” as said Diane (transcript: 14/11/2011). On one hand, they were concerned whether their grandson could get the required academic grades to enter his first choice university, which was situated in another part of the country. On the other hand, they worried how he would get on with everything in a new place while being away from the family. The couple’s caring about their grandson reiterated the close family relationship they had which, in turn, influenced how their grandson responded to them. For instance, I noticed that they had a couple of cups which were marked as ‘grandma’ and ‘grandpa’ and bought by their grandchildren in Disneyland in Florida when they went there for Dave’s birthday. This close intergenerational relationship played a significant role in the family dynamics.

At the end of my third visit, based upon detailed conversations about the couple’s family structure, I mapped their family genogram which is shown in Figure 16.
Figure 16. Structure of the Family of Diane and Dave
When exploring the family structure, the couple were clear that the family was the most important part of their lives. The couple reported that they have “a very close family” (transcript: 02/09/2011) and the family’s support was important for the couple when living with dementia.

Despite this closeness, Dave felt that being the main carer for Diane was stressful as, in addition to the majority of the domestic chores, he had taken on other community positions and responsibilities for three committees he had joined. Dave also felt that taking up his new role and responsibilities as carer impinged upon the time he could spend outside the home, a feeling he neatly summarised as: “so there’s pressure” (transcript: 22/08/2011). From Diane’s point of view, she believed that Dave supported and looked after her ‘well’. Although Diane had to give up certain roles, she supported Dave as and when she could, given her physical and cognitive challenges. To overcome such obstacles took ingenuity; for instance, as Diane was unable to go out on her own, she often enlisted the support of her daughter to help her go out and buy her husband gifts as a token of her continued love and affection for him. This maintenance of autonomy and affection is seen in the following slice of interview data:

“Lisa took me to the garden centre one afternoon after work. Don’t know where Dave was but we went there and got it [a bird feeder], so we could put it in her car. Because it was all dismantled in separate pieces and fitted in a box like that. It was quite heavy, so Lisa took it home and then brought it back for Dave’s birthday.” (transcript: 04/05/2012)

This example also illustrates that it was a considerable undertaking for Diane to get a present for Dave and then kept it a secret from him until his birthday. The maintenance of the quality of the relationship as a couple and long-held family and social roles were important for Diane, but required some subtle diplomacy and negotiation to make it happen.

Despite the altered structure, both Diane and Dave derived a great deal of pleasure from socialising and meeting people, such as participation in local committees and going out for afternoon tea with friends, although Diane was less able to do this independently.
However, the supportive relationship and similar interests enabled the couple to maintain a full and active social life which was significant in their lives. The support Diane gained from the family was crucial for maintaining her autonomy after being diagnosed with dementia.

4.5.3 Mapping the Neighbourhood

4.5.3.1 Personal Meanings
After exploring the family and relational dynamics together, it was apparent that ‘neighbourhood’ was a meaningful concept to Diane and Dave that they were happy to talk about and identify with. Consequently, from my third visit onwards, we discussed what their understanding of a neighbourhood was and what it personally meant to them. As Diane and Dave had been living in the same village since 1972, and all their friends lived in the same area, they considered that their neighbourhood was “associated virtually with the whole of the village” (transcript: 02/03/2012). The village was pretty much where all the significant people that Diane and Dave knew lived.

From the couple’s point of view, a fundamental aspect of the neighbourhood was their social network which included their friends and close neighbours. This social network and the majority of the social activities were all within close geographical proximity of their home. The couple met with their friends weekly, such as through the Over Fifties Club which was usually held in the village hall. The Over Fifties Club was crucial for Diane and Dave to connect and re-connect to their neighbourhood and participating in the club shaped how they attached to the places and belonged to their social group. The significance of friendships in the life of the couple can be demonstrated via the photograph shown in Figure 17, which was taken by Dave in February 2012.

This photograph presents two good friends of Diane and Dave, and pictures a conversation taking place in the village hall. Dave often went to watch rugby with his best friend who is on the left of the photograph. The person shown on the right of the photograph was another good friend, whom Diane and Dave had known since 1995. This friend and his wife used to cook two turkeys for the Christmas Party organised by the Over Fifties Club.
The photograph was chosen to illustrate not only the importance of the friendships but also the village hall in the life of Diane and Dave. They also used this photograph to demonstrate the meaning of neighbourhood, a place where they socialised with their friends regularly.

Moreover, the couple had longstanding relationships with their neighbours. The next door neighbours on one side had also joined the Over Fifties Committee and occasionally hosted the committee meetings in their home, so Diane and Dave attended meetings in the neighbour’s house. This neighbour was also a named person in Diane’s emergency contact list and had a spare front door key to Diane and Dave’s home. This level of trust meant that the neighbour could come into the house to check on Diane should Dave be out for any reason. Both Diane and Dave felt that they had ‘super neighbours’ and had a reciprocal caring arrangement. All these activities combined together to forge positive experiences and relationships which became an integral aspect of Diane and Dave’s neighbourhood.

4.5.3.2 Visual Representation

Once we had discussed the neighbourhood and its personal meanings for Diane and Dave, we began to move towards co-constructing a neighbourhood map as a visual representation of everyday experience. This process started on my fourth visit, and the
couple followed my general guidance and used the materials I provided as detailed in chapter 3. Dave initially took the main role in drawing their neighbourhood map, whilst I provided encouragement to Diane to ensure that the map also represented the neighbourhood from her perspective. The drawing was done on a table in the lounge in the couple’s home. At the end of my fourth visit, the map was completed and it represented the geographical boundaries of their neighbourhood and covered: three public houses, a church, a post office which also doubles-up as a grocery shop, a school, and a village hall. This map, shown in Figure 18, provided the first level of description of the neighbourhood and this was the first stage of the mapping process.

As the couple reported previously, they heavily engaged with the community, participated in social activities, and met with friends who lived in the same village. We agreed to move to the second stage of the mapping process to provide an explanation through illustrating where their friends were located, how often they met to show the level of social engagement, and in which part of the village. Consequently, Diane and Dave felt that it was crucial to mark the following three domains: i) their social network; ii) the level of closeness of the recorded friendships on the map; and iii) the frequency of contact with their friends. During this co-constructing process, I provided guidance and reassurance on how the map could be drawn and how to best present the above information. While Dave was drawing the map, Diane provided me with detailed information about the village and further explained how their social networks were located, and where social activities took place in the neighbourhood. Figure 19 is a photograph of the completed neighbourhood map for Diane and Dave.

The names of three public houses and streets have been redacted on the shared neighbourhood map for the purpose of anonymity. However, to ensure the property of Diane and Dave and local amenities can be easily identified, I have pointed out these locations on the map.
Figure 18. The First Stage of the Neighbourhood Map Drawn by Diane and Dave
Figure 19. The Final Neighbourhood Map Drawn by Diane and Dave
Each sticker on the neighbourhood map in Figure 19 illustrates how often Diane and Dave saw their friends and neighbours, which ranged from once a week to three times a week. Moreover, the level of closeness of the friendship was presented on the neighbourhood map through an allocated number on the left corner of the sticker. For example, number one represented their best friends, number two their second best friends, and so on. The majority of the activities shown on the neighbourhood map were those that the couple undertook together; however, where Dave’s sole activities took place, his name has been redacted for anonymity.

4.5.4 Explaining the Neighbourhood

Once we had co-constructed the neighbourhood map, it presented an opportunity to reflect on the contents and to see existing social relationships, places of importance, and local networks. During our early conversations about the neighbourhood map, Diane and Dave shared information about the buildings marked on the neighbourhood map and discussed the significance of these buildings to their everyday lives, in particular the village hall. Its value and popularity was described by Diane and Dave in the following way: “the most useful thing we had in the village - that we used a great deal - is our village hall ... you’ve got a job to book it if you want to use for any reason because every day it is used” (transcript: 14/11/2011). The village hall held specific meanings to the couple who attached to this place via their regular social participations, which reinforced their emotional connection to the place and formulated part of their life stories. Dave further explained that the new village hall was opened in 1996 although its construction was not without its challenges and the need to adhere to local bureaucracy and planning laws. For example, local residents had significant difficulty in obtaining formal planning permission for the hall to remain as a ‘social amenity’ within the village. Dave used this storyline to illustrate his active role in the establishment of, and personal investment in, the village hall and to demonstrate their attachment to this place over time.

As seen in Figure 19, in the village there was a playing field and a bowls club. Dave felt that the bowls club provided good facilities and had proved popular with a lot of people. Leisure places were clearly identified as important to this couple as they provided many opportunities to maintain their social networks, even with Diane’s failing health. In addition, as shown on the neighbourhood map, Dave indicated that there were three
public houses in the village. Although Diane and Dave went to the public house infrequently, about once every two months, Dave normally went there more often with his friends. Again, Dave identified himself attached to the places that were highly familiar to him.

The local grocery shop was seen by Diane and Dave as essential for people’s daily living. However, Diane and Dave felt that the village lacked facilities and mentioned: “it’s got one very poor village shop which is also the post office, a couple of pubs. There’s nowhere else to shop, you’ve got to go either to Sainsbury’s along there or to Tesco” (transcript: 14/11/2011). In fact, there were more amenities at the other end of the village, which were not easy for them to access due to the distance. Diane and Dave, therefore, suggested that the village would be better served by more shops and greater competition between stores, as this would improve the quality of products available.

Neighbourhood safety and security were identified by Diane and Dave as other important aspects of the village. Dave normally put his car in the garage at about half past six in the evening to ensure that the car would not be damaged overnight as they had become concerned about teenagers’ behaviour in the village. As Diane explained:

“He [Dave] doesn’t like leaving it [the car] out. We have had trouble with youths about ten days ago ... they were picking the crab apples off our tree... off the ground .... and running in the front garden and picking them up and throwing them at the buses when they went by, so several people called the police and they came very quickly and sorted them out.” (transcript: 02/09/2011)

This behaviour had raised concerns and initially was dealt with by the parish council that had tried to engage with the teenagers in the village to understand what they wanted so that the council could provide the necessary facilities for them. Diane had been involved in this process in the past. However, this action did not progress any further as the teenagers just wanted to hang around and then went to the public houses. To ensure the safety and security of the local residents, the second step was to set up a Neighbourhood Watch, as the couple explained: “most roads in the village they appoint
somebody who will look out for anything unusual going on in their road. Or if, like when these youths were running out here they phoned the police” (transcript: 02/09/2011).

Despite the limited local amenities and perceived safety issues in the village, the couple still preferred to stay in the same place due to the warmness of the neighbours and their close friendships, as Diane described:

“I also wanted to move to [another local village] because they’ve got more amenities…but as we came into here the removal van backed in and the man on that side gave me a bouquet of flowers and his wife gave me a fruit loaf straight out of the oven and I said to her that’s why we don’t want to move because you don’t get things like that in five minutes.” (transcript: 02/09/2011)

For Diane and Dave, it was the people and the social capital that had been accumulated over decades of living in the same village that constructed a neighbourhood of choice as they aged. Moreover, Diane and Dave believed that they were ‘lucky’ to have a wide-range of friends in the village, and considered that the most important aspect of their neighbourhood was sociability and friendship. These two factors were embedded within the village and were also what they expected to experience in maintaining their biographical continuity as time passed.

4.5.4.1 Interaction with the Neighbourhood

While living with dementia and other conditions, Diane continued her involvement in three committees, this helped her maintain a degree of autonomy and sustained her biographical interests, even though her roles within the committee had been altered and her responsibilities reduced. Previously she was the chairperson of the Village Hall (Management) Committee, only resigning from this role after her stroke, although she continued to remain involved as a committee member. Whilst Diane was still able to contribute in a different way and met the same people, she missed being as actively involved in the preparation and running of the events. For Diane, simply being on a committee was not as important as possessing agency in relation to that committee; it was the active participation and official involvement in the preparation for the committee’s functions that held specific meanings for her. However, Diane was fully
aware of her reduced abilities, so continuing as a committee member still helped her maintain a degree of autonomy and gave her a sense of belonging.

Secondly, Diane was the member of the Town and Charities Committee and went to the committee meetings three times a year. Her contribution was varied and depended upon how much work needed to be done. Due to the less requirement of the committee with regard to attendance and activities, her involvement in this committee had remained the same over the years. The Town and Charities Committee was established over 200 years ago when the wealthy farmers in the village were unhappy about their children’s education. As a result, they set up a school and provided a house for the headmaster. The Town and Charities Committee provided financial support to the headmaster and aimed to keep them, so providing better education to the local children for as long as possible. Diane felt that it was crucial for children to receive a good quality of education, and this purpose maintained her long-term involvement that fulfilled a sense of purpose in her life and enabled her to gain a sense of self-worth.

The third committee Diane had joined was the Over Fifties Committee which was established eight years ago, Dave was also a member of this committee, and to date, there were approximately 100 members. Dave further explained that half of the members met every Thursday morning, and at the beginning of the meeting, the chairman normally told them what was going on in the village, and what the costs were running at, and selling tickets, all to keep the members up-to-date. This committee was self-funded by raising money in a number of ways; for example, the committee meetings took place in the village hall, the costs of hiring the meeting room came from everybody’s contribution by paying £1 per person. The members also organised a lottery to raise money to cover the committee’s costs.

Diane and Dave felt the Over Fifties Committee was “one of the best things in the village” (transcript: 22/08/2011) and organized a range of events, such as going to Nottingham for a short holiday; most of their social life was played out through this committee and its organised group activities. The committee also organised an event to show how a person with a hearing problem trained a dog and a Guide Dogs for the Deaf event was held in the village hall, as shown in Figure 20. Diane and Dave felt that it was a
wonderful opportunity to see how a person who had hearing difficulties trained the dog. This was the first reason the couple chose this photograph. Secondly, the couple had a lovely dog years ago and saw him as a family member. The dog was a much-loved family pet and gave them the same enthusiastic greeting every day when they came back home after work. Unfortunately, after the dog’s death, the couple had not felt that they could replace him as they would not be able to look after any pets properly due to their advanced age and health conditions.

Figure 20. The Deaf Event

Diane and Dave chose this photograph, not only to emphasise the committee providing them with the opportunities for social participation, but also to highlight the relevance to their biographies and the importance of pets in their past life. This link between the past and present further illustrates how age and multiple conditions changed their lives and shaped their life stories.

The Over Fifties Committee served as a function in facilitating friendships amongst local residents and enabled them to share experiences. In the village, there were a lot of widows, as Diane explained: “if they didn’t have things like the Over Fifties they would be very lonely, because it’s there and they meet other people in the same situation they are happy to come” (transcript: 17/10/2011). Diane also believed that participating in social events would relieve the boredom of being at home all the time. Thinking about other people, and what they might like to do, had helped to keep her mind occupied, from
which she had found motivation in her life. The significance of these social events and being on committees was very important to Diane, it gave her a sense of purpose and enjoyment and maintained her biographical continuity.

In addition to the Over Fifties Committee, Dave was heavily involved in two other committees. He was a member of the Wine Club Committee which, as its name implies, provided members opportunities to taste wines. This committee also arranged for the members to go away for shared holidays. In our conversation, Dave mentioned:

“Now that Wine Club, for the last four years we have been away somewhere. We’ve been to France, we’ve been to Portugal … different parts of France. We’ve been to Portugal twice, right down the Algarve and into Lisbon. Next May, we are going to Jersey.” (transcript: 22/08/2011)

Indeed, the couple enjoyed travelling to different places, with Dave’s support, Diane’s reduced mobility was not an issue in preventing them from going away for holidays. Going away for shared holidays with the members of the club was perceived as another enjoyment for the couple, especially when Lisa and Phil (their children) were busy with their lives and might not have time for this. Such group-based activities not merely provided the couple with a sense of belonging and a pleasurable experience but also promoted their social citizenship through facilitating their social participation.

The third committee Dave had joined was the Conservative Association. Dave did all the paper work to assist those who organise holidays for people with a disability, and supported those who had financial difficulties caused by a number of reasons, such as an accident, illness or fatality. In addition, Dave helped print the village newsletters and then distributed them to local residents once a month. Furthermore, Dave was the flood warden of the village and kept an eye on the river to make sure that it does not get blocked up. These activities signified how important this village was for him and how he invested time and effort to look after the village and served the local residents. Dave’s emotional bonds to, and experiences of interactions with, the village and local residents formed part of his biographical relationships with his neighbourhood.
In addition to the committees Diane and Dave both served on as a couple, they participated in other social events organised by the community, for instance, the games afternoon which took place once a year in the village hall. Usually, 50 members attended the games afternoon and the actual games lasted a couple of hours. The photographs below show some members of the committee playing Roulette (left) and Jenga (right) shown in Figure 21.

Figure 21. The Games Afternoon

Diane and Dave chose these photographs for a number of reasons. Firstly, the people in the photographs were the friends of the couple and they met with each other on a regular basis. Secondly, one of their good friends, with whom they had a longstanding friendship, was shown in the left photograph. Thirdly, the couple felt that people’s enjoyment of the game was captured by the photographs. The final point was that the inside of the village hall could be seen via the photographs. These photographs indicate the significance of social relationships, social participations, and the place where frequent social activities of the couple took place in their life within the defined neighbourhood.
4.5.5 Initial Impressions of the Neighbourhood

Diane and Dave had become closely integrated with their neighbourhood as was illustrated through their frequent interactions with their social networks and the place where they attached to and had a sense of belonging. Over 40 years, the couple’s interactions with their neighbourhood formulated part of their life stories. Within their defined neighbourhood, the couple’s social networks, comprised of their friends and close neighbours who were located near to their property, which provided opportunities for regular social interactions. The places, particularly the village hall, where the social activities took place, held specific meanings to the couple and they identified themselves as being emotionally attached to these places, which gave them a sense of belonging. The village hall was where Diane and Dave’s social life was centred and where their social events largely took place. Frequent contact with this place further intensified the couple’s emotional place attachment as time passed. The couple’s interactions with people and the places influenced their experience of living with dementia and shaped their biographies over time. Diane and Dave’s experience of living in, and their close connection to, their neighbourhood explained why the couple had lived in the village for over 40 years.

This couple placed a major emphasis on the importance of the local committees they joined. Although the family was identified as ‘the most important’ and provided support for Diane to continually exercise her autonomy, this couple did not perceive their family as part of their neighbourhood due to the physical distance from them. This reiterates the significance of the interconnections of people and places near to their home. In addition, the neighbourhood map emphasised the social ties within a close distance, the places within the village where social events took place, and the frequency of contacts between people and the places. Therefore, the couple’s connection and attachment to their self-constructed neighbourhood was manifested via their interactions with their social ties and places.

Diane and Dave were enabled to interact with their neighbourhood through social activities organised by the local committees, with a greater focus upon the Over Fifties Club, this indicates that sociability in the village seemed to be defined and structured by age. Such age structured sociability was also captured by the photographs. The local
committees acted as a proactive agent in facilitating the establishment and maintenance of friendships and helping biographical continuity when living with dementia as well as promoting social citizenship for its members. The committee’s function of being an ‘agent’ was also illustrated by providing opportunities for Diane’s social involvement and engagement with a number of community activities with the support from Dave and her social ties. This type of social network support had a positive effect on her quality of life and ability to maintain autonomy and biographical interests. While there were frustrations with aspects of her social participation from her own perspective, Dave’s support helped Diane continually engage with social events and this engagement provided her with an opportunity to maintain her personal appearance, this was an important aspect of engagement with social activities for Diane. She liked to put a little bit of make-up on when going out with the family or friends. Even when she was in hospital, she still took her expensive skincare products with her. Diane’s personal appearance meant a great deal to her as part of her social presentation and biography despite the decreased ability of active social involvement.

Although the leisure places were well facilitated and easy to access, the lack of provision of local amenities, especially grocery shops, was deemed only as a potential issue as Dave was still able to drive to another supermarket for the grocery shopping. However, Diane felt that they would be in real trouble if Dave had to give up the driving, because the public transport was not convenient for them to access and use due to the frequency of the service which was only hourly. Easy access to quality local grocery stores and adequate public transport was rated highly for the couple, and was brought more sharply in to focus by the potential of Dave losing the ability to drive as he aged.

4.5.6 Summary

Over the year of my involvement with Diane and Dave, they defined their neighbourhood as their social network within a close distance of their home and the places, especially the village hall, where their social activities normally took place. Their social network was where the couple identified themselves belonging to and the places that they attached to. Their close integrations and connections with their neighbourhood were mainly via the local committees, which positively affected their biographical continuity by facilitating constant engagement with the community and
participation in social activities. Such group-based activities also promoted their sense of social citizenship. Additionally, Diane gained significant support from her family and neighbourhood community to enhance her ability to exercise autonomy and to enable continuation with her biographical interests when living with dementia. After living in the village for over 40 years, the couple’s experiences of interactions with their neighbourhood social ties and places formulated part of their life stories. Their emotional attachment and a sense of belonging to their neighbourhood influenced their neighbourhood perceptions and affected their experiences of living with dementia.

4.6 Case Study 4 – Jonathan and Jackie

Main Storyline: Physical and Virtual Places and Outdoor Spaces

4.6.1 Background

Jonathan and Jackie were the fourth couple recruited in this PhD study, and I visited them at their house 10 times over an eight-month period from December 2011 to July 2012, and a total of eight hours spent in gathering data with them. The main activities that we undertook during each visit are summarised in Appendix 9.

At the time of recruitment, Jonathan was 66-years-old and lived with his 66-year-old partner, Jackie. They had been living together since 1988 and moved into their current owned, terraced house in 1990. The couple’s property was located in a suburban area within recruitment area A and about one and half miles northwest of a main town centre (Office for National Statistics, 2011). The UK Census of 2011 shows that this suburban area has a higher immigrant population than the national average and a lower level of residents born in the UK. With regard to the age profile of this area, the population as a whole is younger than the national average. After living in the area for over 20 years, Jonathan and Jackie felt that they could easily access a wide range of amenities, and this was important for their daily living.

Jonathan was diagnosed with Alzheimer’s disease in September 2010. This diagnosis was not a surprise for both Jonathan and Jackie, because Jackie “knew there was something wrong with Jonathan and she insisted on having [him] checked up” (Transcript: 15/06/2012), she had observed a change in Jonathan’s cognitive functioning around performing daily tasks. Jonathan’s Alzheimer’s disease particularly affected his short-
term memory, and he felt embarrassed when suddenly forgetting things, such as what he was going say during a conversation. Apart from Alzheimer’s disease, Jonathan also lived with Parkinson’s disease, which was diagnosed in 1991. Jonathan’s Parkinson’s disease caused severe pain at times and had an impact on his mobility, meaning he could barely walk or stand up for more than a few minutes at a time on his bad days. Jonathan described his experience of the pain as: “it’s killing me” (transcript: 19/02/2012). This constant pain also affected his ability in indulging his passion for carpentry and this had now become a stressful and painful experience, stressful because of the decline in his cognitive functioning and painful due to the ongoing chronic pain he suffered. In addition to Alzheimer’s and Parkinson’s diseases, Jonathan lived with other chronic conditions, including prostate cancer, arthritis, cataracts in one eye, and psoriasis. Despite that, Jonathan believed that his quality of life was good overall.

4.6.2 Family and Relational Dynamics
Although Jonathan’s Alzheimer’s disease caused his short-term memory deficits, he was relaxed about this, mentioning: “it’s one of them things I can’t do anything about it, so it’s no good for me worrying about it” (transcript: 25/03/2012). Jonathan’s response to his condition was in part due to his personality, he perceived himself as: “too laid back” (transcript: 29/01/2012). Conversely, Jackie’s attitude towards Jonathan’s condition seemed the opposite, and as such she seemed to raise more concerns and worries. Jackie strongly believed that Jonathan had lost his ability in doing many tasks that he used to do owing to his cognitive impairment. After consulting with doctors in the memory clinic, Jackie had successfully managed to get appropriate medication for treating Jonathan’s condition. Having taken this medication for a few months, both Jonathan and Jackie saw some improvements in his symptoms, such as improved short-term memory and motor coordination. Consequently, Jonathan started engaging more with his biographical interests that he had not previously been able to do, such as using the computer and doing carpentry in his workroom. After seeing these improvements, Jackie emphasised the importance of early diagnosis and treatment: “the sooner you get on the medication the better it is for the person. He’s proved that…it slows down the deterioration…but I mean the point is because they don’t diagnose people soon enough that’s when they have all the problems” (transcript: 24/06/2012).
With regard to family structure and its dynamics, the couple only had children from their previous relationships but not between them: Jonathan had three girls and one boy from a previous marriage, whilst Jackie had three girls and seven boys from past relationships. All of their children lived quite a distance away from the couple’s current home, and the long distance might be one factor that impacted on the frequency and ways of the couple contacting their own family, in particular for Jonathan.

Jonathan met with his children every three or four months, either he drove down to see them at a time of his choosing or they came up to visit him. For instance, his eldest daughter visited him for his birthday and they then went out for a meal to celebrate. When Jonathan’s son Dave came, he often brought his wife and two girls to see Jonathan together as a family. Jonathan usually described Dave as his “only son” (transcript: 27/04/2012) to express his feeling towards his son and as a reflective regret about the loss of his marriage, saying: “it’s all my fault that’s why. I shouldn’t have divorced; I should still be with my ex-wife…” (transcript: 27/04/2012). Despite these concerns, Jonathan still had a happy life with Jackie, even though the relationships between Jackie and Jonathan’s respective children did not go well, as Jonathan mentioned: “she does not get on with them [his four children] wonderfully well, but she tolerates them” (transcript: 27/04/2012). In contrast, Jackie only had regular contact with one of her children, Ben, whereas her other children simply telephoned occasionally. Jonathan believed that Jackie’s detached family relationship might be because: “they never forgave her for leaving and the way Jackie looks at it is that ‘if they don’t want me, I don’t need them’” (transcript: 27/04/2012). During my visits, Ben and his partner were staying at Jonathan and Jackie’s home as Ben had lost his job. Jackie regularly used descriptive phrases like “what a nightmare” and “pain in the neck” to illustrate her feelings about the current situation. Although Jackie described herself as being ‘selfish’ - in part to explain her reaction to her son and his partner - my impression of Jackie was the opposite as I recorded in my reflective notebook on the 4th December 2011: “overall, she was a sensible person.” Certainly, Jonathan thought that they both did as much as they could to help Ben and his partner by providing a safe shelter and meals as well as giving Ben’s partner lifts in the car to her place of work.
In general, Jonathan seemed to be closer to his children than Jackie. However, despite these diverse and often conflicted family relationships, at the end of my second visit, enough trust had been established and detailed description of the family structure had been provided, I then created their family genogram presented in Figure 22.

Jackie was the main carer for Jonathan, and she described the way she looked after him as: “I had to watch him more, and always wanted to know where he was and what he was doing” (transcript: 24/06/2012). The onset and progression of the dementia altered the relation from a couple’s relationship to becoming more like that of carer and care recipient. However, this role change was less when compared to the previous three couples as Jackie was used to undertaking the majority of the home chores. Fortunately, she mentioned that she enjoyed doing housework, such as cooking and baking. Whilst Jonathan’s chronic conditions affected his capacity, Jackie encouraged him to undertake some tasks in the home and assisted him if required. On his good days, he tried to help Jackie as much as he could, such as by hoovering, washing up, washing the car, and engaging with other tasks in the garden. Undertaking these tasks also enabled Jonathan to gain a sense of autonomy.

Jonathan believed that Jackie was excellent in building up his confidence as she was fully aware of his (remaining) ability and committed to support him. Jackie did this by encouraging him to undertake different types of tasks, providing him with ideas, appreciating what he had done, and illustrating how proud she was about what he could do and what he had done to give him a sense of dignity and purpose. From Jonathan’s point of view, Jackie’s encouragement and motivation towards him played a significant role in his confidence and day-to-day life, particularly living with multiple long-term conditions.
Figure 22. Structure of the Family of Jonathan and Jackie
Jonathan and Jackie’s close relationship was further illustrated by exchanging the role of care and care recipient. This exchange was pronounced during and after Jackie’s bowel cancer operation, Jonathan took great care of her as his Alzheimer’s disease had improved due to appropriate treatment. This operation unfortunately triggered Jackie’s fourth stroke, which caused her to lose the function of her left arm. This loss limited Jackie in doing what she used to do and she found it very difficult to accept this declined functioning. During this period, Jonathan supported, and took care of, Jackie a great deal. I captured my observations and thoughts on these events in my reflective notebook on the 15th June 2012:

“The couple’s relationship seemed to have become even stronger. I could see that Jackie was gradually getting better each time I visited, however, although sometimes she was still unable to participate in the conversation. In fact, from my fourth visit onwards, Jackie only joined our conversation as and when she felt up to it.”

Nevertheless, Jonathan always gave a detailed account about Jackie constantly trying to keep herself active and undertake domestic chores in the way she used to, but in a slightly diminished way. As Jackie’s attitude and behaviour towards being active both physically and mentally and saw the benefits of doing so in her health, she strongly believed that Jonathan would receive the positive outcomes if the similar stimulation strategy was applied along with her increased understanding and knowledge of dementia. This explained why she encouraged Jonathan to be both physically and mentally active, such as inspiring him to do his carpentry work and to read newspapers. However, the application of such a stimulation strategy had caused extra stresses for Jonathan who seemed to be reluctant to do more things when he had already been struggling with several conditions; this occasionally led to a more contentious relationship from Jonathan’s point of view.

Nevertheless, as a couple, Jonathan and Jackie had a strong and supportive relationship and bonded through the experience of living with dementia and other conditions. This commitment and togetherness had a positive effect on their daily life, regardless of their
own detached family relationships. When uncovering the deep feeling about what was important for them, they both perceived each other’s health to be the most important.

4.6.3 Mapping the Neighbourhood

4.6.3.1 Personal Meanings

After discussing the family and relational dynamics, it became apparent that the neighbourhood was a meaningful concept and an essential context to Jonathan and Jackie that they were willing to discuss and identify with. Consequently, from my second visit onwards, we talked about the couple’s understanding of a neighbourhood and what it meant to them personally. Having lived in a suburban area since 1990, Jonathan and Jackie initially defined their neighbourhood with a neat description of: “just this road... each side of the road” (transcript: 29/01/2012), including 51 Victorian terraced houses. The couple took a photograph of the road to show what their neighbourhood looked like, as seen in Figure 23.

Figure 23. The Road

Jonathan and Jackie identified that convenience and easy access to local facilities was important and became more so as they aged. Jackie gave a long account of their neighbourhood community and what it meant to their daily life at the present and to predict the potential effect on their future life when getting older:

“We like it here because there’s a chemist round the corner. There’s a supermarket down there. There’s everything we need, there’s a park and...
everything in it so we just like it … when you get older you have to bear that in mind. Because you won’t always be healthy, you might not always be able to drive into town. And there are loads of buses here as well, very, very convenient. We just walk to the end of the road and there’s loads of buses. Everything’s there.” (transcript: 04/12/2011)

After discussing the key feature of easy access to local services, Jonathan and Jackie were happy to engage in a conversation to further explore their neighbourhood landmarks. This concept encouraged Jonathan to think about the construction of their neighbourhood, and led to the outcome of an enlarged neighbourhood from “just this road” to “… mainly these sort of three or four streets really, I’d call my neighbourhood” (transcript: 24/05/2012). These streets often took twenty minutes for Jonathan to walk around. Furthermore, Jonathan put a major emphasis on a local park and described it as “very important” (transcript: 15/07/2012), as either Jonathan or Jackie, depending on their health, went there every morning and evening to take their dog, Paisley, for a two-mile walk. The couple photographed the park, as shown in Figure 24, to portray the significance of the park in their daily life and to draw attention to the green space and soothing environment.

Figure 24. Local Park
When further discussing the importance of the local park, it was clear that Jonathan and Jackie’s bond to this space were established and facilitated via frequently walking the dog, Paisley, to whom the couple had a strong emotional attachment; the dog is shown in Figure 25. Paisley was a seven-year-old, rescue dog. The couple had Paisley for about three years and saw her as part of their family, saying: “they [dogs] are a tie...she’s his [Jonathan’s] best friend” (transcript: 17/07/2012). The couple used this photograph, which captured a specific moment of the dog sitting on their sofa, to illustrate Paisley’ position as a family member and the importance of her in their lives.

Figure 25. Paisley

In addition to Jonathan’s attachment to outside spaces, Jackie agreed with Jonathan’s enlarged definition of their neighbourhood and she then built on this herself by adding-in more context: “the locality where you work [she used to work in a local supermarket], where you live, you know, the shops yeah ... [the neighbourhood would be] the whole [suburb] area” (transcript: 24/06/2012). Consequently, Jonathan and Jackie both defined their neighbourhood as the whole suburban area as a result of the further exploration of the key features of their neighbourhood and what these features meant to them, whilst Jackie focused on ‘the shops’, which referred to a local grocery shopping centre as shown in Figure 26.
This photograph was taken and chosen by the couple to demonstrate their neighbourhood because i) this shop was just around the corner and located within their direct neighbourhood boundary; and ii) the price was more acceptable for the couple, particularly for Jackie as Jonathan perceived her in the following way: “she’s going to the most beneficial place [for shopping]” (transcript: 15/07/2012).

4.6.3.2 Visual Presentation

Once we had discussed the neighbourhood, its boundaries and its personal meanings for Jonathan and Jackie, we then moved towards co-constructing a neighbourhood map to illustrate the places which the couple connected and re-connected to. On my sixth visit, Jonathan and I began the co-constructive mapping process and he followed my general guidance and used the materials I provided as described in chapter 3; unfortunately, Jackie was not well enough to take part in this process due to her recovering from an operation and the effects of her fourth stroke. However, I did check with Jackie to ensure that the map also represented her neighbourhood once it had been completed.

The drawing was carried out on a table in the lounge of the couple’s home while Jonathan and I sat opposite to each other. Jonathan wanted to draw the map to exactly reflect the road and street names and geographical locations. However, he could not
remember, or did not know them all, so he decided to use a local map to prompt him with the detailed information about the area. After his first attempt, he was unhappy with how the map looked and said he would like to continue with it after the interview. I reflected on my observation of Jonathan being a perfectionist and recorded this in my reflective notebook on the 24th May 2012: “Jonathan aimed to do everything perfectly, always tried to present the best to people, and so far he was the only informant with dementia who produced the map independently in my study.”

As he promised, on my seventh visit, Jonathan showed me two maps that he had produced and asked me to select one as the final map. To ensure the chosen map was the best representation of the couple’s neighbourhood, I reflected the question back to him and explored which one he thought would provide the most representative picture of their neighbourhood. Subsequently, he chose the one with a circled area, which clearly illustrated the couple’s direct neighbourhood, even though he felt the outside of the circle on the map was also part of their neighbourhood. The circled area was pointed out in Figure 27.

Once the final neighbourhood map was selected by Jonathan, I double-checked with Jackie who agreed that the map also represented her neighbourhood. This was done during my last two visits when Jackie physically felt up to participating in the conversation with me. For the purpose of anonymity, the names of local roads, parks, and a public house have been redacted. However, to make sure the couple’s house can be easily seen, Jonathan had pinpointed their location, marked as ‘home address’, on the neighbourhood map. The couple’s direct neighbourhood consisted of the three streets, a local club, a grocery shopping centre, a chemist, a hairdresser, and a florist. The neighbourhood map also covered a local park, indicated on the right side of the map, where the couple walked their dog every day, and a general practice, shown near to the other park, where the couple felt it was crucial to be able to easily access, especially as they aged.
Within the circle, it was the couple’s direct neighbourhood.
4.6.4 Explaining the Neighbourhood

After co-constructing the neighbourhood map, an opportunity was raised to reflect on the contents and to further elaborate upon how Jonathan and Jackie interacted with their neighbourhood. Based on our earlier conversations, easy access to local amenities within the neighbourhood community was probably the most important element that kept Jonathan and Jackie living in the area for over 20 years, such as a local shopping centre, a local sports club, a doctor surgery, and a park. These places held specific, significant meanings in the couples’ lived experience which, in turn, gave them a sense of belonging. From our early conversation, the local park was ‘very important’ to Jonathan. When he took the dog, Paisley, for a morning walk, he often went along the main road towards the park, walked all the way around the park, headed to a local paper shop to pick up the newspapers, and then came back home. Reading the newspapers was a must-do task for Jackie every day and she enjoyed this enormously. The park was the place where Jonathan and Jackie’s routine activity took place, and where they spent time together with their dog that gave them great pleasure. Thus, the couple emotionally attached to this place that captured their life stories and held specific meanings to them.

When the couple took Paisley for a walk, they always took care of the environment by bringing plastic bags with them to pick up the dog’s mess or other rubbish on the pavement. This was due to the fact that the couple often saw other people throwing their garbage on the ground rather than putting it in the bin, so they took the time to pick this up and dispose of it to help keep their area clean. This demonstrated the way in which the couple connected to their neighbourhood and their connection to this physical surrounding as an extension of their home in that they wanted it clean and looking nice. Living in a clean neighbourhood environment was important for the couple, and Jonathan expressed his emotional connection to his neighbourhood by raising concerns that some local residents still left their bins outside, even though the date for collecting the bins had changed, and this change was communicated out via leaflets.
Easy access to local facilities was the key factor for the couple living in the area for a long period. Jackie recounted a detailed story of their perceptions of the neighbourhood community and what it meant to them at the present time and in the future:

“It’s the flat ... both of us are slightly disabled. I’m slightly disabled and he’s getting quite bad and everything’s close, so if we can’t drive any more then we have everything round us that we need. The doctor’s is just up the road, the chemist is just round the corner, the post office, the banks, and everything we need is accessible ... So if they stop us driving for any reason in the future we have everything we need round us.” (transcript: 15/07/2012)

Despite all the positive factors around their neighbourhood, the couple expressed concerns as to neighbourhood safety and security. Jonathan described that there were some ‘foreigners’, such as Hungarians and Polish people, living in the neighbourhood, and they tended to drink to excess and then “shout and holler in the earlier hours of the morning” (transcript: 29/01/2012), and sometimes violent behaviour occurred. Such behaviour evoked unsafe and insecure feelings for the couple; such feelings altered their perception of how and when it would be safe to walk the dog.

4.6.4.1 Interaction with the Neighbourhood

From our conversations it was clear that Jonathan enjoyed doing carpentry and so Jackie encouraged him to design and build their own furniture. As a matter of fact, most of their home’s furniture was made by Jonathan. His engagement with this type of activity enabled him to become an active home-maker. Jonathan also exercised this role in creating their own fish pond and waterfall in their garden, as shown in Figure 28. Jackie took the photograph to show the fish, the fish pond, and the plants, and more importantly, to present Jonathan’s dignity and autonomy. She described the meaning of the fish pond for them: “that’s his [Jonathan] pride and joy, his pond. It’s only a little pond but I like it as a little pond” (transcript: 15/07/2012).
Not content to talk about it, Jackie was keen to show me, and ushered me into the garden to show off ‘Jonathan’s pond’. This fish pond was an illustration of Jonathan’s physical and emotional investment in their garden, and he also worked hard in maintaining the garden. The fish pond and the garden clearly demonstrated how Jonathan actively made this space into a meaningful place that captured part of his life story and represented his biographical interests. This place provided Jonathan and Jackie with pleasurable experiences when spending time there, as Jackie said:

“We sometimes sit in the garden, have a cup of tea, and listen to the water, it’s lovely...we feed the fishes and they jump up and they sort of go up and they sort of flick their tails. It’s amazing to watch them.” (transcript: 17/07/2012)

In addition to the establishment of the fish pond, Jonathan also decorated the pond using lights with different shapes and colours. The couple felt the garden as so beautiful when all the lights were on in the evening as shown in Figure 29. The garden and the fish pond held a significant meaning for the couple and recorded part of their life stories, particularly for Jonathan in his daily life, which, in turn, gave him a sense of belonging. Jonathan’s attachment to the fish pond was also strengthened over time which had an effect on his personal biography.
The couple had owned these fish since 1997 and they loved their fish, particularly Jonathan, as Jackie described: “these fish are his [Jonathan] pride” (transcript: 25/03/2012), and she liked the biggest fish the most, saying: “he comes right up and nudges me” (transcript: 25/03/2012). Jonathan and Jackie gave a great deal of attention to their fish and gave me a long, detailed account about the fish, their names and behaviours. The couple’s attachment to the fish was also illustrated by the fact that they believed that looking after the fish was their responsibility rather than a burden, and they took this responsibility very seriously by taking great care of them and not leaving them for more than one week, even for their holidays. Thus, it would probably be safe to say the fish were almost family to them. The couple’s efforts were rewarded by their pleasurable experience of watching the fish playing, and such experience strengthened the couple’s bonds to the fish pond and formed part of their biographies.

Jonathan and Jackie continued to explain how they interacted with their neighbourhood, outside their house. The couple included a local sports club as part of their immediate neighbourhood, as shown on the neighbourhood map in Figure 27. Jonathan went to this club every Monday evening with their next door neighbour, Richard. Going to the club gave Jonathan an opportunity to meet people while watching Richard playing snooker. Although socialising with people in the club did not help Jonathan form any new friendships, it gave Jonathan a sense of enjoyment and helped maintain his current friendship. Occasionally, Jonathan would take Jackie along to the club as they both
found this a pleasurable outing and a chance for interaction with others. Jackie also 
gained a sense of enjoyment from meeting with her friends for lunch and keeping in 
touch with people she used to work with. Those people Jackie had regular contact with 
lived nearby and this close proximity helped facilitate opportunities for frequent 
socialisation.

Jonathan and Jackie’s close relationship with their immediate neighbour, Richard, and 
his family, was also illustrated by them feeding Richard’s pet when he went on holiday. 
This task also gave them considerable enjoyment as they both loved animals. In this 
case, pets were a basis for connection and neighbourliness. In general, the couple were 
very kind towards their neighbours; for instance, although they did not know James very 
well, they invited him to share Christmas with them. James was a neighbour across the 
road who lived on his own and who suffered from a number of health conditions. 
Jonathan and Jackie’s kindness did not mean that they had close social relationships with 
other neighbours. Unfortunately, the couple seemed to experience a difficult 
relationship with one particular neighbour and felt that this neighbour abused their 
trust. However, the couple used to have a close relationship with their previous 
neighbours who unfortunately moved out 10 years ago. The change in the composition 
of the neighbourhood community population affected the couple’s experience of living 
in the same neighbourhood, and others’ attitude and behaviour towards them 
influenced how they responded back.

In addition to going to the club with Richard, Jonathan specified people with whom he 
had contact via Facebook and email as part of his neighbourhood. These could be 
labelled as a ‘virtual neighbourhood’, even though those people were not reflected on 
the neighbourhood map. Jonathan had started using Facebook in 2011 as a means of 
communicating with his friends and children, and he often spent half an hour to one 
hour communicating with people on his good days. Thus, Jonathan’s definition of the 
neighbourhood also included his connections via the internet, and this point was also 
echoed by Jackie’s view. I reflected on his view and noted my thoughts in my reflective 
notebook on the 25th March 2012:
Jonathan was the only person living with dementia in my study using Facebook to connect with his family and friends and included this virtual neighbourhood as part of his neighbourhood. This inclusion was an innovative approach, and Jonathan made a significant point to illustrate his boundary-free neighbourhood.

Further to using the computer for contact with friends and family, Jonathan and Jackie also used it to keep up to date with what was going on in their neighbourhood and to find information about their Neighbourhood Watch. What’s more, the role of this technology in the couple’s daily life was demonstrated by its usage in online shopping or for booking a holiday. When booking a holiday, Jonathan also put Jackie’s wishes first, and he mentioned that he would not dream of going anywhere without her, regardless of whether he would enjoy a holiday on his own. This was a moving illustration of a strong, supportive bond between the couple.

4.6.5 Initial Impressions of the Neighbourhood
Neighbourhood places played a significantly important role in Jonathan and Jackie’s lives, with a specific focus on the places and outdoor spaces. These places and spaces were where their routine activities took place, and their experiences of these activities formulated part of their biographies. Regular contact with places increased their familiarity with, and facilitated a sense of belonging to, the physical environment; this feeling intensified over time to form emotional place bonds. The neighbourhood places captured the couple’s life stories and held specific meanings for them, and these meaningful places would further inspire their interactions and eventually influence their biographical relationships with their neighbourhood.

The person-to-place bond to the local park was established via their dog, Paisley, who acted as a connector, this bond then further shaped the definition and meaning of the neighbourhood for the couple. This type of person-to-place bond was also illustrated by the couple’s attachment to their garden and particularly to the fish pond; the fish, that the couple had for many years, facilitated this connection. Although these fish required a significant amount of Jonathan’s time in looking after them and therefore affected the duration of the couple’s holidays, the fish stimulated Jonathan’s role in active contact
with the place and helped him establish emotional place attachment. These experiences and feeling further shaped his life story.

Jonathan’s physical investment in their home was also illustrated by his active role in making most of their furniture. Creating, through his love of woodwork, gave Jonathan a great deal of enjoyment and purpose, helped build and sustain his confidence, maintained autonomy, and enabled his biographical continuity. Jackie was so proud of what Jonathan had done for their house that she took a photograph of him sitting in their kitchen that he built, as shown in Figure 30. Jackie chose this photograph to illustrate i) Jonathan and his health were most important to her; ii) her pride in his talent and capability to maintain his dignity; and iii) his ability to continue with his passion which gave him a sense of satisfaction, autonomy, and continuity in his biographical interest. Home played a central role in Jonathan and Jackie’s daily life and held historical significance and diverse meanings for them. Taken together, home gave the couple a sense of belonging and represented aspects of their life stories.

Figure 30. Jonathan in the Kitchen that He Built

In addition to the emotional significance Jonathan and Jackie attached to places, they acknowledged that the important element for them was easy access to local amenities in their neighbourhood. This feature was one of the key factors that kept the couple living in the current area for nearly two decades, and demonstrated they were thinking
ahead to future selves and anticipated the potential benefits of living in this neighbourhood when getting older, particularly around the environmental design, the availability and accessibility of a local shopping centre, a general practice, and public transport for their (daily) essentials when they would reach the stage of being unable to drive. Based on their experience of living in the neighbourhood, the couple reflected on their current life and were able to predict their future interactions with their defined, self-constructed neighbourhood where they desired to remain living when becoming older. The couple also stressed the significance of their neighbourhood being clean, safe, and green.

Apart from the couple’s attachment to the places and spaces, Jonathan and Jackie also acknowledged their interactions with their social ties and how this associated with their daily lived experience. In addition, Jonathan viewed his neighbourhood beyond a geographical distance and placed a focus on the virtual neighbourhood where he kept regular contacts with his friends and family via Facebook and emails. This innovative way of seeing neighbourhood was also supported by Jackie’s belief that the virtual neighbourhood formed an integral part of their neighbourhood. The use of technology provided a modern way of understanding the relationships between the couple and their social ties and brought a new dimension into their neighbourhood construction. Above all, technology played a significant role in affecting Jonathan and Jackie’s social relationships and influencing their biographical continuity and experiences of living with dementia.

4.6.6 Summary
My involvement with Jonathon and Jackie lasted almost a year, and during this time, it became clear that an important feature of their neighbourhood was easy access to local amenities and this positively impacted on their daily lived experience of dementia. The couple strongly attached to their neighbourhood places, and their place attachments were established and facilitated via their routine activities and social interactions. It was worth noting the significant role pets played in the couple’s interactions with the physical environment, facilitating the process of establishing their place attachments, and providing them with enjoyable companionship. Thus, pets forged a specific connection with the couple and had a major influence in shaping their neighbourhood
construction and daily experience. The couple’s experiences of interacting with their neighbourhood places and social ties over time contributed to their biographies. Overall, the enabling neighbourhood positively affected Jonathan and Jackie’s daily living and enabled their biographical continuity when becoming older and living with comorbidities.

Although Jonathan placed a boundary on the map as their direct neighbourhood, in fact, the couple’s understanding of their neighbourhood stretched beyond a geographical space as a result of including a virtual neighbourhood. This non-geographically bounded neighbourhood added a new dimension to the daily experience of living with dementia. The use of technology as a means of keeping in contact with friends and family would help mitigate the potential for reducing contacts with social ties as physical health issues developed. Communication technology had an important place in the couple’s daily life, particularly for Jonathan in enabling the continuity of his social connections, even though there were still many things he could not do as an effect of Alzheimer’s disease and other chronic health conditions. In closing, the couple’s lived experience in their neighbourhood was influenced by their connection and attachment to their social and physical surroundings which, in turn, shaped their neighbourhood perception and biographies.

4.7 Case Study 5 – Emily and Tim

Main Storyline: Family and Friends

4.7.1 Background

Emily and Tim were the last couple recruited in this study and I visited their home nine times during a two-month period from June to July 2012. A total of eight hours and four minutes were spent in collecting data with the couple, and the main activities that we undertook during each visit are documented in Appendix 10. The rationale for this timeframe was described in chapter 3.

At the time of recruitment in June 2012, Emily was at age 76 and lived with her 79-year-old husband, Tim. The couple were married in 1955 and had lived in their current rented, terraced bungalow since 2001. The couple’s property was located in a village within recruitment area B. The village is midway between two towns and has a
population of 3,913 and the population of the village as a whole is older than the national average (Office for National Statistics, 2011). After living in the village for 11 years, both Emily and Tim described the area as: “it is nice around here” (transcript: 14/06/2012).

Before moving into the current bungalow, Emily and Tim had lived in a brand new, two-bedroom council house after their business of 27 years, running five public houses, went bankrupt. That council house was situated in a village about six miles away from their present address. The main reason for their relocation was due to Emily being incapable of climbing stairs after she had a fall and needed a hip replacement. At that time, the couple’s youngest daughter, Alex, moved back home and looked after her mother, as her dad, Tim, was admitted to hospital for his prostate cancer operation. Soon after having the hip replacement, Emily suffered a heart attack and her existing living arrangements became too challenging to negotiate. Accordingly, the council officer offered the couple a brand new bungalow, which the couple eagerly accepted and moved into. Without stairs to negotiate it was easier for Emily to move around their home with the assistance of a walking stick. This enabled her to maintain a certain level of independence and autonomy at home.

Apart from Emily’s heart condition and artificial hip, she also lived with other physical conditions: type II diabetes, an enlarged liver caused by her previous excessive alcohol consumption, cystitis, rheumatoid arthritis, glaucoma, and Alzheimer’s disease, which was diagnosed in January 2011. The combination of glaucoma and Alzheimer’s disease had restricted Emily’s ability to drive, and she expressed the feelings of her diminished independence after giving up driving as follows: “… fed up actually because … I wanted to go out to play bingo [in the football club] … I can’t go out on my own” (transcript: 20/06/2012). Despite the fact that Emily lived with multiple conditions, she was quite stoical about her overall well-being and said: “I’m not frightened to die” (transcript: 20/07/2012). Meanwhile, Tim lived with hypertension and migraines which were generally well controlled.

4.7.2 Family and Relational Dynamics

Emily’s Alzheimer’s disease did not affect her short-term memory as Tim pointed out:
“She’s never lost her memory, and she knows who … this morning we was in the shopping centre … and a lady was coming the other way, and she said ‘look who this is’, and I hadn’t recognised her and it was the lady who used to keep the post office … but I hadn’t recognised her.” (transcript: 14/06/2012)

Tim, comparing himself with Emily and her ability to remember and recognise others, seemed to minimise the impact of dementia on Emily’s memory. Indeed, Emily could even remember that the loss of her ability to spell and write had led to the diagnosis of dementia:

“Emily: Well because I took my books [Emily used to write books], right, to a club, they’d asked me to go and talk to the people and then when I’d finished there was an old man, well won’t say an old man, but I said ‘would you like me to autograph it my dear?’, so he said ‘oh yes please’. So I said ‘what’s your name?’, and he said ‘Fred’. And I couldn’t say Fred.

Tim: You couldn’t spell it.
Emily: I couldn’t spell.
Tim: You couldn’t write it or spell it … so it was roughly six months before she was diagnosed.” (transcript: 14/06/2012)

In addition, Emily’s Alzheimer’s disease also affected her ability of going to the toilet, and as such she needed Tim’s help. Emily shared her feeling of loss of self in the following way: “I feel very embarrassed when I do make a mess, yeah, that’s not me, never has been … the only thing that worries me is me going to the toilet” (transcript: 06/06/2012). Meanwhile, Tim was resilient to adjust to change and took up new role and responsibilities without any complaints, and he looked ahead, saying: “it will be better when we got a proper shower room… a special seat with wheels on” (transcript: 06/06/2012). The Alzheimer’s disease had also reduced Emily’s motor skills, particularly when using a knife and fork, and impacted upon her ability in performing other daily tasks; for instance, Emily could no longer take a shower without Tim’s help. Emily appreciated Tim’s support and felt that he had done enough for her, whereas Tim felt that was his responsibility.
When living with dementia, the couple’s relationship structure had altered to adjust to changes. On one hand, Emily gained a great deal of support from Tim and felt that he was the most important person in her life owing to her dependence: “*if anything happens to him I don’t know what will happen to me, because there’s such a lot of things that I can’t do for myself, like dress myself, can I? or anything like that*” (transcript: 25/06/2012). On the other hand, Tim was resilient to renegotiate the relationship and was committed to help maintain Emily’s sense of self. In addition to being the main carer, Tim had to take up a new role and responsibility by undertaking most domestic chores, such as cooking and washing up.

It was clear that Emily and Tim had a loving and supportive relationship, and this foundation extended to their close bonds with their children. Emily and Tim had four children, two boys and two girls, who lived about six or seven miles away from the couple’s home. The eldest son, Graham, was 57-years-old, and he was working in a public transport service. Graham was living with his wife, Gina, and she helped Emily and Tim clean their home each Wednesday, although Emily and Tim felt that it was important that they paid her for this domestic work. If Emily wanted to do something on her computer, Gina also helped her. The couple were not always passive recipients as they went to Graham and his family once a week. When visiting Graham, Tim always drove, though should Emily and Tim wish to go longer distances then they enlisted the help of Graham to drive as Tim no longer felt confident in driving long distances or to anywhere unfamiliar.

The couple’s second son, Nick, was 54-years-old and was living with his partner. Nick used to be a heavy goods driver, however, he was currently out of work after he lost his license for drink driving. Emily and Tim only saw Nick every couple of months, which was less frequent than their other children. If Nick came to visit his parents, he would take the train. Despite the less frequent face-to-face contact, the couple still gained a sense of caring from Nick as he often telephoned and checked whether they were ‘ok’.
The eldest daughter, Emma, was 51 and was living with her second husband, her first husband died of liver cancer. The couple often went to see Emma on Sundays for dinner and felt that they always had a ‘great time’ together. The second daughter, Alex, was 49 years-of-age, and had been living with a bipolar condition for 27 years. Alex had periods of in-patient admission for her mental health condition and she continued to see a community psychiatric nurse for help and support. When Alex was in hospital, Emily went to see and looked after her every day. Nowadays, Alex took care of her parents by telephoning them at nine o’clock every morning, because she did not have a car. Emily felt “she’s always … looking after me kind of thing” (transcript; 14/06/2012). From the couple’s point of view, although they got on well with Alex’s family, her house was small and it was not convenient to visit and stay there. Tim summarised this as follows: “normally we couldn’t go there” (transcript: 10/07/2012).

Overall, the couple had close and supportive family relationships, which meant a great deal to them. By the end of my third visit, our discussions enabled me to produce their family genogram as shown in Figure 31. Despite the frequent contact with the family, the couple felt that they led “a very quiet life” (transcript: 25/06/2012) as they estimated that they only went out a couple of times a week.

4.7.3 Mapping the Neighbourhood

4.7.3.1 Personal Meanings

Once we had discussed Emily and Tim’s family and their relational dynamics, it became clear that they had a clear understanding about their neighbourhood. On my third visit, we started discussing what the neighbourhood was and what it meant to the couple. Initially, Emily and Tim shared with me a joint summary of their neighbourhood, the next door neighbours they were friendly with and the places they were familiar with within a proximate distance from their home:
Figure 31. Structure of the Family of Emily and Tim
“Emily: Well it is just an estate actually.
Tim: It's quiet ... We don’t really know anybody else in the area, and we know
the person next door, and we know people by sight.
Emily: And we always speak, you know, when we saw each other.
Tim: But we’ve never got friendly with anybody have we?
Emily: Not really.
Tim: It’s just our neighbourhood is just this little street.
Emily: This is it, and all these houses and flats are just eleven years old isn’t it?
Tim: Yeah. We all very much grew together, but that’s our neighbourhood .”
(transcript: 20/06/2012)

During this conversation, Emily and Tim portrayed their different views of approaching
their neighbours. For Tim, he only knew
people by sight except for the immediate
neighbour, whereas Emily posited a friendly atmosphere that they always talked to
others when seeing them. This divergence might be caused by their personalities. Emily
enjoyed interacting with people and described herself as: “a chatterbox ... because of
writing books” (transcript: 06/06/2012). Tim echoed this self-analysis: “Emily has always
been like that, she’s always been very outgoing, she’s sings, she still sings twice a week,
she’s singing well” (transcript: 06/06/2012). However, Tim perceived himself was “just
the opposite [to Emily]” (transcript: 06/06/2012) and “more of a shy person... a bit more
withdrawn” (transcript: 25/06/2012). Nevertheless, the couple presented their sense of
familiarity with the built environment and drew the same boundary of their
neighbourhood. More importantly, the couple identified their neighbourhood,
particularly relating to the physical environment, as part of their ageing process and
physical conditions.

In terms of the social environment, the couple further explained their relationships with
a few neighbours with whom they were more familiar but did not identify themselves
with. The first neighbour the couple mentioned was Vanessa, who lived opposite and
owned a dog. The couple and Vanessa moved into the current location at a similar time,
so they might have a shared experience of the locality. Occasionally, they had a chat
with each other when they were out. The second neighbour was Sarah, who worked
night shifts in a care home. Although the couple felt that they were not close to Sarah, she was often willing to help them by doing some additional grocery shopping in the local co-operative store should the couple be unable to get out due to inclement weather. Finally, the couple shared their knowledge of the current and previous immediate next door neighbours, the discussion of knowing their neighbours over a period of time cemented Emily and Tim as part of their neighbourhood and gave them a sense of belonging, not only through the social interactions with their neighbours but also through the dimension of time. The previous immediate neighbour, James, who had moved to his daughter’s home to look after her as she had a bipolar condition, rented his house out to Matthew, who was the couple’s present next door neighbour. Matthew had recently had an operation for lung cancer. Emily and Tim felt they had lovely immediate neighbours and knew much of their histories, but the couple did not class their immediate neighbours as friends. The description of the couple’s neighbourhood focused on geographical boundaries, places, and people, yet there was also a notion of the importance of time that featured within their definition, which provided an additional relational context for the couple, although both Emily and Tim did not identify themselves with their neighbours as an important social group. Nevertheless, for Emily and Tim, the area was described as “a real old village” (transcript: 29/07/2012) which for them meant that neighbours tended to know one another, would look out for each other, and through this forge an informal community.

4.7.3.2 Visual Presentation

After discussing the neighbourhood and its personal meaning for Emily and Tim, we began to move towards co-constructing a neighbourhood map to visually represent the landmarks of their defined neighbourhood. When starting the mapping process, the process described in chapter 3 was followed. The carer, Tim, took the main role in constructing their neighbourhood map.

When Tim started drawing the map, Emily immediately recommended the rugby club, the football club, and the Scout room. In addition to Emily’s suggestions, Tim also drew the playing field (this space was for children and was also used for a local tennis tournament and an archery tournament), the houses and flats, and the green grass area where children often played football to represent their neighbourhood. Their ‘little
street’, as shown in Figure 32, was represented and Tim marked their home number on the map as ‘No. 25’ as Emily felt that this was the best way to highlight their bungalow. Tim also underscored the three neighbours, but their real names have been redacted and pseudonyms used instead.

At the end of the drawing process, Tim mentioned: “Emily doesn’t go no further .... If I go up the street [to the local co-op and the post office beyond the neighbourhood boundary] I go up in the car...” (transcript: 25/06/2012). It was clear that the couple defined their immediate neighbourhood as those landmarks within a walkable distance, whilst their social activities extended beyond their neighbourhood boundary.

4.7.4 Explaining the Neighbourhood
Once we had co-constructed the neighbourhood map, Emily and Tim further explained its contents, the significant places, and how they interacted with their social ties. Having lived on the estate for nearly a decade, the couple noted: “lots have changed from what it was before” (transcript: 20/06/2012). Despite that, the couple still connected to places that derived from travelling through time and space over their life span, and as such these places held significant memories and had specific meanings to them. This point is perhaps best illustrated by the fact that there used to be a shoe factory where Emily’s best friend worked and there was a palpable sense of loss once the factory had closed down and her best friend had passed away. Such a place had accumulated over the years within the couple’s life stories and would continue to influence their biography and remain to be part of their locality, even though people and places might be absent and disappear.

Once the factory had closed down, the local borough council bought the land and built 51 houses and flats and five bungalows on it just opposite the football pitch, as seen in Figure 32. When the couple first moved into the estate, Emily used to go to the football club to play bingo, but over the years the numbers of people playing bingo steadily decreased and eventually it stopped. Emily also explained that her passion for football was inherited from her father who was a football referee and this helped cultivate her interest in the sport.
Figure 32. Emily and Tim’s Neighbourhood Map

- Vanesa’s home
- Sarah’s home
- Matthew’s home
- Emily and Tim’s property
In fact, Emily was passionate about sports and watched most sport programmes on the television: “I watch every kind of football ... I love rugby ... oh the tennis, I watch it all” (transcript: 13/07/2012). Although Emily did not actually go to the football club and the rugby club nowadays, these remembered places held her life story, and gave her a sense of belonging to the neighbourhood and a connection to her past. Emily’s attachment to these places also clarified why she immediately mentioned these two clubs when Tim started drawing the neighbourhood map. Indeed, Emily’s passion about sports was also demonstrated throughout my visits. There were a few times when I visited the couple while they were watching the sport programmes at the time, and Emily also invited me to join them: “if you like football, you could watch the football with us then...” (transcript: 06/06/2012). In addition to Emily’s passion about football, she also inherited her talent of music from her father:

“I love musicals... as my father was in a brass band and he used to stand when Memorial Day was on in November and he used to be at the cenotaph at all Saints Church and he’d play the Last Post, and then my brother took it up.” (transcript: 13/07/2012)

Further to the historical and remembered places, the couple’s garden played an important role in their daily life, as Tim shared: “it [the garden]’s important to our bit of life... and we also love our garden” (transcript: 13/07/2012). On my visit of the 25th June 2012, Emily showed me their little beautiful garden, mentioning: “I’ve got loads of roses, and Tim does the baskets ... and that’s a plum tree ... I’ve got a lilac tree, my friend brought it for me for my seventieth birthday” (transcript: 25/06/2012).

This storyline illustrated that Emily’s attachment to the flowers in the garden to emotionally connect with her friend and Tim’s actively making this space into a meaningful place. Not content by simply showing me their garden, Emily also photographed it as displayed in Figure 33.
This photograph illustrates a table, two chairs, and roses. Emily used this image to represent the loveliness of the garden and tried to portray the pleasurable experience they gained when sitting there by detailing that, when the weather was nice, the couple would often sit outside to have a cup of tea or coffee and to enjoy the view of the roses and their garden. The great sense of pleasure the couple gained from watching the flowers was also indicated by another image shown in Figure 34.
This photograph was also taken by Emily to illustrate ‘the Sweet Williams (flowers)’. It became clear that for Emily, the garden was an important space which held emotional significance for them. While their wider neighbourhood seemed to change, their garden was a constant for them and provided an opportunity to maintain a longstanding enjoyable activity. The couple’s attachment to the outdoor space did not simply reflect a pleasant view but also demonstrated their physical and financial investment. This was illustrated when Emily spoke about how the recent weather had stopped them enjoying the garden and how this had impacted on her emotionally in the following way: “all this rain has really depressed me ... I mean we’d got a garden of flowers, and the rain absolutely blew them to bits, and it just depressed me because we spend a lot of money on our garden...” (transcript: 20/06/2012).

Emily and Tim not only personalised their garden but also decorated their home to reflect who they were. For example, in the sitting room, the couple hung a clock on the wall and this clock played Beatle’s music with eight different tunes that played on the hour. The couple loved this clock and enjoyed listening to the music it played. This was also the case for the rest of the family who desired to inherit it from the couple:

“Tim: Because we’ve got four children so now we’d got to the state because we are getting old who is going to have the clock. [Laughter] They’re arguing who’s going to have the clock, so we said ‘shall we take it out and sell it?’
Emily: My daughter … her little girl said ‘Nan, what are you going to do with it?’ I said ‘I am going to put it in my coffin duck so I can have a sing song then.’” (transcript: 06/06/2012)

This storyline clearly indicated emotional attachment of the family, in particular Emily, to the clock and their shared experience when listening to the music. This attachment to, and importance of, the clock was illustrated by the photograph, which was taken by the family and presented in Figure 35. Unfortunately, the photograph only captures part of the clock. The photograph also displays the moment when Tim was resting and Emily was reading a magazine. She enjoyed reading and used to read books until four o’clock in the morning. However, the Alzheimer’s disease had significantly impacted on this
aspect of her life, as Tim described: “since she’s had the Alzheimer’s disease she doesn’t touch a book” (transcript: 06/06/2012). Nevertheless, to continue biographical interest, Emily was still able to engage with some form of reading although not as avidly as before. This photograph appears to capture multiple important aspects of Emily and Tim’s narrative.

Figure 35. Emily and Tim

4.7.4.1 Interaction with the Neighbourhood

From our early conversations, it was apparent that Emily and Tim kept in frequent contact with their family and friends. The couple felt that it was due to Emily’s personality that she had so many friends, some of whom were living abroad. When the couple had a party to celebrate their golden wedding, 160 people attended, even though she had not seen many of them for years. Emily used to write, and send, 135 Christmas cards each year, but now writing the greetings on these cards became Tim’s job due to her cognitive impairment and this was a source of frustration for Emily, as she explained: “…what really upset me is that I can’t write no more” (transcript: 14/06/2012) and “…the only thing I miss is that I can’t write to anybody” (transcript: 13/07/2012). Communication via writing used to be a key vehicle for Emily in maintaining contact with social ties; writing was also a significant aspect of self as she used to be an author. Such ability deficits meant a significant disruption in her biographical continuity. Tim now did all the writing and helped maintain Emily’s relationships with her social contacts, this support played a vital role in the continuity of her biographical interest.
Although Emily had many friends, the couple had six close friends with whom they met once every two or three weeks. These friends lived between 10 to 15 miles away from the couple’s home, and Emily and Tim often “saw them out somewhere, shopping or something” (transcript: 29/06/2012) and sometimes they visited these close friends at home. Occasionally, the couple went a long distance to have a day out while meeting with friends. For example, Emily and Tim went to Skegness on the east coast, and their eldest son Graham took them there as this long drive was a challenge for Tim. On their way back, they went to visit some of their old friends, they had some lunch in a busy café and sat there for two or three hours talking and reminiscing; for Emily “it was absolutely wonderful”, and these trips out and meeting people were vital as she described: “I’ve got to get out” (transcript: 20/06/2012).

Apart from maintaining the existing friendships, the couple had made new friends with those who attended the Alzheimer’s Club each month in a neighbouring town. Emily believed: “to be perfectly honest, the people that we meet up there … are our friends now …” (transcript: 25/06/2012). Tim further explained how they established friendships with the members of the Alzheimer’s Club: “we usually sit, eight of us, together around a table, and we are usually all the same people, every time, so of course you get to know everybody” (transcript: 29/06/2012). At the Alzheimer’s Club there was always somebody to give a talk, Tim gave a detailed description:

“There’s somebody to come to speak to us. The fire service can come or the ambulance service, they explain all the things they do. The police came … that sort of thing to give you that helps you along so … it is a break and see all that’s going, she[Emily] looks forward to going.” (transcript: 14/06/2012).

When attending the Alzheimer’s Club, the shared experience amongst all the members enabled both Emily and Tim to identify with the group and gave them a sense of belonging over time, as well as the pleasurable experience they gained each time.

In addition to the face-to-face contact, technology, such as the computer and telephone, also played a vital role in Emily’s communication with people in the UK and abroad. For
example, Emily contacted some of her friends via email, with Tim’s assistance. Emily also frequently used the telephone to communicate with her family, and sometimes telephoned her 90-year-old aunt who lived in America, and other friends living aboard. The telephone was extremely important to her, and so the cost of calling abroad had to be accounted for by the couple. Fortunately, their daughter-in-law had found a company offering a good deal on calling abroad and she had helped the couple switch providers, saving money and ensuring Emily could remain in contact with her friends.

Having a large social network meant a great deal for Emily and also for Tim. However, the couple were now experiencing a fairly constant loss of friends as they aged. On a few of my visits, the couple mentioned that they had been to funerals or had sent sympathy cards, as Emily shared: “we just lost two more friends this week” and Tim followed the conversation up as: “you go to more funerals than weddings when you get to our age” (transcript: 29/06/2012). Indeed, Emily sadly mentioned: “I’m afraid of this we shan’t have much now ... I’d better start scrubbing some of these [friends’ names] off because they’ve all gone...” (transcript: 13/07/2012). When talking about the deaths of friends, there had been conversations amongst the family around the scenario of what would happen should Tim die, Alex was willing to become a ‘live-in carer’ to fulfil Tim’s role of being a carer and take care of Emily.

The close and supportive family was further illustrated when Tim developed issues with his knee in July 2012. He was experiencing a great deal of pain and his leg was swollen, he was unable to walk without the assistance of a walking stick. At the time, the eldest daughter, Emma, and her family came and brought dinner over to see how her dad was and help carry out some of his domestic duties, such as cooking. It was clear that Emily and Tim retained a significantly important position within the family structure and their children were willing to undertake new responsibilities to look after their parents as and when needed.

During that visit, the family photographed the time when they had dinner together, as presented in Figure 36, to illustrate a strong sense of unity as a family. Tim also neatly summarised: “family’s important” (transcript: 13/07/2012).
4.7.5 Initial Impressions of the Neighbourhood

Emily and Tim defined their neighbourhood as a ‘little street’, a walkable distance, and this walkable distance was captured by the co-constructed neighbourhood map in Figure 32, with an emphasis of their home. The couple’s desire of having a bungalow had come true, and they were in a good economic situation. This was important to them having been declared bankrupt in the past. The couple’s emotional reaction to their bankruptcy was a positive one, Emily described her feeling as “happy!” and Tim responded: “yes, a weight had been lifted off” (transcript: 10/07/2012) as it meant that they were no longer constantly worried by having to find the money for their debts. The couple’s level of satisfaction with the present home was influenced by their past experience. More importantly, Emily and Tim loved their home and were emotionally attached to the garden, as Tim described “it [the garden]’s important to our bit of life...” (transcript: 13/07/2012). This outdoor space gave them a sense of enjoyment and belonging, and it also influenced how they interacted and negotiated with this space and their experiences of these interactions formed aspects of their life stories. As their emotional attachment to the garden was strengthened over the years and they spent more time at home while their neighbourhood shrank, this outdoor space and home significantly shaped their lived experience of dementia and biographies.

The location of Emily and Tim’s home was seen as a nice, quiet area. Within this area, the couple connected and reconnected to their social and physical environments and their experience of these connections formed their life stories. In terms of the social neighbourhood, the couple were integrated with a few neighbours who looked out for
each other, this type of social integration gave the couple a sense of belonging and safety. In relation to the physical neighbourhood, after living in the current location over 10 years, the couple clearly demonstrated their familiarity with the local physical places with good knowledge of the built environment and the changes it had been through. For example, they remembered that an old shoe factory used to stand where there were now 51 houses and flats, and that this factory was where a close, and now departed, friend of Emily’s used to work. Contact with this place gave her a sense of continuity for her past social relationship. Additionally, the physical neighbourhood included places that enabled Emily to connect to her biographical past and biographical interest; such as the football club where she used to play bingo and both the rugby and football clubs held significant meaning for Emily as her passion for sport was inherited from her father. These meaningful places stemmed from the couple’s biography accumulated over the years, which strengthened their attachment to the built environment.

More importantly, Emily and Tim’s lived experience focused on their interactions with their social networks and they identified themselves with their family and friends; this gave them a strong sense of belonging. Emily and Tim had a close and supportive family which was vitally important to the couple and significantly influenced their daily life through intense contact. Family interactions played a significant role in shaping the couple’s biographies, even though their life stories could be influenced by many other factors over their life span. A close, supportive family helped instil their sense of belonging and stability, and as such, Emily and Tim posited a clear picture of their daily life being positively affected by their interactions with the family and a strong sense of unity. Although the Alzheimer’s disease reduced Emily’s ability in performing daily tasks and undertaking activities as she used to do, the support she gained from the family enabled her to continue to exercise her autonomy and maintain her biographical interests. The family’s assistance was also the preferred source of support for the couple when seeking and receiving help.

For Emily, having friends was absolutely essential, and she attributed this to her ‘type’ of personality. From her descriptions, it was clear that social interactions were a pleasurable experience for her. Although she had lost her ability to write, which previously was her main communication vehicle, Tim supported her by carrying out all
the tasks relating to writing to maintain her social contacts and biographical interest. In addition, technology played a role in retaining Emily’s social connections, and it acted as a vehicle in the continuity of her biography. Emily’s biography was partially shaped by her experience of social interactions, then it was equally influenced and maintained through technologically supported interactions as much as physical outings such as going to the Alzheimer’s Club or meeting up with friends. Although Tim described himself as “not mixing [with people]” (transcript: 25/06/2012), the couple had “always been together” (transcript: 20/06/2012) when engaging with any social activities and equally seemed to bond through the experience of dementia. This meant that Tim responsively connected to a wider social network through Emily’s influence, which also contributed to their biography as a couple.

To enable the outdoor activities to continue, transport was of great importance to the couple, and so by extension their means of transport was also of importance. Emily often kept an eye on their car via the sitting room window. When Emily saw the children, who lived in the same street, playing football on the grass, she described her emotional feeling and concern as: “they get on my nerves” (transcript: 06/06/2012) as “I don’t want my car being damaged” (transcript: 20/06/2012). The window allowed Emily to pay attention to what was important to her, the new car, which was the main vehicle enabling her to engage with social activities outside the home, and was a significant financial investment for the couple. For Emily, it seemed the view from the front window was a cause of worry. In contrast, Mary perceived her sitting room window as a means of enabling her to connect to the outside world, while Patricia did not see the bedroom window as a vehicle for her engaging with the world outside, but instead it came increasingly to represent the level of disconnection from her present neighbourhood. A window is not simply an opening, it can clearly represent part of an individual’s biography and illustrates what is important to the person in relation to emotional connectivity to the wider world.

4.7.6 Summary
Over my nine visits to Emily and Tim during a two-month period, they explicitly defined their neighbourhood as a ‘little street’ and related this to a walkable experience owing to Emily’s declining ability to walk and a sense of safety when out and about. Within this
walkable area, the couple detailed a sense of familiarity, belonging, and safety with their neighbourhood. This area also provided them with a feeling of connection to their past social relationships, rooted within their personal biography, such as the local closed shoe factory where Emily’s, departed, best friend of used to work. Emily and Tim’s experiences of interactions with their neighbourhood over time formulated and influenced their biographies and gave them a sense of connection to their neighbourhood. Within the neighbourhood boundary, the couple’s satisfaction with their home was pronounced and this subjective perception was influenced by their past experience. A key feature for the couple was their interactions with their family and friends, facilitated via a number of methods, with technology identified as playing an important role in maintaining Emily’s social engagement and enabling a sense of continuity in her biographical interest.

4.8 Summary of Case Studies

Each couple defined their neighbourhood via their own unique lens and gave specific meanings to it. The explicit meanings of neighbourhood were further explored and visually represented via the co-constructive neighbourhood maps. This creative, participatory approach was a suitable vehicle to balance the relationship between participants and me as a researcher, to promote an ethical collaboration, to enhance their narrative agency, and to gain a greater depth of knowledge.

The neighbourhood maps clearly illustrated the key components of people and places of the five couple’s self-constructed neighbourhoods. These social and physical surroundings were further unpacked via the interactions and connections between each couple and their neighbourhood. When interacting with the social neighbourhood, the couples identified family, friends, and neighbours as part of their neighbourhood as they felt part of, and an emotional bond to, their neighbourhood social ties. When negotiating with the physical neighbourhood, the couples identified their neighbourhood places as where they had a sense of familiarity, safety, and emotional attachments. The couples’ experiences of connecting and re-connecting to their neighbourhood formulated and shaped their biographies over time, affected their relationships with their neighbourhood, and influenced their neighbourhood perceptions. Although individual functioning, both cognitive and physical, significantly

221
influenced how the persons living with dementia interacted with their neighbourhood, this could be mitigated by a range of support to improve their lived experiences and re-shape their biographies. Such support could be from neighbourhood social ties, formal care services, and the use of assistive tools and technology. Technology played a significant role in maintaining biographical continuity in communication with the neighbourhood and brought a new dimension in understanding how a neighbourhood boundary can be constructed in this modern era.
CHAPTER 5

Findings: Cross-case Analysis of the Five Case Studies

5.1 Introduction

Based upon the five in-depth case studies presented in chapter 4, this chapter discusses a cross-case analysis of all the data. The chapter begins by identifying and describing two cross-cutting themes of ‘connecting to people’ and ‘connecting to places’. This chapter will then present how ‘resources’ and each couple’s ‘relationship’ mediated their interactions and negotiations with their neighbourhood. This chapter will conclude with the meta-theme ‘biographical connectivity to the neighbourhood’ that draws together the whole data set and the lived experience of dementia. A heuristic is presented at the end of the chapter to provide a visual representation of the importance of personal biographies in affecting neighbourhood connectivity through a cumulative pattern when living with dementia. Before describing the findings, each case study is outlined here as a summary to provide a context and act as an aide memoir for the cross-case analysis that follows. The themes are numbered in the text; this is not to denote hierarchy, more as a way of communicating and structuring the findings and developing the theoretical concept.

Case study 1: Mary and Steve

Mary was diagnosed with Alzheimer’s disease in 2010, she and her husband Steve had been living in their current owned, semi-detached bungalow since 1958; their property was in an urban area within recruitment area A. They felt connected to a compact social network comprising of a few close neighbours, their best friend, and the people who attended the Friendship Club. The couple gained a sense of belonging to their home and garden, and a sense of connection to a local school. All these important people and places were incorporated in the couple’s neighbourhood map. While Steve took the lead in drawing the neighbourhood map, I was aware of the importance of encouraging Mary to express her views to ensure the map also represented her experience. The final map is shown in Figure 5.
Case study 2: Patricia and Brian
Patricia had been diagnosed with a mixed type of dementia in 2007, she and her husband Brian had lived in their current owned detached house since 2006; their property was in the constituency of recruitment area B. The couple had weekly contact with their daughter and often met with their two friends. The places the couple, particularly Patricia, had regular contact with were a local store, a local shopping centre, the Conservative Club, and a Flower Club. Interestingly, they included their previous house, where they had lived for 27 years, as part of their neighbourhood; this demonstrated the importance of their past place attachment. All these important social contacts and places were included in the couple’s neighbourhood map. During the mapping process, Brian took the lead role by printing two local maps and marked the important points on these maps, whilst I facilitated a process of continually checking with Patricia to ensure her understandings and experiences were also represented. The final maps can be seen in Figures 11 and 12.

Case study 3: Diane and Dave
Diane’s Alzheimer’s disease was diagnosed in 2009, she and her husband Dave had lived in their owned terraced bungalow for over 40 years, which was in an affluent and well established village within recruitment area B. The couple regularly connected to friends and neighbours, and frequently visited places in the village, especially the village hall. They were heavily involved with a number of committees and it was these frequent connections which gave the couple a sense of belonging and identification. All the important friends, neighbours, and places in the village were included in the couple’s neighbourhood map. As with the previous couples, there was a need to support and encourage Diane to ensure the map was representative of her perception of neighbourhood when the carer, Dave, took the lead in the map creation process. The final map is presented in Figure 19.

Case study 4: Jonathan and Jackie
Jonathan had been living with his Alzheimer’s disease since September 2010, he and his partner Jackie had lived in their current owned terraced house since 1990; their property was in a suburban area within recruitment area A. The couple maintained contacts with friends, neighbours, and their children. The places and spaces the couple frequently
interacted with were their garden, a local park, a local club, and a local shopping centre. Additionally, the couple identified a virtual neighbourhood where they communicated with their family and friends via the internet. When diagramming their neighbourhood Jonathan took the lead role, and the drawing was done during and between the interviews as he preferred that their neighbourhood map should accurately reflect the local area and geographical distance, so a local map was used to provide reference. In using this local map, it imposed a geographical boundary that did not reflect the importance of their virtual neighbourhood identified through their storyline. Although Jackie was not well enough to participate in the diagramming, I ensured she was happy with the map by checking with her when she was well enough to participate. The final map is shown in Figure 27.

Case study 5: Emily and Tim
Emily had been living with Alzheimer’s disease since January 2011, she and her husband Tim had lived in their present rented, terraced bungalow since 2001 and their property was in a village within recruitment area B. The couple’s bungalow was situated in a little street and the couple defined their neighbourhood by Emily’s cognitive and physical capabilities, which was clearly delineated by a walkable experience. The couple frequently interacted with family, friends, and neighbours and these connections were significant in their everyday life, and allowed Emily to continue her biography in social contacts. However, only the important people and places located in their street were identified in their neighbourhood map, highlighting the significance of Emily’s walkable experience. When mapping the neighbourhood, the carer, Tim, took on the main role, while I sought to balance the conversation to ensure the map also represented Emily’s views and experiences. The final map can be viewed in Figure 32.

5.2 Theme 1: Connecting to People
Across the five couples, the construction of ‘people’ consisted of family members, friends, and neighbours. This construction was influenced by regular connections and emotional attachments derived over time, particularly in the ways in which ‘people’ responded to the person living with dementia and how those actions were perceived by the couple. It was these frequent connections with social ties that created life events, and it was the experiences of those events that formed part of their life stories in
relation to neighbourhood connectivity. This connectivity further shaped personal biographies, which re-shaped personal relationships with ‘people’. That is, the accumulation of ‘connecting to people’ over time formed part of neighbourhood connectivity and the continuation of this interactional process enabled biographical relationships with the neighbourhood to be maintained. Here, time was an important factor in the neighbourhood construction and in the formation of biography through a cumulative, interactional process.

When connecting to family members, family relational dynamics were complicated and comprised of close, detached, and virtual dimensions. These relational dynamics were affected by, and were illustrated through, each couple’s neighbourhood construction. When connecting to non-family members, friendships were developed and maintained through participation in personalised group-based activities with these events occurring over time. This connection influenced how the participating couples located their friends and neighbours in time. Interestingly, friendships could be seen to move beyond human-based relationships into other relational dynamics, specifically those of pets. Moreover, connecting to friends and neighbours over time formed what I have termed ‘neighbourhood support’ where people knew, looked after, and watched out for one another in both overt and covert ways. This ‘neighbourhood support’ and its associated sense of safety and security enabled the formation of positive views and experiences of a neighbourhood. Each of these areas of ‘connecting to people’ will now be developed further.

5.2.1 Sub-theme 1: Connecting to Family Members
Across the five case studies there was a consensus that family was important and a clear attachment to family was observed. However, only three of the five couples – Patricia and Brian, Emily and Tim, and Jonathan and Jackie - included their families as part of their self-constructed neighbourhood through conversations, diagramming, and/or photographs. The neighbourhood construction illustrated the family’s role in the couple’s daily life, especially how the family approached the person living with dementia both emotionally and practically and how that role was perceived by the couple. Each couple’s experiences of connecting to their family formed part of their life stories and their perceived quality of these interactional experiences influenced their relational
biographies as a family over time. Although complex, relational dynamics existed within families, the couples’ connections with their family could be categorised as three different types: close, detached, and virtual. These categories were associated with emotional bonds, practical support, and/or geographical location between the couples and their respective family members.

Close connections meant that the family members provided tailored practical support and had close emotional bonds to the couples; this type of connection shaped their biography as a couple and their relational biographies with the family. For example, both Emily and Tim, and Patricia and Brian, enjoyed this close family connection as they frequently met up with, and were looked after by, their respective family members. This close connection became even more important when the spousal partners needed a break and the family members were willing, and able, to step into the caring role. However, the close family connections had variation for each couple. For Emily and Tim, for example, this close emotional bonding within the family gave the couple a strong sense of unity and enabled the couple to include their wider family as part of their neighbourhood during conversations and photographs. For Patricia and Brian, the key function of their close family connection was to help maintain Patricia’s personal care needs by washing and setting her hair and to keep her occupied and active by taking her shopping or going on an accompanied walk. So, for Patricia and Brian, their daughter’s support and close family connection resulted in the couple positioning her as part of their neighbourhood maps (see Figures 11 and 12).

In contrast, detached family connections referred to the situation where any of the three factors - the practical support, emotional bond, and geographical distance – did not meet the specific needs of the couples and their neighbourhood perceptions. Consequently, this type of connection led to the exclusion of family members from the neighbourhood construction. This was especially illustrated through the narratives of Diane and Dave, and Mary and Steve. Geographical location was visibly indicated through Diane and Dave’s narrative as their family lived outside the village where the couple had lived for over 40 years. Although the couple were in regular contact with their children, the couple did not include their family in their neighbourhood map. Interestingly, for Diane and Dave, the family detachment was not part of a dispute with
their family members, but was expressed in terms of geographical location and the couple’s strong emotional attachment to the village when constructing their neighbourhood map (see Figure 19). Arguably, from an emotional perspective, the couple closely bonded to the village where they could independently and comfortably live their lives. So, the detachment meant an ambivalence between the couple’s emotional ties to their family and their sentimental attachment to the village; this ambivalence continually shifted its balance and meaning as time passed and their daily needs increased.

Emotional and behavioural responses affecting the inclusion of the family to the self-constructed neighbourhood were also a feature in Mary and Steve’s storyline. The way in which the couple’s daughter responded to Mary, who lived with dementia and multiple long-term health conditions, resulted in the couple’s failure to maintain a close emotional connection with their only daughter, even though this was not what they desired. This conflict was shared in the following way:

“Steve: She [their daughter] won’t push the wheelchair.
Mary: She won’t go on holidays with us. We wanted her, well Steve wanted her to come on holiday with us.
Steve: For years and years I took them on holiday, I took them to America, I took them to Europe and I’ve paid. As soon as she [Mary] got a wheelchair they won’t come
Mary: Because they don’t want.
Steve: We relied on them for assistance you see and she said, ‘I’m not going to push a wheelchair’.” (transcript: 22/07/2011)

Mary and Steve attributed their daughter’s seemingly purposeful rejection as down to the ‘wheelchair’ and the additional work that such a mobility aid would bring. Additionally, although the daughter helped Mary and Steve with weekly grocery shopping, many items were not what the couple wanted and this increased their shopping bills. A more significant impact on the couple was that their daughter just dropped the shopping off and was not willing to have a chat with Mary and Steve. It was how the couple’s daughter responded to their emotional and practical needs that led to
a detached family connection. This detached connection further influenced the couple’s experience and perception of their interactions with their daughter and re-shaped their relational biographies as a family over time.

The virtual connection added a new dimension to how people living with dementia connected to family members, extending the meaning of a neighbourhood beyond a physical geographical space. Here, ‘virtual’ is representative of connections that are created and facilitated by computer software (Oxford Dictionaries online, n.d.), in that without this facilitation the connection would be far less frequent and may not even exist. This was illustrated through the case study of Jonathan and Jackie where Jonathan used Facebook and email to maintain connections with his children and to continue his family life storyline, as he shared: “my daughters and sons are all on there [Facebook], my sister and her kids, and I speak to them sometimes, sometimes I just look and see what’s on there and who’s on there, to be honest” (transcript: 25/03/2012). Jonathan had been using Facebook since 2011 and spent time each day communicating with his family and friends as Jackie described: “Jonathan can spend an hour on there when he’s really in the mood” (transcript: 25/03/2012). It was this daily contact with social ties that formed a cumulative pattern over time, resulting in the emergence of a ‘virtual neighbourhood’. The effect of this cumulative pattern of social interactions contributed to the establishment of neighbourhood connectivity fuelled through biographical and social relationships. The importance and strength of this family contact was represented through his conversations with me as the researcher. Whilst Jonathan’s face-to-face connections with his children were less frequent when compared with the other couples in the study, it would not be possible to say that his sense of belonging, connection, and enjoyment were less because of this. The inclusion of family members through a virtual connection as part of the neighbourhood construction emphasised that emotional family attachments were more important than a physical location and this type of neighbourhood will be described further in section 5.3.4.

5.2.2 Sub-theme 2: Connecting to Friends and Neighbours
Across the five couples, ‘connecting to friends and neighbours’ was established in a variety of ways, but particularly in the way that friendships were built and maintained through participation in personalised group-based activities. These activities provided
opportunities for three purposes, namely: establishing new connections, maintaining existing friendships, and gaining a sense of self-worth. It was important in connecting to who they are as ‘people’ because connecting to ‘people’ created life stories, shaped personal biographies, and developed ‘neighbourhood support’.

Establishing new connections was a clear feature in the storylines of Mary and Steve, and Emily and Tim, and they did this through attending the Friendship Club and local Alzheimer’s Club respectively. Participating in these activities over time enabled these two couples to gain a sense of enjoyment, have shared experiences, and feel part of a group where age and/or dementia were a starting point for commonality and participation, which stemmed from their biographical journey. Formulating new friendships was particularly important for the couples, allowing for the continued evolution and maintenance of biographical social connections. This, in turn, motivated the couples to continue their social engagement and their biographical connections with their social ties. The newly built friendships were clearly depicted through the neighbourhood map and/or during conversations.

The maintenance of existing connections with friends and neighbours was a further purpose in taking part in personalised group-based activities. For example, Jonathan retained his friendship with his neighbouring friend through going to the local public houses where he could have a chat with his friend and watch the friend play snooker. As part of this activity Jonathan socialised with others to continue his biographical interest, but the notion of forming new friendships was not a concern or an ambition. Similarly, for Patricia, the primary reason for attending the Flower Club with her friend each month was to continue the existing friendship alongside the activity of flower arranging. This activity included the dimension of time by the continuation of her biographical interest from the past through to the present. These continued biographical interests helped maintain connections with neighbourhood social ties over time and the existing friendships were highlighted through the research interviews and in the presentation of the neighbourhood maps.

Gaining a sense of self-worth was a third purpose of participating in personalised group-based activities over time, although it might be more accurate to say that gaining self-
worth was an important outcome of the process of engaging in personalised group-based activities that were enjoyable. For instance, gaining self-worth was illustrated through Diane and Dave’s contribution to the committees and participating in committee-based activities over time. This enabled the couple to gain a sense of connection with, and feel responsibility for, the group which resulted in the formation of close bonds over time. Hence, the dimension of time was again important to the couple in locating their friends in their self-constructed neighbourhood. These neighbourhood social ties included all the couple’s friends who lived in the same village and these friends were also members of the local committees in the community. Diane and Dave attended their local committee meetings as part of their roles in the committees and as an act of service to their community. To support this, Dave gave an example as a way of illustrating his responsibility:

“We do have a walking group about twice a month we go out walking which I organise...there could be ten or twelve of us out walking on Wednesday morning. They [newcomers] come along as well so they’ve joined in with us, they’re new and we’ve got them involved in the village in various ways and so we try to get new people to get into the village and get, become, part of the village.”
(transcript: 22/08/2011)

For Dave, actively organising this recreation provided opportunities for the existing members and for those people who had newly moved in to be part of the well-engaged village and to share the village life. This village life was greatly valued by the couple, and their experience of this formulated a great part of their biographies. For Diane, although her level of contribution had reduced due to her health conditions, the local committees continued to welcome her and made adaptations to enable her participation, she was acutely aware that her active participation continued to diminish, as she shared:

“Only instead of being part of ... organizing and laying out tables and things like that I now sit back and let other people do it ... but I do miss it ... I used to do the raffle, then taking the money and drawing the raffle and sorting out the prizes ... I did that because I could sit down and do that you see ... but someone else will do it know.” (transcript: 14/11/2011)
Diane’s continued participation in the committees’ meetings was a way of presenting the importance and usefulness of the committees to her and to the local residents. Through this participation and advocacy Diane maintained a sense of self-worth. The couple both agreed that the main motivation for their actions was the positive impact of the committees on their social life:

“Dave: Well it [participating in committees] doesn’t leave us a lot of time to do other things.
Diane: But it gives us a very good social life.
Dave: It gives a good social life.
Diane: And all the pleasant times we have.
Dave: You know people...you get to know a lot of people...
Diane: ...I think it’s the social life, we’ve got a lot of friends.” (transcript: 17/10/2011)

It was this important social life Diane and Dave had built within the village that motivated the couple to continue their engagement with and to be part of their neighbourhood. Although Diane’s health conditions created challenges for her participation, the local committees offered alternatives for her involvement. In so doing, Diane continued her biographical interest in social participation, and ultimately maintaining her relational connections to her neighbourhood. The continuity of these interactional events facilitated a sense of place and social connection. Indeed, this couple’s storyline clearly illustrated neighbourhood connectivity derived from an accumulation of interactions with the village over time and this connectivity both shaped, and continually re-shaped, their biographical relationships with their neighbourhood.

Within all the case study data the personalised group-based activities provided opportunities to not only establish new and cement existing friendships, but also contribute to and take responsibilities for the groups. Arguably, through these activities, the couples’ social connections and sense of self-worth was both retained and enhanced, and so, their biographical relationships with their neighbourhood were
continued. More significantly, their experiences of engaging with these activities contributed towards, and re-shaped, their biographies in relation to their neighbourhood connections to formulate a fluid process through time.

Interestingly, in this study, friendships moved beyond human interactions, with narratives identifying the significance of pets through the role they played in companionship and connection to places, such as a local park and garden, and in providing positive experiences in participant’s daily lives. In addition, participants felt a clear sense of responsibility towards their pets. This human-pets bond shaped behaviour and attachment in connection with neighbourhood, and was clearly illustrated through the storyline of Jonathan and Jackie who had fish and a dog, and Patricia and Brian who had two cats. The couples described their pets as a ‘tie’, a ‘best friend’ and ‘great company’, with the importance of pets illustrated through photographs and conversations.

Jonathan and Jackie’s sense of responsibility was demonstrated through their interviews where they specifically spoke about not leaving the fish for more than a week at any one time, and taking their dog for a walk twice a day. For Patricia, her sense of responsibility was illustrated through always making sure the cats were fed, and she expressed a dislike for being away from her pets. This sense of responsibility towards pets further shaped these two couples’ relationships with their neighbourhood. These close emotional ties led to the transformation of the pets being seen not merely as family pets but, instead, they became family ties through the formation of emotional bonds. Words on a page do not do justice to the way in which the couples expressed their affection about their pets and how their speech became more animated when talking about them. For example, Jackie shared: “he [the largest fish] comes right up and nudges me” and “she [dog] never gets told off [even when she had an ‘accident’ in the house]”; while Patricia described: “sometimes you have a lovely cuddle with them [cats] and they get comfortable and go to sleep”.

Whilst only two couples – Patricia and Brian, and Jonathan and Jackie - had pets during the interviews, all five couples in the study had had pets at times during their life time. The importance and impacts of pets over their life course was reflected in the fact that
even for the couples who no longer had pets, family pets still formed part of their shared life stories, like lost friends featuring as part of their biographies. It became clear that pets were important in the couples’ daily living regarding companionship and positive experiences. Above all, such human-pet relationships had a positive impact on the couples’ day-to-day life, and the continuity of human-pets bonds helped maintain their neighbourhood connections.

5.2.3 Sub-theme 3: Connecting to the Neighbourhood Support
Examination of the case studies revealed that connecting to neighbours and friends over time meant that participants gained a good knowledge of, and developed a close relationship with, one another. More importantly, these relationships formed what I have termed ‘connecting to the neighbourhood support’ where participants and their neighbours and friends looked after, and watched out for, each other. This ‘neighbourhood support’ enabled the couples to feel safe and secure in their neighbourhood. Hence, ‘connecting to the neighbourhood support’ posited a significant role in the couples’ daily lives and illustrated the resourcefulness of local residents which helped maintained their neighbourhood connections. Above all, ‘connecting to the neighbourhood support’ influenced how the couples formulated the social side of their neighbourhood and was shown in their neighbourhood maps through the identification and support of daily tasks and ‘watching out’ for one another in a visible – and sometimes covert or invisible - way.

To illustrate the statement above, support for daily tasks was demonstrated through two domains. First, couples who needed more support to live their lives independently at home received help from neighbours; for example, neighbours helped Mary and Steve with their plumbing issues and pushing the ‘wheelie bin’ up their sloping drive each week. Similarly, Emily and Tim’s neighbours offered to do the grocery shopping when the weather ‘was bad’. These tasks were simple yet vitally important in that they ensured that the couples could maintain independent living and be part of the community. Second, couples who had abilities to fully live their lives independently at home provided support to others. As an illustration, Jonathan and Jackie looked after their neighbour’s pet while they were away, and they invited another neighbour to their home for Christmas dinner.
Additionally, there existed a reciprocal process where participants helped their friends and neighbours who, in turn, provided support to them; this process was evident in Diane and Dave’s narrative. Over the years, this couple had made significant contributions to the village via the local resident committees and, in return, the residents provided a degree of care and support for them. To take but one example, Diane and Dave’s immediate neighbour was named on Diane’s emergency contact list alongside Dave and the family. In this case, the neighbour had accepted a degree of responsibility for crisis management. In another example, Mary and Steve regularly saw and spoke to their neighbour Fiona and if they did not see her for a few days they would telephone her to check if ‘she was ok’, and vice versa. In this way, the couple experienced a sense of safety and security in, and felt part of, their neighbourhood. Therefore, contributing to, and having responsibilities for, others was important to each couple who, in turn, received others’ help and support. These reciprocal interactions contributed to the establishment of the couple’s neighbourhood connectivity over time and enabled them to have a sense of place, as will be described further in the next section.

‘Connecting to the neighbourhood support’ therefore encapsulated the process of how the community watched out for people living with dementia, leading to a sense of safety and security. Support was also covert, provided in a more nuanced and subtle way that aimed to protect the self-worth and independence of the person living with dementia. For instance, in Patricia and Brian’s case study, a local shop keeper, who was aware of Patricia’s diagnosis, kept an eye on her when she went to, or passed by, his shop. This covert caring action helped Patricia to maintain her presence ‘out and about’ in the neighbourhood and enhanced Brian’s reassurance in her going to get the newspapers on her own and/or going for a short walk. The fact that this might seem a small task should not diminish its importance in empowering Patricia’s presence in, and enabling her to continually connect to, her neighbourhood. Again, ‘connecting to the neighbourhood support’ captured the couples’ numerous life events and their experiences of these events formed part of their life stories. It was the continued accumulation of ‘connecting to people’ that formed neighbourhood connectivity over time, and the experiences of
these connections contributed towards the couples’ personal biographies which further shaped their relationships with their neighbourhood.

5.3 Theme 2: Connecting to Places

Analysis of the case studies revealed that ‘places’ referred to where the couples had emotional attachments and these emotional attachments were associated with the dimension of time and experiences of connecting to the physical environment. It was these interactional experiences that established neighbourhood connectivity which, in turn, contributed to, and re-shaped, personal biographies over time. These emotionally attached ‘places’, which captured memories and life stories, were illustrated through the neighbourhood construction and presented aspects of self through the life course. ‘Places’ were comprised of regularly visited and remembered places. They originated with the ‘meanings of home’ and then expanded to encompass a broader geographical area, which was seen to exist at three levels: a walkable distance, a commutable distance, and a boundary-free neighbourhood. Each of these areas of ‘connecting to places’ will be developed further.

5.3.1 Sub-theme 1: Meanings of Home

Cross-case analysis revealed that home was a place in which the couples expressed themselves through personalising its features to illustrate their life stories, while the presented meanings elicited different emotional responses. Additionally, the level of familiarity of home was closely associated with each couple’s length of stay in their current house or bungalow, with this association affected by both positive and negative living experiences and by how the persons living with dementia adjusted to their condition. Pleasurable memories rooted in the present location helped retain connection to the current home environment for longer compared to an unpleasant living experience. More importantly, this familiarity enabled the couple, particularly the persons living with dementia, to perceive home as a safe and comfortable place.

To support the above analysis, apart from Patricia and Brian, the other four couples demonstrated a significant sense of familiarity with their house or bungalow as their home, and they were fully aware of the detail of its layout. This was particularly the case for Mary and Steve who had lived in their bungalow for 53 years and, due to Mary’s
declining ability to go out and participate in social activities, their lives had become centred around their home. Despite that, the couple demonstrated a great sense of satisfaction with, and positive experience of living in, their home: “it [buying the bungalow]’s the best thing we have done in our life ... she [Mary] wouldn’t be able to get upstairs now ... we are happy we have got everything we want” (transcript: 03/06/2011).

Furthermore, the couple perceived home as a ‘safe’ place, contrasting the fear of being mugged in the local area: “we won’t step out that door [pointing to their front door] in the dark” (transcript: 03/06/2011). This indicated that the couple’s sense of connection to their neighbourhood was temporarily disrupted by their belief that the neighbourhood was unsafe at night. This meant that feelings of safety and a sense of connection to the neighbourhood could be threatened by the dimension of time, a change from day to night.

Conversely, at five years, Patricia and Brian had the shortest time staying in their current home, and over the course of the study Patricia experienced the greatest decline in cognitive capabilities because of her diagnosis of dementia. Towards the end of my involvement, although Patricia’s awareness of her home environment was present for much of the time, she sometimes appeared to be ‘lost’ and lacked a sense of familiarity with her own home. Additionally, the couple’s memories of the current home were dominated by unpleasant experiences around Brian’s cancer diagnosis and Patricia’s own diagnosis and decline in health, which both came not long after their relocation. Arguably, it was this cumulation of negative experiences that disrupted Patricia’s connection to home and affected her sense of belonging as she forcibly stated: “we live here and it’s not a place I know” (transcript: 19/10/2011). This negative perception further prevented her from feeling a sense of connection and from forming a sense of belonging to her ‘new’ home. Moreover, towards the end of our time together, Patricia’s dementia had progressed rapidly and she developed hallucinations believing that there was often someone listening at the door; this caused her considerable distress. Whilst this was distressing enough, the lack of positive attachment and familiarity with her home might have exacerbated these experiences.

In addition to familiarity with the home environment, the findings of cross-case analysis indicated that home was a place where the couples personalised their everyday living
environment with objects that represented their life events and held specific meanings
drawn over the life course. These meaningful objects represented aspects of biography
and inspired the couples to connect to their home environment and beyond. For
instance, Emily and Tim had a clock which was important to them as it gave the couple a
great deal of pleasure when it played Beatle’s music on the hour and triggered
memories about their holiday in America where they bought the clock. So, this clock not
only fulfilled a functional purpose, but provided a means of personal expression and
captured life stories within the home. Additionally, Diane and Dave had two cups
decorated with the words ‘grandma’ and ‘grandpa’ that were bought for them by their
grandchildren in Disneyland in Florida when they went there for Dave’s birthday. These
cups emphasised close family bonds and evoked memories for the couple about
pleasurable experiences which again contributed to their biographies. For Brian, his
passion and hobby was presented through several antique clocks in the home and
reminded him of all his enjoyment in spending time restoring these clocks. In Mary and
Steve’s home, there was a British Empire Medal which the Queen awarded to Steve in
recognition of his fifty years of voluntary service as a motorcycle instructor. There were
also the couple’s marriage photographs on the sitting room wall and these photographs
prompted Mary to provide a detailed account of their wedding day, they allowed Mary
to actively participate in the conversation, evoking a positive, happy response from her:

“It was all arranged at the church, we got married at the village church here, you
know... [pause] ... we always said that, when we used to go out for a walk, we
used to say, ‘yes, we’ll get married there.”’ (transcript: 03/06/2011)

It became clear that the home was an important conduit in representing each couple’s
life story, and these meaningful objects provoked memories about their past and
illustrated their life stories. These objects had a potential reminiscent function to trigger
memories which facilitated a sense of connection to neighbourhood and maintained a
sense of self.

The specific meanings represented by the features in the home could evoke either
positive or negative effects depending upon an individual’s capacity and emotional
responses. The positive effect was shown in Jonathan’s narrative in that he hand-built
most of the furniture in the home, giving it both a very personal touch and a way for Jonathan to project a favourable image of himself as a craftsman. This positive effect motivated Jonathan to continue with his biographical interest and so maintain his engagement and connection with the home environment. This home connection contributed to his neighbourhood connectivity over time. In contrast, Patricia used to be an accomplished pianist and her piano was kept in her ‘office’, this allowed Patricia to play when she wanted and it helped maintain a sense of biographical continuity from past to present. However, the piano also came to represent frustration and loss, reminding Patricia that she was no longer the person who she used to be as her ability declined. This negative effect discouraged Patricia to continue her biographical interest and ultimately diminished her sense of connection to her home. This conflicted home connection further disrupted her neighbourhood connectivity over time. Her frustration and sadness was expressed through playing the piano less frequently, as Brian observed:

“The problem there is her ability ... playing the piano is becoming more of a hardship for her, more of too many mistakes, go back and .... I just sense that because of that she is playing it less and less and less ... it must be very difficult for her ... because she was and still is ... a very intelligent lady.” (transcript: 28/08/2011)

It was not just personalisation that gave meaning to the people living with dementia and affected their home connectivity, the everyday common features of the home also affected their daily experience. For instance, windows served as a connection between indoor and outdoor spaces in a way that held greater meaning than something to simply look through. Windows enabled the person living with dementia to connect to the outside world, to link to what was important personally, or to act as a reminder of disconnection. For example, for Emily, the window in her front room allowed her to connect to her neighbourhood and enabled her to ‘keep an eye’ on their new car, which was important to her and which was the main vehicle enabling her to interact with her social networks outside the home and so retain her social connections. In contrast, Mary purposively positioned herself next to the sitting room window to interact with the outside world as she explained during our time together: “I never thought sitting here I could see somebody coming ...” (transcript: 24/06/2011). However, the window also
represented a sense of vulnerability and an aimless passing of time, as Mary later said: “I spend hours looking out that window there [pointing to the sitting room window], what else can you do?” (transcript: 25/11/2011).

In contrast, Patricia did not see her bedroom window as a vehicle to engage with the present neighbourhood but, instead, it came increasingly to evoke her memories about the past through the constant comparison between her living experiences in the current and previous neighbourhoods, as she described: “I don’t have a lot of feelings for it [pointing to her bedroom window] to be honest, we live here and it’s not a place I know, it isn’t like the last time I lived in [names previous home/neighbourhood area]...” (transcript: 19/10/2011). For Patricia, there was a sense of sadness, as if the connection to her current neighbourhood was disrupted.

Windows provided a view to both the past and present in the lives of the persons living with dementia, and these openings became a conduit for meaning resting on their biographies, affecting how they connected their home to the neighbourhood beyond. It was understanding this relationship that was key to seeing the home as something more than a static presence on a street, familiarity and happiness with the home was the starting point for connecting the persons living with dementia to the spaces and places outside their home. It was when this familiarity and happiness with the home became compromised, as with Patricia, that wider connections also seemed to become disrupted, this disruption negatively impacted upon how the home was seen as a place of safety and so disrupted the biographical connection.

5.3.2 Sub-theme 2: Regularly Visited Places

As seen in the data, the five couples interacted and negotiated with specific places on a frequent basis. Through these repeated visits, the couples were familiar with, and had assigned specific meanings to, their physical neighbourhood. Over time, the couples’ experiences of regularly visiting their neighbourhood places formulated part of their life stories and helped establish emotional place attachments. These behavioural and emotional connections to the physical surroundings formulated neighbourhood connectivity which shaped and re-shaped personal biographies. Regularly visited places were comprised of outdoor spaces and built places and they became a landscape of
captured memories and life stories. Put simply, they represented aspects of the couples’ biographies and provided a meaningful context to understand the lived experience of dementia.

Outdoor spaces included public parks and private gardens, and these spaces provided opportunities to connect to the neighbourhood, to gain a sense of belonging and to continue biographical activities with pleasurable experiences. For example, frequently going to the local park enabled Jonathan and Jackie to become familiar with this place and space, providing enjoyable experiences while interacting with their dog. This outdoor space became a place that recorded the couple’s interactions with their family pet as part of their life stories; this space was displayed in their photographs and neighbourhood map (see Figure 27).

The garden was another important place identified by the couples who had physical and emotional investment in this space. So, like the park in the example above, the garden was not purely a physical space but a place of enjoyment, connection to nature and activity. For instance, Jonathan built a fish pond and decorated it with coloured lights, while Steve built a summer house and spent time maintaining the garden. These life events contributed towards their life stories and enabled the everyday personalised spaces to be transformed into meaningful shared places, especially when the couples spent time together in such an environment. For instance, when sitting in the garden, Mary and Steve felt connected to the local school where school children played sports on the playing field opposite to their home. While the school and the children did not directly interact with the couple, the green space and sounds of life acted as a point of connection to their neighbourhood. Given that Mary and Steve experienced limited social interactions, this connection was important to the couple in continuing contact with their neighbourhood and re-shaped their biography as a couple. This importance was illustrated through the inclusion of the school in their photographs and neighbourhood map (see Figure 5). Moreover, connecting to social networks through the garden was illustrated in Emily and Tim’s narrative, as a feature in their garden represented the friendship between Emily and her good friend: “I’ve got a lilac tree, my friend brought it for me for my seventieth birthday” (transcript: 25/06/2012). In this case, the garden was both a space and place that embodied Emily’s memories and
represented aspects of her biography as well as shaping her biographical relationship with her friend.

Built places referred to buildings the participating couples had regular contact with, such as local shopping centres and a village hall. The local shopping centres were the most common places where the couples frequently visited, with ‘going shopping’ identified as one of their favourite activities. This seemingly mundane and regular activity was important to participants in terms of their social engagement and autonomy, as it was through this activity that the couples could go out to meet and talk to others, have a measure of exercise and choose the goods they wanted. This sense of enjoyment was clearly and succinctly summed up by Jackie when she enthusiastically said: “I love shopping!” (transcript: 04/12/2011). Frequent interactions with built places contributed to the establishment of neighbourhood connectivity over time and the positive experience of these interactions constructed part of the personal biographies, which impacted positively upon person-to-places relationships on most of the participants in this study. Such relationships would further influence personal biographies and neighbourhood connectivity.

Across the five couples, the accumulation of their interactions with outdoor spaces and built places formed part of their neighbourhood connectivity. It was through regular neighbourhood connections that the couples gave these places specific meanings and formed emotional place attachments. These attachments then stimulated further connections to these important places where their life stories were encapsulated; this re-shaped their biographies over time. This constantly evolving process in creating and strengthening emotional bonds to places affected how each couple constructed, and interacted with, their neighbourhood over time. Put another way, the couples’ current experiences of interactions with the physical neighbourhood were influenced by their past biographies, and these present experiences would contribute to, and formulate part of, their future biographies over time.

5.3.3 Sub-theme 3: Remembered Places
In the neighbourhood construction, remembered places captured memories and life stories and demonstrated a significant effect when connecting to places. These
remembered places became even more prominent when a combination of the following factors came in to play: moving to a new place, a decline in a person’s cognitive performance and physical ability, and losing friends when becoming aged. Through these remembered places, the persons living with dementia obtained a sense of biographical continuity. For instance, because of relocation and dementia progression, the remembered place was important to Patricia, who brought her past community into her present neighbourhood. In this remembered place, Patricia retained good memories about her past, where she was familiar with and where she felt she belonged to. This remembered place could be seen as a way of maintaining a sense of social integration and as a means of compensating for a sense of loss when experiencing difficulty connecting to the present neighbourhood. Although Patricia was no longer socially active within the previous community, emotionally connecting to this remembered place added a new dimension to her neighbourhood connectivity which re-shaped her biography. An important component to connecting to places was that of time, not only were people making connections in the present, but they were also connected to their past, demonstrating that a person’s present neighbourhood was constructed by ‘places’ from both the past and the present, often with present places being rooted in past connections. The combination of time and these important connections were vital to the creation of neighbourhood connectivity.

The increasing importance of the remembered place was keenly illustrated in Emily’s storyline. For instance, Emily no longer visited the football club where she used to play bingo because the numbers of people playing this game steadily decreased over the years and eventually it stopped; while the housing estate was identified as a place of importance as it was built on the site of the old shoe factory where her, now departed, best friend used to work. The emotional attachments of Patricia and Emily to the remembered places revealed a transactional process between ‘people’ and ‘places’ where important personal relationships were transposed to places. This process appeared to have enabled Patricia and Emily to maintain a connection to past personal relationships when the relationships could no longer be maintained. As such, they still sustained their social connections, and this new form of interaction re-shaped their biographical relationship with the remembered places. Interacting with these places contributed to neighbourhood connectivity over time and their vital importance was
demonstrated by their inclusion in the neighbourhood maps. For Patricia, her past house was illustrated in her neighbourhood map (see Figure 12), while, for Emily, the football club and the housing estate were presented in her neighbourhood map (see Figure 32).

5.3.4 Sub-theme 4: Neighbourhood Boundaries

Constant analysis and re-reading of the written and visual data indicated that the neighbourhood ‘places’ were located within a distance ranging from the home to a much broader boundary. These neighbourhood boundaries could be categorised into three levels: a walkable distance, a commutable distance, and a boundary-free neighbourhood. These categories indicated participants’ perceptions of the importance of their capabilities or biographical connections, and emphasised how these perceptions affected their neighbourhood construction.

Firstly, a walkable distance, as its name implies, was the distance that a person living with dementia could walk before being stopped by either their physical condition and/or the person with dementia’s feeling of safety when out and about, as summarised by Tim: “Emily doesn’t go no further than the little street [as shown on their neighbourhood map]”. For Emily and Tim, such an experience impacted upon their neighbourhood construction and resulted in the exclusion of their friends beyond a walkable distance, even though their social activities extended beyond this zone as Tim was still able to drive. This highlighted the importance of the walkable distance in self-constructing the neighbourhood boundaries regardless of the frequency of contact with social networks or the access to transport in daily life.

Secondly, a commutable distance defined the neighbourhood boundary as the distance travelled by participants using their own car, alternative transport (including public transport), and/or accessed support to compensate for decreased abilities and so enable biographical continuity. For example, Mary and Steve were stopped from using public transport because of the steep hill that their local bus stop was located on. To overcome this, the couple accessed a door-to-door car service provided by their local authority which enabled their attendance at the Friendship Club. By finding a practical solution to a geographical and planning problem meant that Mary and Steve could continue their biographical engagement with their neighbourhood, as Steve put it: “how far you would
go to know people”. Similarly, for Diane and Dave, Dave’s access to a wheelchair to assist with Diane’s decreased mobility, maintained Diane’s interaction with “the whole of the village” and continued a presence in a community where they had lived for over 40 years. For Patricia, using a private car and adapting support from proximate relations enabled her to maintain her social activities within a five-mile commutable distance from their present house as shown in the couple’s neighbourhood maps (see Figure 11 and 12). This commutable distance emphasised that maintaining neighbourhood connections which were associated with personal biographies was more important than the walkable experience.

Thirdly, Jonathan and Jackie’s use of technology gave rise to a proposed boundary-free construction of the neighbourhood. This resulted in the production of a virtual neighbourhood that created and encompassed the couple’s connections with ‘people’ and ‘places’ beyond a physical boundary, such as a walkable or commutable zone. Jonathan and Jackie used Facebook and email to maintain contact and connection with their friends and family, and they used their internet connected computer to book holidays and to look for information on the local Neighbourhood Watch. This increased their interactions with, and knowledge of, the wider world beyond a boundary constrained neighbourhood. The connections facilitated through the virtual neighbourhood were important in continuing the couple’s biographical relationships with their neighbourhood, especially when going out became an increasingly challenging task. However, it was worth noting that the inclusion of this virtual neighbourhood depended on Jonathan’s ability and feeling of confidence in using technology which may change in the future. Interestingly, although Emily used an internet connected computer to email her social ties, the couple did not include those friends as part of their neighbourhood map (see Figure 32). The couple’s neighbourhood construction was determined by Emily’s ability to walk irrespective of the effect that the use of technology had on their lives. Again, this phenomenon could also be explained by Emily’s lack of confidence in using technology when making connections with her friends. This led to less frequent usage and as such, the benefits gained from a cumulative pattern in social connections was not formed.
In summary, the connectivity to neighbourhood places emerged from an accumulation of frequently ‘connecting to places’ over time, the places were where the couples had emotional attachments and/or where their biographical interests were continued. This neighbourhood connectivity was affected by, and further shaped, personal biographies through time.

5.4 Mediating Factors

Based on the findings of cross-case analysis, ‘connecting to people’ and ‘connecting to places’ were mediated by ‘resources’ and ‘relationships’. These two mediating factors affected how the couples, especially the persons living with dementia, encountered the challenges when dealing with the environment and performing tasks. This meant that the mediating factors could either enable or disable the persons living with dementia to independently stay at home and/or to continue their biographical activities, and impacted on how the couples interacted with their neighbourhood. These interactional experiences would further influence their biographies and neighbourhood connectivity through time. Put simply, the mediating factors shaped and re-shaped the couples’ biographical relationships with their neighbourhood over time when living with dementia.

5.4.1 Mediating factor 1: Resources

The combination of advancing age, living with dementia and other chronic conditions, resulted in health and functional ability losses across all participants. It was clear from the cross-case analysis that the decreased functioning led to increasing challenges in performing daily tasks and interacting with the neighbourhood (however this was constructed), even though the environmental characteristics remained the same. This association had a greater chance in influencing an individual’s independence and autonomy. To enable independent living at home for as long as possible and to maintain biographical continuity in relation to neighbourhood connections, seeking and accessing supportive resources helped empower the persons living with dementia and enhanced their capability when dealing with the environment.

Analysis of the case studies demonstrated that the five couples actively sought support and used various tools to become change agents and adapted their behaviour to adjust
the dynamics between self and their environment. These resources influenced the lived experiences of dementia, affected how the couples negotiated with their physical and social surroundings and thus re-shaped their biographical relationships with the environment over time. These resources related to the home environment, an enabling environment, and local services.

5.4.1.1 Home Environment
The findings of cross-case analysis showed that home was an important place as the couples spent most their time there and each couple’s perception of home was associated with their living experience. To maintain independence and to enhance their daily experience when living at home, the couples altered their living environment to optimise the persons living with dementia’s capabilities when dealing with the environment. This was done through a variety of means, including relocation, home modification, access to support tools, and (assistive) technologies.

Relocation was the primary action taken by three of the five couples to proactively change their home environments and so maintain autonomy and independence, and gain better support. Taking Diane and Dave, and Emily and Tim as examples, relocation to a bungalow allowed easy access around the home and enabled aspects of individual autonomy to be maintained. Patricia and Brian also moved to a smaller, more practical house, and more importantly, their relocation was intentionally planned to live in an area where they could easily access local amenities and get the support they needed as they aged. In fact, Patricia and Brian’s storyline posed a dichotomy in that accessing support seemed to be the priority for their daily living, whereas, at an emotional level, social relationships and emotional connections were more important for Patricia and affected her subjective view of stability in her day-to-day life. The couple’s relocation seemingly created a negative effect on Patricia’s social relationships and so disrupted her biographical relationship with her social and environmental connections. This negativity and disruption had a cumulative effect on her current neighbourhood connectivity, leading to a (seemingly) emotional connection to places now in her past.

To maintain living independently at home, the spousal carers repeatedly assessed the ability of the persons living with dementia to identify environmental challenges and then
brought about practical solutions to enhance their abilities and living experiences. For instance, to meet Emily’s specific needs, the couple put a wheeled shower seat in their shower room so that she could continue to shower independently. This type of home modification matched Emily’s remaining capabilities in performing essential tasks.

To enhance the abilities of the persons living with dementia in performing tasks, support aids were adapted. This was illustrated by Jonathan who, on bad days, was unable to stand for long periods due to living with Parkinson’s disease. To help overcome this challenge, Jonathan bought two stools – one for the workroom and the other for the kitchen. This enabled Jonathan to remain engaged with his carpentry and helped him undertake other more mundane tasks, as he shared: “[it’s] easier to do the washing up” (transcript: 27/04/2012). With the assistance of the stools he could undertake tasks independently, continue with his biographical interest, and maintain connectivity to his home and everyday life. Similar creative and adaptive practices were adopted by Diane, Mary, and Emily who used a walking stick or a pusher when moving around their home.

Technology also provided participants with a sense of safety and security and helped reduce the family’s stress, especially when the person living with dementia stayed at home alone. For instance, Diane used an emergency alarm, which would alert four named persons at a time of emergency. The couple adopted this assistive alarm after an incident when Diane fell over in the kitchen while Dave was out shopping. The alarm works by connecting to a call centre when Diane activates it, the call centre provides 24 hours a day support and the agent in the call centre contacts the named people and asks them to check on her. If the call centre cannot get hold of any of these named people, one of the agents from the call centre would go to see Diane. So, the use of this technology enhanced the confidence of Diane and her family in her independently staying at home alone if needed.

Technology was also identified in this study as a way to activate memories. This was illustrated through Brian creatively using an iPad to produce a life story book, consisting of family members’ photographs. This life story book aimed to stimulate Patricia’s memories of their family and so enable her to continually connect to their family members and to sustain her sense of self. Similarly, Brian also used the iPad to
photograph me so he could remind Patricia before each of my visits. In addition to stimulating memory, technology was used for the purpose of information storage, Brian used the same device to produce a telephone directory to store their family and friends’ telephone numbers. Brian hoped this would ease Patricia into connecting to her social ties as and when she wanted and so continue her biographical relationship with her neighbourhood. Although Brian taught Patricia how to find this information on the iPad, her impaired cognitive functioning – reasoning and memory - prevented her from understanding alphabetical order, unfortunately this meant that it was actually no easier for Patricia to find the relevant information. Despite that, on her good days, she enjoyed using the iPad to play simple word-based online games. Although it only lasted for a very short period, it allowed the continuity of her biographical interest as she used to love completing crossword puzzles. Patricia’s experience with technology indicated that it needed to be meaningful, tailored, and sensitive to her capabilities and biography to ensure it could be used successfully.

5.4.1.2 Enabling Environment

To assist the couples to live in their neighbourhood independently, the findings of cross-case analysis highlighted the need for both a physically and socially enabling environment. This environment offered equality to local residents in accessing local services and participation in the local community, and facilitated biographical connectivity in engaging with the neighbourhood. An enabling physical neighbourhood was a key feature in Jonathan and Jackie’s storyline in that their neighbourhood enabled the couple access to a wide range of local amenities and services and allowed the couple to continue living independently in their neighbourhood as time passed. As such, their connectivity to their neighbourhood could be continued. Such an enabling environment was also the main reason for Patricia and Brian’s relocation, facilitating the couple to access more support as they aged. However, the outcomes of the relocation were not exactly what they expected, as the current locality was not ideal as it had disrupted Patricia’s ability to maintain her biographical social connections which had been an important element in her life. Arguably, this present neighbourhood disabled her connectivity to her social ties and/or prevented her from establishing new social connections. This re-shaped relational biography further discouraged her interaction
with the present neighbourhood. Instead she travelled from present to past to find, and connect to, a meaningful past neighbourhood.

Additionally, to have equal opportunities for neighbourhood participation and contribution, an enabling social environment was also important for the couples. This enabling social environment was predominantly illustrated in Diane and Dave’s storyline through their ‘neighbourhood hub’. It was this hub that offered the couple equal chances, as other citizens, to contribute to their village, to serve on local committees, and to gain a sense of self-worth. Hence, this hub promoted opportunities for the couple’s participation in their neighbourhood, in addition to providing opportunities for maintaining their emotional bonds with their friends and neighbours. More importantly, this hub offered the couple, particularly Diane, opportunities in continuing her biographical relationship with the village, resulting in neighbourhood connectivity being continued rather than disrupted. These positive cumulative effects further encouraged the couple to continue their neighbourhood connectivity and shaped their relational biographies with their neighbourhood.

Conversely, the lack of access to an enabling environment had a negative impact on daily living, particularly for those who had lost the ability to drive and were unable to use public transport. This was demonstrated in Mary and Steve’s case study in that although they loved going shopping and undertaking social activities, the lack of available local amenities and difficulties in accessing public transport prevented the couple from pursuing these activities and from continuing their biographical interest. This phenomenon highlighted that the couple were disabled by their environment rather than by their physical conditions and emphasised the importance of the environment in influencing their relationships with their neighbourhood.

5.4.1.3 Local Services

When growing older and living with dementia and comorbidities, quick and easy access to health care services was increasingly important in meeting health needs and to remain living independently at home, ultimately maintaining relationships with the neighbourhood. The right to health was important in the daily life of the persons living with dementia and their carers. However, timely access to health care services was
highlighted as an issue in several areas: difficulties in booking an appointment, long waiting times, and appointments being delayed or cancelled. In addition, the need for improving the quality of local services was highlighted. As an example, Brian shared his experience of engaging local private formal support services to care for Patricia as Brian felt that the family’s ad-hoc support no longer met her health needs. The primary purpose of seeking professional support was to identify meaningful activities for Patricia and maintain her social engagement. As such, Brian hoped that Patricia would develop her interest in pursuing recreational activities that would be enjoyable for her, such as activities that would be sensitive to her ability and relevant to her biography. Secondly, purchasing the local private service would reduce the burden and stress of Brian as the main carer for Patricia, thereby improving the quality of life and well-being of the couple. However, when supporting Patricia with an outdoor activity, this service failed in this aim as Patricia became lost on a local trip out, resulting in stress and anxiety for Brian and the family. Consequently, this service was cancelled and it reduced Brian’s confidence in allowing others to care for Patricia.

Despite Brian’s reluctance to engage further outside help, Patricia’s caring needs increased and required professional help. As a result, Brian requested an adult social care assessment for Patricia; the results would determine what care support would be appropriate for her. Adult social care was supposed to undertake this assessment within two weeks of the first request, however, at the time of interviews taking place it was two months after the initial request and the assessment had still not been started. This assessment was vital for Brian’s decision making regarding which services to pursue which might help Patricia, such as day care. To highlight the negative effect and express the urgency of need, Brian was explicit in voicing his frustrations:

“The services in this area are poor, she [Patricia] had seen in the last year her psychologist may be twice ... we need help and I’m happy to pay for help, but nobody would come in and do the assessment which enables me to buy the help...I’m annoyed and the local services are poor.” (transcript: 08/07/2012)

At this stage, lack of timely access to good quality services was detrimental for all aspects of their lives, these services were crucial to help maintain Patricia living at home
while reducing Brian’s stress, thereby continuing to stabilise their lives and to maintain their collective relationships with their neighbourhood as a couple.

To conclude, connecting to ‘resources’ contributed towards the improvement of the couples’ daily living experience and so continued their neighbourhood connectivity, which further shaped their biographies over time. The key to the success of connecting to ‘resources’ was that ‘resources’ should be relevant to personal biographies and sensitive to their capabilities.

5.4.2 Mediating factor 2: Relationships
Each couple entered into a collaborative venture when facing the constant challenges in their lives, and their lived experience of dementia was influenced by their relationship. This relationship affected their bonds and the level of resilience that allowed the couples to face the unknown future. More significantly, the couple’s relationship influenced how they connected to their neighbourhood and their perceptions of the lived experiences of dementia. These experiences formulated part of their biographies as a couple. Each couple’s journey, from the onset of dementia to the stage of living with the condition, could be described through three relational perspectives: role change, resilience, and togetherness. These perspectives were not explicitly distinguished but were interrelated.

After the onset of dementia, changes appeared across the five couples in roles and responsibilities in relation to their new situation. These changes were associated with traditional gender roles where, for example, the woman would undertake most of the domestic chores. This study observed how the reduced capabilities meant the women living with dementia had to relinquish certain roles whilst the male carers took up new responsibilities. For instance, in addition to taking on the main caring role, Steve undertook most of the domestic chores and became responsible for managing their finances. Dave also carried out most domestic chores in addition to being the main carer for Diane. A similar situation also applied for Emily and Tim. Although Brian gained support from a paid cleaner, he did undertake some domestic chores and carried out the main caring role. However, for Jonathan and Jackie there was less role change, as Jackie was the only female carer and undertaking home chores had always been her role. Despite the traditional gendering of household tasks, Jackie encouraged Jonathan to
undertake tasks in the home as a way of maintaining mobility and independence, and she always kept an eye on him and lent a hand if required.

The change in roles and responsibilities also altered the relationship structure, moving from a sense of shared equality in the relationship to one of a care giver-recipient structure, however a strong sense of togetherness was retained. ‘Togetherness’ was defined as the process by which the spousal carer placed the person living with dementia at the centre of their relationship and provided support for those activities, thereby helping maintain their relationships with their neighbourhood. Within this definition, there were two levels: one, the couple undertook social activities together; and two, the spousal carer utilised social support to help the person living with dementia to continue with their biographical activities and connections. To support the first level, Dave pushed the wheelchair to enable Diane to attend local committee meetings with him; similarly, Steve sought alternative transport and pushed the wheelchair on the flat ground so that he and Mary could participate in the Friendship Club. Tim helped Emily maintain her social contacts by taking her out to meet friends, which also provided a sense of enjoyment for Tim. ‘Togetherness’ for this couple was neatly summarised by Emily: “we’ve always been together” (transcript: 20/06/2012). In this phrase, Emily placed their time together above their time before they met and predicted their relationship going forward in time, as life and health changed, their relationship would endure. To illustrate the second level of ‘togetherness’, Brian gained support from family and friends to accompany Patricia in undertaking social activities and continuing her biographical interests, ultimately continuing her neighbourhood connectivity. Jackie proactively searched for treatments for Jonathan’s Alzheimer’s disease and then successfully negotiated with doctors in the memory clinic to get appropriate medications, which led to improvements in his short-term memory and motor coordination. As a result, Jonathan began to engage with his biographical interests by using the computer to maintain social contacts and was able to re-engage with his passion of carpentry. This indicated that the continuity of Jonathan’s biographical interests played a significant part in his neighbourhood connectivity.

‘Togetherness’ affected the interactions of the couples with their neighbourhood and often empowered or enabled the persons living with dementia to maintain those
interactions. This led to the continuity of their cumulative connectivity to their neighbourhood. It was worth noting that ‘togetherness’ did not mean that there were no conflicts or tensions within each couple’s relationship, but they still closely bonded to, and supported, each other by identifying alternatives and solutions. This ability to negotiate through difficulties was determined by the couple’s ‘resilience’.

Resilience meant each couple, particularly the spousal carer continually searched for alternatives and explored solutions to fulfil the specific needs of the person living with dementia who could then undertake tasks independently and ensure biographical continuity. As an illustration, Tim continually identified alternatives to modify the home environment to enhance Emily’s ability so that she could maintain her independence. For Brian, his life was centred around Patricia and he had to be flexible, changing his daily routine to fit with Patricia’s needs, while surrendering his own hobbies and social activities. Additionally, Brian continually assessed Patricia’s ability and identified activities and support to allow her to maintain meaningful social contact and keep active by engaging with activities that were relevant to her biography and suitable for her capability. For instance, Brian helped Patricia to establish a friendship with Emma, once this relationship had been built, Emma then escorted Patricia to places that she was familiar with, such as their local shopping centre and garden centre. Emma also accompanied Patricia when pursuing her hobby, decoupage. All these activities contributed to Patricia’s continued biography and offered opportunities for neighbourhood connections. In this case, the continuity of Patricia’s biographical interests played an important role in maintaining her neighbourhood connections.

While in receipt of support, the person living with dementia was not simply a passive recipient, the support allowed the person to renegotiate his or her role and remain an active co-contributor to the relationship. For instance, Mary helped Steve prepare the vegetables for dinner, and Jonathan took on a caring role during and after Jackie’s bowel cancer operation. Resilience enabled the couple to look after each other and to improve their lived experience of dementia as well as increasing their neighbourhood interactions, particularly for the persons living with dementia. Resilience also helped maintain a sense of togetherness, strengthened their abilities, and shaped their biographies when living with dementia through time.
The couple’s relationships impacted on their daily living and experiences of interacting with their neighbourhood, and specifically influenced the biographical continuity of the persons living with dementia; biographical continuity affected, and was affected by, the cumulative pattern of neighbourhood connectivity. The three relational perspectives of each couple’s relationship - role change, resilience, and togetherness - portrayed a picture of a person-centred approach to the persons living with dementia and the carers’ lives were centred around the needs of their spouses living with dementia. However, their caring roles also evolved through time from being the main, sole carers, through accepting help from the wider family, to requiring formal support due to their own and/or their spouse’s health needs. This transitional process was evident in Patricia and Brian’s storyline and such seeking of alternatives predicted the inevitable future for the other four couples. Here, ‘time’ was the frame that encompassed all the factors that influenced the lived experience of dementia, shaped life stories, and affected biographical connectivity to the neighbourhood.

5.5 Meta-theme: Biographical Connectivity to the Neighbourhood

The meta-theme of ‘biographical connectivity to the neighbourhood’ allowed me to draw together the whole data set and the lived experience of dementia as seen in this chapter and in the overall presentation of the findings. Biographical connectivity to the neighbourhood varied through time and was influenced by the subjective view of couples’ connections to their neighbourhood, such as those explored through ‘people’ and ‘places’. This biographical connectivity gave rise to personal relationships with their neighbourhood and such relationships offered a conceptual explanation of the complex interactions between people living with dementia and neighbourhood. As such, the lived experience of dementia could be better understood within a biographical phenomenon.

It was this biographical lens that gave a unique meaning for each couple to their self-defined neighbourhood and resulted in a variation in their neighbourhood construction and boundaries which would change over time. This biographical lens highlighted a need to move the neighbourhood concept beyond a homogeneous understanding of being a lived place within a geographical boundary. The self-defined neighbourhood was centred around where people living with dementia lived, was a product of their connection to ‘people’ and ‘places’ both past and present, and was an outcome of their interpretations.
of ‘a sense of being in places’. Consequently, personal biographies facilitated a fluid notion of neighbourhood and its continuance affected a sense of being in place.

As the data revealed, personal biographies were crucial to neighbourhood interactions as participants’ emotional belonging to ‘people’ and attachments to ‘places’ derived from, and were influenced by, their cumulative experiences and life histories. It was the importance of personal biographies that enabled the person to assign specific, unique meanings to their neighbourhood, and that affected how they interacted with their neighbourhood in, and through, time. Their experience of each interaction re-shaped personal biographies to create a circular effect. An accumulation of these circular effects on interactions with neighbourhood over time formed neighbourhood connectivity. The key to neighbourhood connectivity was the maintenance of biographical continuity. That is, biographical connectivity to the neighbourhood derived from an accumulation of interactions with the neighbourhood over time, with these interactions being meaningful to personal biographies. These meaningful interactions resulted in the continuation of personal biographies through personal relationship with ‘people’ and/or ‘places’ which further influenced the cumulative neighbourhood connectivity. The importance of personal biographies also indicated that even though each couple had a collective definition of their neighbourhood, each individual’s experiences and subjective view of their connections to their neighbourhood could differ due to the variation in personal life stories.

‘Biographical connectivity to the neighbourhood’ provided a way of understanding the dynamic relationships between the couples and their self-constructed neighbourhood encompassed within the dimension of time. The meta-theme implied that neighbourhood connectivity relied on whether biographical continuity could be maintained through the journey of living with dementia. Indeed, biographical continuity affected the assumption the couple held of how their stability related to connecting to ‘people’ and ‘places’ in their daily life, which in turn influenced their perceptions of the lived experience of dementia. It was this sense of stability that motivated the couples, particularly the persons living with dementia, to employ a variety of means to identify opportunities for neighbourhood connections and to continue their biographies. As such, their relationships with their neighbourhood were re-shaped over time.

256
Even when complicating factors affected connectivity to the neighbourhood, causing connections to breakdown and destabilise the couples’ biographical connectivity to their neighbourhood, they constantly identified opportunities (such as participating in personalised group-based activities) and searched for alternatives (such as adapting ‘resources’) to maintain and/or establish new connections with ‘people’ and ‘places’. This led to the continuity of their biographies and ultimately retaining a sense of stability in neighbourhood connectivity. More significantly for Patricia, when this stability was threatened, she started travelling through time, via deeper rooted memories, to seek out familiar past spaces to continue her biographical connections to her past neighbourhood. This meant that the neighbourhood could be either rooted in the present, or the past, or a combination of both, as well as extending beyond a commutable geographical location. This experience of travelling through memory based time enabled Patricia and Brian to regain a sense of belonging and safety and to continue self-perceived biographical connectivity to the neighbourhood. That is, the couples’ biographical connectivity to the neighbourhood had been, and would be, continued through constant, dynamic interactions with ‘people’ and ‘places’ over time, with the central focus of biographical continuity within each interactional process. These cumulative, interactional experiences affected the subjective view of stability the couples held on their relationships with their neighbourhood and on their daily lived experience of dementia.

‘Biographical connectivity to the neighbourhood’ revealed that personal biographies influenced connecting to ‘people’ and ‘places’ and each interactional event contributed toward neighbourhood connection. The experience of each event formed part of life stories which re-shaped personal biographies to form a circular pattern. When personal relationships with ‘people’ and ‘places’ were continued and repeated, this process increasingly strengthened the circular pattern. As such, neighbourhood connectivity emerged from an accumulation of interactions with the neighbourhood over time. The experiences of neighbourhood connectivity influenced the subjective views of stability in person-neighbourhood relationships as well as leading to the evolving neighbourhood construction over time. However, when connectivity to the neighbourhood was broken-down or threatened, caused by complicating factors, participants adapted various
resources to support and maintain their existing connections, or to establish new ones, even travelling through time (memory) to search for familiar places where they could regain a sense of safety and security. In doing so, their biographical connectivity was continued, even if this was with a past neighbourhood. This demonstrates the importance of enduring biographical relationships. It is the significance and desire to maintain these relationships and associated experiences that shaped and re-shaped personal biographies, resulting in ‘biography re-shaping’ over time.

A heuristic displaying the significance of personal biography in influencing the lived experience of dementia in a neighbourhood context is presented in Figure 37. This biographical phenomenon provides a conceptual understanding of the lived experience of dementia in relation to how people living with dementia and neighbourhood are interlinked based upon a cumulative pattern.

Figure 37. Personal Biography Influencing the Lived Experience of Dementia

5.6 Conclusion

A cross-case analysis applied to the data developed a meta-theme of ‘biographical connectivity to the neighbourhood’ which drew two themes of ‘connecting to people’ and ‘connecting to places’, and linked them together by two mediating factors of ‘resources’ and ‘relationships’. The meta-theme of ‘biographical connectivity to the neighbourhood’ was dynamic, encompassed by the passage of time, and was in a state of continuing evolution, with periods of stability only a temporary pause in the dynamism of renegotiation. The meta-theme brought greater attention to personal biographies and its diagram highlighted the crucialness of personal biographies in
affecting the subjective view of the interactional experiences with the neighbourhood over time, with these experiences re-shaping personal biographies. The diagram illustrated that neighbourhood connectivity stemmed from cumulative interactions with the neighbourhood over time, with personal biographies being continued. Biographical continuity affected the perception of stability in neighbourhood connections. This significant perception of stability further inspired biographical connectivity to ‘people’ and ‘places’ through numerous ways even when this stability was threatened. It is this important understanding of the fluid, dynamic relationships between participants and their neighbourhood through a biographical lens and associated effects on the lived experience of dementia that brings significant contributions to public health and the existing literature.
CHAPTER 6
Discussion and Conclusion

6.1 Introduction
This chapter begins with a review of the key findings of the study, emphasising a theoretical model of ‘biographical connectivity to the neighbourhood’ that drew together the lived experience of dementia. This is followed by discussing how the outcomes contribute to the existing knowledge base in the fields of public health, geography, and environmental gerontology. As this study was located within a broad context of the literature, and the findings captured multiple dimensions of the lived experience, the chapter will outline the implications of the model and its supporting properties for practice, policy, education, and research. This chapter will conclude with a presentation of methodological reflections and a discussion of how qualitative rigor was maintained throughout the study. As a point of context all the participating people living with dementia were assessed as clinically ‘mild’ for the duration of this study.

6.2 Contribute to Knowledge
6.2.1 Summary of Findings
The five case studies examined the daily lived experience of dementia, described how the couples interacted with and connected to their neighbourhood, and illustrated how they attributed specific meanings to their social and physical surroundings. The co-constructed neighbourhood maps represented each couple’s self-defined neighbourhood. The emphasis in the writing was placed on the creation and pictorial representation of the neighbourhood maps with data collection led by the persons living with dementia and/or their carers.

A cross-case analysis illustrated an emergent meta-theme of ‘biographical connectivity to the neighbourhood’, which highlighted the significance of personal biographies in influencing neighbourhood connectivity through a cumulative pattern. Personal biographies affected how the persons living with dementia connected to ‘people’ and ‘places’ to construct their neighbourhood connectivity over time and their experiences of these connections further influenced their personal biographies over time. This constantly evolving process illustrated a cumulative effect of ‘biographical connectivity
to the neighbourhood’ and the key to this was biographical continuity. Equally importantly, ‘resources’ and ‘relationships’ mediated how the persons living with dementia interacted with, and assigned meanings to, their neighbourhood social ties and places.

Therefore, the meta-theme was supported by two themes of ‘connecting to people’ and ‘connecting to places’, and was held together by two mediating factors of ‘resources’ and ‘relationships’ within the dimension of time. These two factors influenced how the couples, particularly the persons living with dementia, dealt with environmental opportunities and challenges and so affected their biographical continuity and daily living experiences. This meta-theme also presented the significance of personal and relational biographies in influencing the fluid, subjective view of the experiences of interactions with the neighbourhood based upon a cumulative effect. A visual presentation of this meta-theme as a model in Figure 38 depicts how biographical connectivity to ‘people’ and ‘places’ both influenced, and was influenced by, the mediating factors and the process was affected by each moment in time and by the passage of time. This model illustrates the main findings and original contribution this study has made and emphasises the inside view of the world outside from the perspectives of people living with dementia and their carers. Moreover, it is important to recognise the fluid, complexity of a neighbourhood and that its supporting properties were not the same for all participants in the study.

Figure 38. A Model of Biographical Connectivity to the Neighbourhood
When ‘connecting to people’, the couples identified family, friends, and neighbours as their neighbourhood social ties and the essence of this was the couples felt part of, and a close bond to, these groups. This emotional attachment was associated with how people responded emotionally and practically to the persons living with dementia, it also impacted on how the couples reacted to those interactions. That is, the construction of ‘people’ was influenced by the couples’ sense of belonging, which derived from the quality of their interactions and connections with others. It was this important feeling of belonging that affected how the couples located ‘people’ in their neighbourhood in time, which was observed to be fluid. Such feelings and experiences of interactions shaped personal biographies and re-shaped interactional relationships with social ties through time to formulate a cumulative pattern. Additionally, the feeling of belonging influenced how the couples interacted with their neighbourhood social ties and stimulated an emotional feeling of responsibility towards these groups. This sense of responsibility triggered further philanthropic actions towards ‘people’, giving rise to feelings of self-worth. This meaningful, constantly evolving interactional process enabled the couples, particularly the persons living with dementia, to maintain their relational biographies with their neighbourhood, ultimately contributing towards their future biographies and influencing their potential living experiences. Interacting with people over time established ‘neighbourhood support’ where people helped and looked out for one another and which provided the couples with a sense of safety and security and facilitated biographical connectivity to the neighbourhood. The accumulative effect of ‘connecting to people’ over time contributed to neighbourhood connectivity and the continuation of this interactional process enabled biographical relationships with neighbourhood to be maintained. It was this biographical continuity in connection with neighbourhood social ties that affected the subjective view the couple held of their stability and lived experience in the moment.

When ‘connecting to places’, the construction of ‘places’ were influenced by emotional connections and attachments which were in close association with the dimension of time and frequency of contact. But a more important factor was the interactional experience, because positive experiences helped maintain emotional connections to the neighbourhood, whereas negative experiences created feelings of rejection towards the present neighbourhood, as presented in Patricia’s storyline. These emotions and
experiences affected neighbourhood interactions which shaped and re-shaped personal biographies through time. Over time, an accumulation of ‘connecting to places’ contributed towards the establishment of neighbourhood connectivity. This cumulative process indicated that ‘places’ captured memories and life stories, consisting of regularly visited and remembered places. The latter suggested an emotional transposed process where important social relationships were presented through the physical environment to form part of biographies over time. ‘Places’ started from ‘home’ where the couple, especially the persons living with dementia felt safe and comfortable. Home was also where life stories were demonstrated through personalised objects and these objects had effects on the persons living with dementia depending on their capacities and emotional responses in the moment. The concept of ‘places’ then broadened to three definable areas: a walkable distance, a commutable distance, and a boundary-free neighbourhood. These areas were significantly defined by the individual’s perceptions of their capabilities and biographical connections, and by the feelings of safety and comfort regarding their environment. Taking these factors together, the physical neighbourhood was constructed by ‘places’ that represented the couples’ life stories, where they had emotional connections and/or attachments and where they felt safe and comfortable in the moment. In what can be seen as a fluid process, these emotional bonds and feelings changed over time, affecting how the couples located ‘places’ in their neighbourhood at moments in time. It was the cumulative interactions with ‘places’ that contributed to neighbourhood connectivity through time and the experiences of these interactional events with neighbourhood places formulated part of the couples’ biographies over time and affected their perceptions of their biographical continuity and stability through, and in, time.

The couples’ connections to their social and physical neighbourhood varied through time and were mediated by ‘resources’ and ‘relationships’ which closely interwove with each other. To maintain independently living at home and to sustain biographical connectivity to the neighbourhood, the use of resources helped reduce or negate the impact of external obstacles and enhanced personal abilities in dealing with the environment. As such, their biographical relationships with their neighbourhood were then re-shaped over time. The couples actively sought and adapted resources, which were associated with the home environment, an enabling environment, and local services, to optimise...
the capabilities of the persons living with dementia in performing tasks and to improve their lived experiences. Here, attention should be paid to the fact that these resources were not the experience of all participants as they used different types of resources at different times and that their experiences of adapting support might change over time. This highlighted the need for resources to be sensitive to the person’s capability and meaningful to the person’s biography so that (s)he could adopt these resources and change behaviour to control the dynamics between self and the environment at that point in time. The adaption of resources not only empowered the persons living with dementia to cope with the environmental challenges but also highlighted its positive effects on their biographical continuity and stability through re-shaping person-environment interplays. Moreover, each couple’s relationship affected their daily living experience and how they interacted and negotiated with their neighbourhood. When living with dementia, the couples experienced three relational perspectives - role change, resilience, and togetherness – in various degrees. So, the couple’s relationship was important in influencing their neighbourhood connections which further affected their personal and relational biographies, ultimately affecting their daily living experience through the journey of living with dementia.

In short, the theoretical model of ‘biographical connectivity to the neighbourhood’ illustrated the complex, continually evolving dynamic connections between the couples and their self-constructed neighbourhood, encompassed within a framework of time. The model highlighted the significance of the biographical phenomenon which stemmed from a cumulative pattern of interacting with the neighbourhood, leading to the evolution of a fluid, multi-layered neighbourhood through time. This biographical phenomenon portrayed a clear picture of how people living with dementia and their neighbourhood were biographically interlinked. It is this important conceptual understanding of personal biographies and biographical connectivity to ‘people’ and ‘places’ through a cumulative pattern that adds new insights into the knowledge base in the field of public health, geography, and environmental gerontology.
6.2.2 Public Health

6.2.2.1 The Neighbourhood Concept

In this study, although the term ‘neighbourhood’ held diverse meanings for each couple, it was constructed around two dimensions of ‘people’ and ‘places’, with these two dimensions consistently located within three geographical concepts: a walkable distance, a commutable distance, and a boundary-free neighbourhood. These findings challenge Blackman’s (2006) definition: “the neighbourhood starts as we leave our front door. Where it ends varies according to many spatial and temporal factors but, in public health terms, the concept of a walkable zone of experience is important” (p.33). Blackman places a significant emphasis on the physical aspect of neighbourhood. His statement focuses on the importance of a ‘walkable zone’ and draws attention to an individual’s capability. It seems to neglect a wider view of the area outside of this ‘walkable zone’ and gives little credence to the importance of the social environment. The findings derived from this study not only broaden the ‘neighbourhood’ definition by stressing both its social and physical dimensions, but also make a significant contribution through the proposal of a commutable and boundary-free neighbourhood, calling greater attention to personal biographies. This proposal is derived from observations on the use of transport, the access of support, and the adaptation of technology to connect to ‘people’ and ‘places’ beyond a ‘walkable zone’ to maintain neighbourhood connections and a sense of stability in personal biographies. The boundary-free neighbourhood is developed from the creation of a virtual neighbourhood and places technology at the fore in this modern era.

Nevertheless, the findings demonstrated that a neighbourhood definition was based on the perceptions of the significance of an individual’s capabilities or biographical connections, and the feelings of safety and comfort towards the environment. This understanding underscores that a neighbourhood is a subjective construction created from personal meaning and perceptions, and it is located socially and spatially. This claim reinforces Breakwell’s (1986) argument that a place is not necessarily a product of geographical hierarchy, and it echoes Peace’s (2013) view that a place is constructed and shaped by social relations of power and its boundary is defined by rules that have meaning for the individual.
Larger systems, for instance Governments or Health Trusts, may be attracted to simpler, single concepts, such as a ‘walkable zone’, for ease of planning. However, to enable people living with dementia to live well and enjoy a good quality of life, this study highlights that their needs are far more complex and nuanced than a single concept can allow for. This understanding further contributes towards a bottom-up approach to the development of a neighbourhood model on dementia.

6.2.2.2 A Neighbourhood Model on Dementia

The diagram of ‘personal biography influencing the lived experience of dementia’ (see Figure 37) presents the significance of personal biographies in shaping neighbourhood connectivity through a cumulative effect, ultimately influencing the lived experience of dementia. The theoretical model of ‘biographical connectivity to the neighbourhood’ provides insight into the dynamic, complex relations of people living with dementia and their carers with their neighbourhood social ties and places. It is this important lens of personal biographies that brings a new dimension into the development of a neighbourhood model on dementia and contributes to a bottom-up approach. As such, people living with dementia could gain meaningful connections to their social and physical surroundings and maintain their biographical continuity, ultimately contributing towards local social cohesion. Additionally, in this study, all the persons living with dementia also had other long-term conditions. This suggests that a neighbourhood model should pay greater attention to both the ageing and dementia population, this will entail a much broader approach when dealing with dementia. This observation echoes the claim made by the All-Party Parliamentary Group on Dementia (2016) that ‘dementia rarely travels alone’. To meet the needs of people living with dementia and an ageing population, this study endorses Turner and Morken’s (2016) approach on the merging of age-friendly and dementia-friendly communities. Above this, personal biographies should be the central foci in creating such enabling communities. As such, the person’s inside view of the world will shape the configuration of society.

Biographical Connectivity to ‘People’ and ‘Places’

The findings revealed that regularly connecting to ‘places’ formed a sense of familiarity and belonging and such cognitive effects were then intensified over time to establish person-to-place bonds, which further shaped personal biographies. This echoes the
concept of ‘physical insideness’ (Rowles, 1983), familiarity of the physical environment, and the notion of ‘place attachment’ (Low & Altman, 1992; Hammitt, Backlund & Bixler, 2004; Kyle, Graefe, Manning & Bacon, 2004). In this study, ‘places’ were constructed around regularly visited and remembered sites that captured memories and life stories. This finding also reiterates Rowles’ (1983) ‘autobiographical insideness’ that represents historical dimensions and/or remembered places. However, what is more important is the cumulative pattern that makes the couples’ connectivity to their neighbourhood biographical. It is this biographical phenomenon that provides in-depth insight into the impact of neighbourhood on the lived experience of dementia in a daily context and so this knowledge makes a significant contribution to public health.

This study indicated that the essence of the self-constructed neighbourhood was an integrated and supportive culture where people living with dementia and their family carers gained a sense of safety and security and felt a sense of inclusion and belonging. When connecting to social ties, knowing and contributing to the local community helped maintain social connections and enabled ‘connecting to the neighbourhood support’. This finding is in close association with Rowles’ (1983) ‘social insideness’, relating to integration with social fabric of the community, and ‘social credit’, derived from contributions to social networks over time. This study also demonstrated that close neighbours were willing to take responsibility for crisis management, such as Diane’s neighbour being on her emergency contact list. This finding echoes Donnellan et al. (2016) work in that neighbours are more likely to serve an essential role of crisis management.

‘Connecting to the neighbourhood support’ revealed the predominant role of social support and protection in the daily life of people living with dementia and their carers. This finding supports the argument that social support is a key characteristic when developing dementia-friendly communities for people living with dementia (Innovations in Dementia, 2011) and stresses the significance of ‘safeguarding’. The findings from this study also echo Wiersma and Denton’s (2016) claim that when interacting with a local community, a feeling of ‘knowing everyone’ leads to a sense of safety within that community, so people living with dementia feel protected by their community. Additionally, this study highlighted that the wider family played an important role in
looking after the persons with dementia and helped lessen the spousal caregivers’ duties. This claim reinforces Gideon’s (2007) work that the family helps undertake some caring responsibilities and reduces the emotional burden for the spousal carers. Above all, this study indicated the significance of emotional support from, and connection with, the family in the daily experience of living with dementia.

To support ‘biographical connectivity to the neighbourhood’, attention should be paid to personal biographies by maintaining the existing person-to-neighbourhood bonds, while providing alternatives and new opportunities for establishing new attachments. Offering new and alternate opportunities is especially important as people age and relocate, taking notice of how their world gradually shrinks; this empowers people living with dementia to take actions to slow down that process with the potential to continually build social cohesion. As such, their perception of stability in their biographical connectivity and daily life would be maintained. Understanding the theoretical concept of ‘biographical connectivity to the neighbourhood’ provides substantial insights into the daily life of people living with dementia, this connectivity is fostered through a sense of belonging under a biographical phenomenon. The significance of belonging is reiterated by Wahl and Oswald (2010) who argue that belonging is particularly important for an ageing population as it increases as people age, and by Wahl et al. (2012) that older people’s well-being is related to a sense of belonging and autonomy.

Support for the Equal Rights of People Living with Dementia
The findings revealed that the availability, accessibility, and quality of ‘resources’, in relation to the home environment, an enabling environment, and local services, influenced how the persons living with dementia interacted with their neighbourhood and their person-environment experiences. This study brings the equal rights of people living with dementia to the fore by placing an emphasis on these resources and supports the social model of disability with human rights principles recommended by Mental Health Foundation (2015).

The findings indicated that accessing resources regarding the home environment helped maintain independently living at home and continue biographical interests. Supporting people living with dementia to remain in their homes is associated with one principle of
a dementia-friendly community (Alzheimer’s Disease International, 2016). However, this study calls attention to personal biographies which is a fundamental step to a person-centred, bottom-up approach to developing a neighbourhood model. As such, personal biographical interests would be continued and so empower the person and enhance his or her quality of life when living at home. Taking technology as an example, whilst it helps maintain biographical continuity in social connections, it must always be reviewed to ensure it matches the person’s needs and capabilities to avoid potential worry or additional confusion caused by adapting it. Despite this concern, the significance of technology in maintaining biographical connectivity to the neighbourhood reiterates Lawton’s (1998) claim that technology plays a vital role in the ‘new’ environment for ageing well and should be part of the wider consideration of interacting with the environment.

The findings demonstrated that adapting resources relating to an enabling environment contained two perspectives: enabling social connections and easy access to local amenities. Such an enabling environment promoted social citizenship by providing opportunities for social engagement, promoting equal rights for social participation and contribution, and claiming a place where people living with dementia connect to their neighbourhood. As such, people living with dementia and their carers could exercise their rights to access services and their rights to participation in a daily context. More importantly, ‘resources’ as a mediating factor in the biographical connectivity model reinforces the importance of the disability agenda to be embedded in, and woven through, the whole system in order to change the direction of dementia discourse.

Couple’s Relationships
This study highlighted the vital role of the interpersonal relationship of each couple; this relationship mediated their biographical connectivity to the neighbourhood and influenced their daily experience of living with dementia. The lived experience of dementia as a couple, in turn, affected the quality of their relationship and re-shaped their relational biographies. As dementia progresses, the couple’s relationship gradually modified and was affected in three dimensions, those of role change, resilience, and togetherness. This finding reiterates the claim made by Evans and Lee (2014) that the marriage and marital relationship steadily changes and the couple experience
‘transition’ in their relationship, roles, and intimacy alongside dementia progression. The two dimensions of ‘role change’ and ‘resilience’ are also reflected in Merrick, Camic and O’Shaughnessy’s (2016) writing of ‘altered structure’, ‘flexible scaffolding’ (recognising the remaining ability of the partner and then providing support accordingly), and ‘reviewing the plans’ (awareness of self and the partner and then update the plan).

In this study, ‘resilience’ drew attention to the continuity of the negotiated, changing process to support individuals living with dementia so that a sense of ‘personhood’ was maintained. In addition, this study indicated that a couple’s interpersonal relationship played a significant role in maintaining a sense of ‘togetherness’ for the couples. The concept of ‘relationships’ refers to ‘couplehood’ which has been previously explored within the field of dementia studies (Kaplan, 2001; Hellström, Nolan & Lundh, 2005) and it served as a means of capturing a couple’s joint commitment to their relationship. Therefore, while maintaining personal biography has been demonstrated to be of great significance, the personal biography can safely be located within the couple’s relational biographies when travelling through the unknown journey of dementia.

In sum, this study portrayed a much richer picture and explanation of the dynamic, multifaceted relationships between people living with dementia, their carers, and their fluid neighbourhood through time to answer the research question. Stemming from a cumulative interactional process, this study revealed deeper, comprehensive insights into the subjective view of the lived experience of dementia in close association with a sense of biographical continuity to neighbourhood connections via the lens of personal biographies. More importantly, the model of ‘biographical connectivity to the neighbourhood’ suggests that the fluid neighbourhood provides a setting for social cohesion which derives from an individual’s investment in social contacts in formulating social cohesion. From this viewpoint, it is fair to say that the stronger the sense of biographical connectivity to their current neighbourhood for people living with dementia, the higher the level of social cohesion they can gain, and the more likely it will positively affect their biographical continuity and stability. The findings also support Dempsey’s claim that the neighbourhood offers a setting for social cohesion (Dempsey, 2007). Put another way, it is this important insight into biographical continuity that brings an individual’s contributions to neighbourhood social cohesion that supports an
assets-based approach to a neighbourhood model on dementia. Therefore, I urge for a stronger focus upon the model in dementia and ageing societies, particularly in the key priority of supporting people living with dementia to independently live at home and in the community through creating enabling environments.

6.2.3 Geography and Environmental Gerontology

This study fills the evidence gap of geography and environmental gerontology in dementia care by researching how people living with dementia and their carers interacted with their neighbourhood through the lens of personal biographies. The model of ‘biographical connectivity to the neighbourhood’ illustrates a constantly evolving interactional process between a ‘person’ and the neighbourhood through time as the person’s experience of connections with ‘people’ and ‘places’ both affect, and are affected by, personal biographies. The cumulation of these constant interactions builds up neighbourhood connectivity which influences biographical continuity. This understanding echoes Lawton’s (1998) final view of the person-environment relations from an ‘interactional’ perspective: “although person and environment form a unified system where what is inside is philosophically inseparable from what is outside, for heuristic purposes, it is necessary to speak of, and attempt to measure, them separately” (p. 1).

This study moves Lawton’s work further into dementia research and demonstrates that ‘people’ and ‘places’ are the key components of neighbourhood across the five couples who assigned different meanings to each dimension. Although these two components are interlinked and present a holistic view of the neighbourhood, each component has its unique construction and influences on people’s daily life. The findings offer in-depth insights into the complexity of the people-environment relationships which can only be clearly captured and explicitly explored when the social and physical aspects were seen separately and given equal emphasis.

The findings derived from this study contribute to Lawton’s (1989) conceptual framework, encompassing the three environmental functions: ‘maintenance’, ‘stimulation’, and ‘support’, but what is more is the biographical phenomenon.
i. Maintenance function of the environment: This function was associated with the personal meanings of home for people living with dementia and their carers, the construction of their neighbourhood, their emotional attachments to their neighbourhoods, and how their experiences of interactions with their neighbourhood and emotional bonds affected the continuity of their biographical relationships with their neighbourhood.

ii. Stimulation function of the environment: This function referred to the ways in which the couples connected and re-connected to ‘people’ and ‘places’ within their defined neighbourhood boundaries. These connections were influenced and motivated by a sense of belonging and emotional attachment to maintain a sense of biographical continuity and their assumption of stability in neighbourhood connections.

iii. Support function of the environment: The ‘support’ function linked to how people living with dementia and their carers coped with the demands of their neighbourhood from social and physical aspects through adapting ‘resources’ to enhance their capabilities. Considering connecting to ‘resources’ as part of the biographical connectivity model broadened the understanding of the interrelations between older people living with dementia and their environment regarding the concept of optimisation. According to Wahl and Oswald (2010), optimisation aims to improve the quality of life of the older population through means of interventions.

The findings revealed that home was a place in which the couples expressed themselves through personalising its features to illustrate their life stories. This echoes Rubinstein’s (1989) exploration around the meaning of home, particularly a person-centred process which is a process of expressing a person’s life course in objects of the home environment. The findings also indicated the effect of home objects in stimulating personal memories. This links to what Augè (1995) calls ‘anthropological space’ where the presence of familiar objects helps negotiate with the place and provides a sense of safety. However, this study takes this a step further and gains richer insights into the presented meanings of the home features in eliciting different emotional responses. Additionally, the findings illustrated that the level of familiarity of home was closely associated with the length of stay in the current property, with this association affected
by both positive and negative living experiences and by how people living with dementia
adjusted to their condition. The effects of these variables are subjective and the weight
given to these effects influences how people living with dementia view and respond to
their environment. This helps explain why familiar environments can become unfamiliar
for them.

The findings illustrated rich insights into a complex place-making process which was
affected by ‘time-space compression’. The findings also indicated that the self-defined
neighbourhood was a lived place, a product of people living with dementia’s interactions
with ‘people’ and ‘places’, and their interpretations of ‘a sense of being in places’. Such
feelings were an outcome of maintaining biographical connectivity to the environment.
This study reiterates some key literature findings on space, place, neighbourhood, and
home as discussed in section 1.5. However, this study gives a new perspective by
highlighting the importance of the biographical lens that offers a significant
understanding to the neighbourhood concept and that enriches the concept of a lived
place by moving it beyond purely geographical boundaries. It is the significance and
desire to maintain biographical relationships with the environment that motivated an
ongoing place-making and remaking process and that affected people living with
dementia’s perceptions of a sense of being in place. This finding furthers the idea of bio-
geographical disruption and flow (Meijering et al., 2017) by recognising the fluid,
dynamic notion of neighbourhood. This facilitates an understanding of the closely
intertwined process between disruption and flow with the continuance of biographical
connectivity to the neighbourhood being the key stimulus. This new knowledge also
contributes to how a sense of being at home can be maintained for people living with
dementia as their meanings of home constantly shift.

Overall, this study connects with, and adds new knowledge to, the geographical and
environmental gerontology literature on space and place at several scales, and focuses
upon relationality between people and environment with personal biographies being the
central foci in an everyday context.
6.3 Implications

The findings of this study have significant implications for policy, practice, education, and research, striving to improve the lived experience of dementia by placing personal biographies at the centre of attention to support a bottom-up, assets-based approach to the development of a neighbourhood model on dementia.

6.3.1 Recommendations for Policy

This study revealed that all the participating people who lived with dementia had other chronic conditions. This significant factor calls for dementia policy to pay greater attention to older people living with multiple conditions rather than merely dementia itself. To achieve this, this study endorses the idea that a neighbourhood model should be inclusively developed for both ageing and dementia populations based upon collaborative principles of age-friendly and dementia-friendly communities. The key should be focusing upon the maintenance of personal biographical continuity in neighbourhood connections. This biographical lens gives rise to people living with dementia’s inside view of the world shaping the configuration of neighbourhood. This bottom-up approach makes an ideological move from society predicting the needs of people living with dementia, to them telling society what is important through their verbal and visual narratives. Such an important inside out view challenges the current top-down structure of dementia-friendly community work.

Additionally, this biographical continuity focused approach not only understands the needs of people living with dementia but also enables and values their contributions to society. Put another way, the theoretical model endorses an asset-based approach to neighbourhood building by promoting social participation and contribution for people living with dementia and by effectively using their skills, knowledge, and assets. As such, their biographical continuity can be maintained and neighbourhood social cohesion can be built and potentially increased. This asset-based approach promotes well-being by shifting the focus of meeting needs towards building and encouraging the strengths and resources of local residents and community (Social Care Institute for Excellence, 2017).

The promotion of social engagement has implications for future policy in that not only should it focus on the physical elements, such as easy access to local amenities, but also
give credence to personal biographical interests to understand and ensure all important connections can be maintained. For example, to ensure there are places and group activities for people living with dementia to connect to and engage with, and such activities need to be meaningful, enjoyable, and sensitive to an individual’s capability and biography in time. In so doing, they can gain a sense of belonging and retain their biographical continuity. This claim adds an important dimension to the social participation element in the principles of age-friendly communities and dementia-friendly communities recommended by the World Health Organisation (2007) and Alzheimer’s Disease International (2016) respectively. This new dimension can maintain personal biographies in neighbourhood connections and build an individual’s social capital which contributes to neighbourhood social cohesion.

Moreover, the model of ‘biographical connectivity to the neighbourhood’ presented significant insights into the impact of ‘resources’ on the complex interactions between the couples and their neighbourhood. This indicates that ageing and dementia policy should focus upon the provision and accessibility of ‘resources’ to help enhance their abilities in dealing with the environment and to improve their daily living. In parallel, it is essential to offer necessary training to individuals living with dementia and their carers on how to access resources and use support tools. The provision of multiple support is especially important in delivering the social model of disability with human rights principles in the dementia landscape. As such, people living with dementia can exercise their equal rights in society to achieve social change via enabling environments. Placing ‘resources’ at the forefront of dementia policy will increase society’s ability to better accommodate people living with dementia beyond a geographical boundary, and inevitably achieve a state of equal rights as citizens. The provision of ‘resources’ is also important to carers in reducing their stress and enabling them to provide better care for their loved ones living with dementia. Therefore, policy-makers should give careful consideration to this element and embed the provision of ‘resources’ into the current ageing and dementia policy utilising a person-centred approach, ensuring the incorporation of personal capacities and biographies.

Furthermore, the findings demonstrated that the couple’s relationship added a vital dimension to their daily life and influenced their interactions with their neighbourhood
as well as affecting their emotional responses and their sense of ‘couplehood’. This proposes the need to see the person living with dementia and the spousal carer as a joint unit as well as seeing them as separate individuals when seeking to assist them, as this is important in maintaining their relational biographies alongside personal biographies.

6.3.2 Recommendations for Practice

The model of ‘biographical connectivity to the neighbourhood’ and its supporting properties have the potential to inform public health practice and draws attention to the following areas:

- Social integration: The findings illustrated that belonging and social participation was important for people living with dementia, particularly how they were responded to and approached by others. This supports social inclusion and participation of people living with dementia as active citizens in the community. More importantly, maintaining biographical continuity in social connection should be the predominant foci, in so doing their skills, knowledge, and assets can be effectively utilised and they also gain a sense of self-worth. When creating an enabling neighbourhood, social integration needs to be facilitated by providing group-based activities. Some examples from this study were the Friendship Club, Alzheimer’s Club, Flower Club, and the social events organised by the local committees. Here, attention should be given to the activities that are sensitive to an individual’s functional abilities, such as different dementia stages, and relevant to personal biographies. In so doing, the activities hold meaning for the person, increase his or her level of engagement, enhance a sense of belonging and attachment, and so continue personal biographical interests. It would be beneficial if these activities enable the carers to participate, as this would contribute to the maintenance of their relational biographies as a couple. Moreover, the promotion of social participation via the lens of personal biographies at a neighbourhood level contributes to social citizenship in the dementia landscape.

- Neighbourhood support: The findings highlighted the significance of ‘connecting to the neighbourhood support’ in the daily life of people living with dementia
and their carers. This calls attention to establishing such ‘neighbourhood support’ by effectively utilising resources and assets of the community, such as offering opportunities to encourage face-to-face communications and community-based social participation to make friends and build ‘social credit’ (Rowles, 1983). This will result in an increase in neighbourhood social cohesion.

• Environmental design: The findings illustrated that these aspects of environmental design - familiarity, comfort, cleanliness, accessibility, and safety - were important factors of the physical environment to the daily life of people with dementia and their carers. This echoes the work of Mitchell and Burton (2010) who identified six design principles for people with dementia when living in the community: familiarity, legibility, distinctiveness, accessibility, comfort, and safety. In addition, flat ground and smooth pavements are particularly important aspects for supporting people having mobility impairments. However, where it is impossible to achieve flat ground due to the nature of the landscape, alternative mechanisms should be considered to allow people to easily access local services and facilities, such as public transport. All these important aspects of neighbourhood design contribute towards transferring ‘spaces’ into meaningful ‘places’ to gain a sense of familiarity and belonging.

• Transportation: The findings revealed that accessibility of appropriate transportation was particularly important for those who could not drive and this affected their biographical connectivity to the neighbourhood. To maintain biographical connectivity, it is crucial to ensure that people living with dementia can easily access public transport and/or a range of alternative transport services; the environment can then better accommodate their needs and facilitate their participations and contributions to society. The absence of adequate alternative transportation services is also highlighted by Rosenbloom and Herbel’s work (2009) and by the AARP Public Policy Institute (2005) that argue for the development of multiple transportation services and mobility options.

• Technology: In this study, a number of technologies were used to continue biographical interests, stimulate memories, maintain a sense of independence, and increase safety, such as an internet connected computer to maintain social contacts, an iPad to create a family story book for reminiscing, and an assistive
alarm for safety. However, using technologies entailed challenges and required assistance from the carer and other family members. This highlights the need for training and support for both the persons living with dementia and their carers so that they could successfully adapt the technology. This echoes the work of Brittain et al. (2010) and Hanson et al. (2007) that training and support should be provided for both people living with dementia and their carers when using technologies, attention should be given to individuals living with dementia who live alone and lack family support. This study also suggests that support needs to be available to fix technical problems should they arise. Additionally, technology should be easy and convenient to use, providing people living with dementia with a sense of being in control without additional frustration and stress, in line with ethical considerations, such as safety and security issues. More importantly, technology and associated support need to be sensitive to an individual’s ability and biographies.

- Home environmental modification and support: The findings demonstrated the significance of proactive assessment and appropriate modification of the home environment to ensure that people living with dementia could live in their homes safely and independently, maintain dignity and independence, and reduce family carers stress. This is especially important for those with mobility issues, as the home environment influences the living experiences of people with a disability (Wahl et al., 2009). The AARP Public Policy Institute (2005) makes similar observations relating to the need to create a range of housing supports and choices. Above all, supports and choices should be sensitive to an individual’s capabilities and relevant to personal biographies. Additionally, effective use of meaningful home objects contributes to memories stimulation, facilitating a process of reminiscence at home. That is, the physical objects help shape the daily living experience and influence the way in which people living with dementia interact with their home environment. This gives rise to a question: how can these personalised objects be best used to stimulate memories in current dementia practice?

- Collaboration across sectors to improve quality of care and/or support: The outcomes indicated the diverse needs and assets of people living with dementia and their carers. These multiple needs can only be met by a tailored,
collaborative approach across sectors, covering public health, health care, social care, and third sectors. This approach can make a significant contribution to help people living with dementia to maintain independence and stay living at home and in the community for as long as possible. This also supports carers in delaying the need to engage with the high-cost institutional care for people living with dementia. The key to success is that the services provided should be easy to access and the quality of services should be guaranteed. In parallel, raising awareness of local services with appropriate signposting is essential. This collaborative approach reflects the recommendation of the World Health Organisation and Alzheimer’s Disease International (2012) in a coordinated multi-sectoral approach to support people living with dementia and their carers. This collaborative approach supports the development of a neighbourhood model on dementia through effectively utilising local resources. As such, the lived experiences of people living with dementia and their carers can be improved, in return, they can contribute their skills, knowledge, and assets to their communities to help build neighbourhood social cohesion.

Nevertheless, maintaining personal biographical connectivity to the neighbourhood should be the primary consideration for dementia practice, which affects an individual’s assumption of stability in their life and daily lived experience of dementia. It is this important inside view of the world outside – the biographical phenomenon - that challenges the existing policy and practice on ageing and dementia.

6.3.3 Recommendations for Education
This study developed a model of ‘biographical connectivity to the neighbourhood’ and highlighted the significance of personal biographies in influencing the person assigned specific, unique meanings to their neighbourhood and affected how they interacted with their neighbourhood in, and through, time. The maintenance of biographical continuity should be a predominant consideration when enabling people living with dementia to live well in their communities and increase their social inclusion and participation. To change the culture and services of public health, health care, and social care towards a more person-centred approach, it is necessary to incorporate the model of 'biographical connectivity to the neighbourhood' into training materials as part of education and
development for professionals and professional care providers. Professionals can then better understand the lived experience of dementia through the lens of personal biographies.

This recommendation is in light of an increasing recognition of the need to involve people living with dementia and family caregivers in the process of service improvement, policy making, and workforce development (Eley, 2016). This movement has evolved from a recognition that people living with dementia should have an equal right to voice their views and take responsibility and ownership of the services they (potentially) use and that the best ideas come from those who have the lived experiences of dementia (Eley, 2016; Milton, 2016). Such involvement encourages the culture of family-centredness and ensures the services meet the user’s needs (Eley, 2016). More importantly, it is the emphasis of personal biographies that should be the foci of dementia education and that brings a clearer direction to the person-centred approach. This recommendation helps to understand the needs and assets of people living with dementia and so support the movement from simply meeting the needs towards recognising and building assets to reframe the dementia narrative (Social Care Institute for Excellence, 2017).

6.3.4 Limitations and Recommendations for Future Research

The sample of this PhD study was small, and all participants were White British, living in one county in the East Midlands of England. The sample, therefore, lacks representativeness and generalisability. Although this latter aspect is not the purpose of qualitative research, the limitation suggests scope to further develop the model through a larger sample size, focussing on other geographical areas of the UK, and taking into account other ethnic backgrounds (non-White British) to understand how biographical connectivity maps on to differing cultural identities within the UK.

In this study, the participating people living with dementia consisted of four women and one man, this female dominated sample suggests a need for further research to explore various meanings in the interactions of men living with dementia with their neighbourhood and to understand their biographical phenomena. The gendered nature was also reflected on the map-creating as all the men in this study led on drawing the
neighbourhood maps. Whilst the co-constructed neighbourhood maps represented each couple’s joint perception of their neighbourhood, the gendered relationships to maps might be worth exploring further. Additionally, the sample did not cover those living alone with dementia who may have different experiences. It would be worthwhile considering how people living alone with dementia connect and re-connect to their neighbourhood and what experiences they encounter.

The model has significant practical implications and contributes to the current priorities in dementia and ageing policy. To transform the knowledge into practice, it would be beneficial to gain professional insight and understanding of the proposed model, especially relating to its practicality, feasibility, and potential challenges and barriers of its implementation. This will make a further contribution to the gap and challenge of linking theory, research, and application.

The quality of life of the persons with dementia was measured twice, at the start of the fieldwork process and again at the end, using the DEMQOL questionnaire and its proxy version (Smith et al., 2005). However, it has become clear that the DEMQOL questionnaire has a limitation in that it measures a person’s subjective view of their quality of life at a specific moment in time. This measure may be subject to variables that skew an overall perception. To counter this and to gain greater insight, utilising the DEMQOL questionnaire at each point of contact with the couples would have provided a richer insight to this phenomenon over the period of the study. When measuring quality of life, this study purely focused on people living with dementia. It would be beneficial for further research to assess and measure the carers’ quality of life to provide quantitative data to supplement the qualitative findings of this study.

**6.4 Methodological reflections**

Environmental gerontology was adopted to set up the research question and design, uncovering the dynamic and complex relationships between participants and their neighbourhood, and how those relationships impacted on their everyday living. Narrative inquiry with participatory methods enabled an in-depth exploration of the lived experience of dementia within a neighbourhood context.
6.4.1 Innovation

In this study, the application of a participatory approach with multiple methods of data collection allowed for the emergence of rich insights into the lived experience of dementia; enhanced narrative agency of people living with dementia; and brought opportunities for them to have control over their narratives. For example, participatory mapping was adopted to represent the participant’s neighbourhood. This is the first study where people living with dementia and their carers mapped their own neighbourhood via a participatory approach and sought to provide an understanding about how they engaged with spaces, places, and people that they identified with. The neighbourhood maps are dynamic and illuminating and, together with the photographs the couples selected, demonstrate their neighbourhood construction and/or their activities to indicate their use of community services and resources. This information is crucial for understanding perceived needs and thereby proactively planning service provision for effective utilisation of resources in the community.

Participatory methods also brought the use of technology to life which acted as a voice for itself. The adaptation of technology simplified the mapping process for Patricia and Brian, enhanced Brian’s confidence in drawing the neighbourhood map and gave him a sense of enjoyment. Brian also used the iPad to photograph the significant areas of their neighbourhood and to keep diaries for Patricia as part of the data collection of this study. The use of technology also appeared in Jonathan and Jackie’s storyline and they used their digital camera to photograph the important areas of their neighbourhood; Jonathan also used a computer to write his diary. Diane and Dave also used their digital camera to take photographs of their neighbourhood.

In addition, maintaining a flexible approach when applying participatory methods during data collection empowered the participants to have control over their stories and enabled them to feel comfortable and confident. This innovative approach offered participants more space to express themselves. As a result, the five couples seemed to enjoy using the different techniques to tell their lived experience, and they also perceived the whole process as a useful experience. For example, Jackie felt that keeping the diary and drawing the neighbourhood map were helpful activities for stimulating Jonathan’s cognitive functioning. Jackie encouraged Jonathan to continue with his diary-
keeping after the conclusion of my involvement as she believed he would continue to derive a benefit and pleasure from maintaining it. The adaption of participatory methods enabled participants to understand their own lived experiences of dementia via a variety of means. For instance, Brian felt that the map helped him and Patricia see what their current neighbourhood looked like and how much it had been reduced, which gave them a better understanding of how Patricia’s dementia had limited their social activities and had shrunk their world.

The use of genograms aimed to visualise family composition and structure and helped to elicit family stories and relationships during the interviews. However, in future studies, to reflect the comprehensive family dynamics, genograms would be improved by using colour-coded links with different shapes and weights to display a wider selection of family and emotional relationships, such as close or detached relationships, marriage or partnership, and where family played an important role in the daily life of people living with dementia. Following this way of thinking, the neighbourhood maps could be presented more creatively by locating photographs onto the maps to illustrate key places, including the close family ties presented in the genograms, and highlighting examples of areas where participants might find it easier or more difficult to navigate or connect. The combination of multiple visual data would generate a comprehensive pictorial neighbourhood to represent its meaning, construction, and utility for each couple.

6.4.2 Credibility

The longitudinal approach to the field work and data collection was essential in building trusting relationships with participants to enable them to reveal their detailed experiences of living with dementia in a neighbourhood context. The longitudinal design also increased the credibility of the outcomes (Erlandson et al., 1993; Lincoln & Guba, 1985). Secondly, narrative inquiry was supported via the use of multiple methods of data collection. These multiple methods helped gain deeper and richer insights into the lived experience of dementia and compensated for the limitation of each dataset, and so increased the credibility of the study (Shenton, 2004). Thirdly, the credibility of the findings was enhanced by cross-case analysis and triangulation (Shenton, 2004; Tellis, 1997), consisting of triangulation of qualitative data sources, methods triangulation,
theory triangulation, and triangulation through multiple analysis (Patron, 1999).

Fourthly, the credibility of the outcomes was achieved via repeated interviews and checking with the participants on the key themes. Fifthly, the credibility of the findings was increased via regular meetings and discussions with my supervisors who reviewed and provided feedback on each stage of the research and writing of the thesis. Finally, the maintenance of researcher reflexivity during all research encounters and the reflective note keeping throughout the study, to record thoughts and observations of the situation, data collection and analysis, also served to increase the credibility of the study.

6.4.3 Transferability
The purposive sampling technique not only gained internal validity using multiple data collection methods (Dolores & Tongco, 2007) during a prolonged period, but also led to an analytical generation of the research findings (Johansson, 2003). This means that the findings derived from this study are more likely to be transferable via a two-step process: a conceptual claim and the translation of the emergent theory to a population within similar situations where analogous events arise (Yin, 2010). That is, the conceptual claim for this study is the model of ‘biographical connectivity to the neighbourhood’ and its supporting properties emerged from rigorous analysis of substantial data and from the credibility of this study. The considerable interview data alongside other information provided thick, rich descriptions of the lived experience of dementia from across the five couples when focusing on their neighbourhood as a context and an object. The theoretical claim can then potentially be applied to other people with mild dementia with the same ethnic background who are cared for by their spousal carers when living in their own home.

6.5 Concluding Remarks
This longitudinal dementia mapping study, using narrative inquiry with participatory methods, uncovered the deep, dynamic, multifaceted interactional relationships between the participating couples, where one person has mild dementia, and their neighbourhood. The study explored the couples’ inside view of the world outside and gained an in-depth understanding of how personal biographies affected their experiences of interactions with their neighbourhood in, and through, time. These
interactional experiences, in turn, shaped and re-shaped their biographies. A sense of biographical continuity to neighbourhood connections influenced the couples’ perception of their stability in their connections with ‘people’ and ‘places’ and this assumption of stability impacted upon their subjective view of their daily experience through their journey of living with dementia. The model of ‘biographical connectivity to the neighbourhood’ places personal biographies at the centre of attention. It is this important understanding of the fluid and dynamic relationships between the couples and their neighbourhood under a biographical phenomenon that supports a bottom-up approach to the development of a neighbourhood model of dementia. This challenges the traditional top-down structure of dementia-friendly community work. This significant inside understanding of the needs and resourcefulness of people living with dementia also contributes towards an asset-based approach in neighbourhood building to empower them to participate and contribute their skills and knowledge to their neighbourhood and to build their neighbourhood social cohesion.

In addition, this study emphasises the untenable position of attempting to understand the impact of dementia in isolation, and that dementia needs to be observed and understood in relation to co-morbidities. This study draws attention to the predominant role of ‘resources’ in the everyday living of people with dementia and their caregivers, and brings the social, human-rights based, model of disability to life. The adaptation of ‘resources’ is in line with the principles of health promotion and honours the right of people living with dementia to personhood and full citizenship. The use of ‘resources’ helps optimise their social participation and environmental connection; empowers and enhances their capabilities when dealing with the environment; and enables them to have power and control over their daily life. More specifically, the use of technology creates a ‘virtual neighbourhood’ which provides a new concept of a boundary-free neighbourhood. This broadens the traditional understanding of neighbourhood based upon geographical location and, again, reiterates the importance of the inside view of the world via the lens of personal biographies.

This PhD study also bridges the evidence gap between geography, environmental gerontology, and dementia research, and reinforces the link between public health, geography, and environmental gerontology. This study also stresses the important
practical implications to policy, practice, education, and research. The robust methodology and innovative methods adopted in this study are the key to gain thick descriptions of the lived experience of dementia and to obtain in-depth insights into the participant’s inside view of their external world with a central focus on personal biographies. This is the first study where the persons living with dementia and their spousal carers co-constructed and co-produced neighbourhood maps with the researcher to bring their understanding of spaces, places, and people to life, the process was supported with, and supplemented by, participant-led photographic data.

In conclusion, this study has the potential to shape the direction of policy and practice in dementia care and public health through an inside view of the world outside, paying greater attention to personal biographies. This study may also influence the movement of the social model of disability with human rights principles into the dementia landscape. Through working with the five couples living with dementia in the present study, my knowledge on the lived experience of dementia has increased and been deepened, and my passion for, and interest in, dementia care has continued to grow.
References


Arntzen, C., Holthe, T., & Jentoft, R. (2014). Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family carers. *Dementia, 0*(0), 1-17.


Cahill, S., Begley, E., Topo, P., Saarikalle, K., Macijauskiene, J., Budraitiene, A., ... Jones, K. (2004). ‘I know where this is going and I know it won’t go back’: hearing the individual’s voice in dementia quality of life assessments. *Dementia, 3*(3), 313-330.


Eley, R. M. (2016). Telling it as it is: Involving people with dementia and family carers in policy making, service design and workforce development. Working with Older People, 20(4), 219-222. doi: 10.1108/WWOP-09-2016-0026


292


296


framework. Health and Social Care in the Community, 43-51. doi: 10.1111/j.1365-2524.2010.00947.x


Stuckey, J. (1992). *The relationship between social ties and emotional and physical well-being among spousal caregivers of patients with dementia*. Cleveland, OH: Case Western Reserve University.


### Appendices

#### Appendix 1. Included Studies in the Thematic Review

<table>
<thead>
<tr>
<th>Reference</th>
<th>Sample</th>
<th>Aim</th>
<th>Methods</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social integration</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donnellan, W., Bennett, K., &amp; Soulsby, L. (2016). <em>Family close but friends closer: exploring social support and resilience in older spousal dementia carers.</em> <em>Ageing and Mental Health, 0(0), 1-7.</em></td>
<td>23 spousal carers of people living with dementia</td>
<td>To explore social support as a key component of resilience to identify the availability, function and perceived functional aspects of support provided to older spousal dementia carers.</td>
<td>23 in-depth qualitative interviews with spousal carers of people living with dementia in North West England.</td>
<td>Medium</td>
</tr>
<tr>
<td>Gideon, C. A. (2007). <em>Social environments of dementia caregivers: Relationships between social support, negative social interactions, and caregiver emotional distress.</em> Cleveland, OH: Case Western Reserve University.</td>
<td>64 carers of people living with dementia</td>
<td>To investigate the relationships between positive and negative social exchange in familial and non-familial social contexts.</td>
<td>A cross-sectional study employed a single sample correlational design.</td>
<td>Medium</td>
</tr>
<tr>
<td>Author</td>
<td>Study Population</td>
<td>Research Design</td>
<td>Methodology</td>
<td>Findings/Results</td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td>------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Stuckey, J. (1992). <em>The relationship between social ties and emotional and physical well-being among spousal caregivers of patients with dementia.</em> Case Western Reserve University.</td>
<td>80 spousal carers of people living with dementia.</td>
<td>To test the hypothesis that the number of social ties and satisfaction with social ties make independent contributions to caregivers burden and emotional and physical welling among spousal caregivers of people living with dementia.</td>
<td>A cross-sectional study: self-administered questionnaires on 80 individuals providing care to a spouse with Alzheimer’s disease or a related disorder.</td>
<td>High</td>
</tr>
<tr>
<td>Tranvåg, O., Petersen, K., &amp; Nåden, D. (2015). <em>Relational interactions preserving dignity experience: Perceptions of persons living with dementia.</em> <em>Nursing Ethics,</em> 22(5), 577-593.</td>
<td>11 people living with mild to moderate dementia.</td>
<td>To explore and describe crucial qualities of relational interactions preserving dignity experience among people living with dementia, while interacting with family, social network, and healthcare professionals.</td>
<td>An exploratory design employing qualitative research interviews of 11 people living with dementia, living in their own homes.</td>
<td>Medium</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participants</th>
<th>Methods</th>
<th>Study Aim</th>
<th>Design</th>
</tr>
</thead>
<tbody>
<tr>
<td>71 participants – 37 health service providers, 15 care partners, 2 people living with dementia and 17 other community members</td>
<td>A constructionist approach with 71 in-depth interviews.</td>
<td>To understand how dementia-friendly rural northern communities were by focusing on the care and support needs from various perspectives, available services and facilitating and limiting factors in caring and supporting people living with dementia in rural communities.</td>
<td>High</td>
</tr>
</tbody>
</table>

---

**Space, place and home**


<table>
<thead>
<tr>
<th>Participants</th>
<th>Methods</th>
<th>Study Aim</th>
<th>Design</th>
</tr>
</thead>
<tbody>
<tr>
<td>Four focus groups with a total of 16 people living with dementia and three carers</td>
<td>Re-analysis of qualitative data from two studies of using technology to support people living with dementia in their outdoor activities.</td>
<td>To explore the meanings and lived experiences of people living with dementia in relation to everyday technologies in public spaces outside the home.</td>
<td>High</td>
</tr>
<tr>
<td>Study</td>
<td>Participants</td>
<td>Methodology</td>
<td>Findings</td>
</tr>
<tr>
<td>-------</td>
<td>--------------</td>
<td>-------------</td>
<td>----------</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Year</td>
<td>Title</td>
<td>Participants</td>
</tr>
<tr>
<td>----------</td>
<td>------</td>
<td>-------</td>
<td>--------------</td>
</tr>
<tr>
<td>Gibson, G., Chalfont, G.E., Clarke, P.D., Torrington, J.M., &amp; Sixsmith, A.J.</td>
<td>2007</td>
<td>Housing and connection to nature for people with dementia: Findings from the INDEPENDENT Project. <em>Journal of Housing for the Elderly, 21</em>(1-2), 55-72.</td>
<td>67 participants – 26 people living with dementia, 23 family carers, 10 professional carers and 8 service providers</td>
</tr>
<tr>
<td>Keady, J., Campbell, S., Barnes, H., Ward, R., Li, X., Swarbrick, C., … Elvish, R.</td>
<td>2012</td>
<td>Neighbourhoods and dementia in the health and social care context: A realist review of the literature and implications for UK policy development. <em>Reviews in Clinical Gerontology, 22</em>(2), 150-163.</td>
<td>N/A</td>
</tr>
<tr>
<td>Neighbourhood design</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blackman, T., Mitchell, L., Burton, E., Jenks, M., Parsons, M., Raman, S., &amp; Williams, K. (2003). The accessibility of public spaces for people with dementia: a new priority for the 'open city'. <em>Disability and Society, 18</em>(3), 357-371.</td>
<td>Collates findings from more than one study</td>
<td>To reviews the literature on indoor design for dementia, reports on research investigating the accessibility of outdoor environments and describes the use of virtual reality technology to test outdoor design with people living with dementia.</td>
<td>Mixed methods.</td>
</tr>
<tr>
<td>Mitchell, L., &amp; Burton, E. (2010). Designing dementia-friendly neighbourhoods: Helping people with dementia to get out and about. <em>Journal of Integrated Care, 18</em>(6), 11–18.</td>
<td>20 people living with dementia and 25 people without dementia</td>
<td>To summarise the ESRC funded EQUAL project with recommendations for outdoor design.</td>
<td>Interviews with a questionnaire and photographs; accompanied walks using an observation schedule; environmental analysis using a checklist of environmental characteristics.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>To identify the needs of older people living with dementia when using the outdoor environment and suggests aspects of design for making it dementia-friendly.</td>
<td>Literature review with a synthesis of the advice for internal design principles and considers their applicability to the outdoor environment.</td>
<td>Medium</td>
<td></td>
</tr>
<tr>
<td>Physical activity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26 dementia studies; 73 survey responses and 12 interviews with dementia service providers</td>
<td>To identify how physical activity may benefit people living with dementia; how and/or if current service provides these benefits; and what support they need to do so.</td>
<td>A realist review of 26 studies included; mapping current service provision through a survey with 73 usable responses; and 12 in-depth interviews with service providers.</td>
<td>Mediu</td>
</tr>
<tr>
<td>50 carers of people living with dementia</td>
<td>To identify factors associated with lower physical activity in older caregivers of demented patients.</td>
<td>A cross-sectional survey of 50 older caregivers living with patients diagnosed with Alzheimer’s-type dementia.</td>
<td>Mediu</td>
</tr>
<tr>
<td>Karp, A., Paillard-Borg, S., Wang, H., Silverstein, M., Winblad, B. &amp; Fratiglioni, L. (2006). Mental, physical and social components in leisure activities equally contribute to decrease dementia risk. <em>Dementia and Geriatric Cognitive Disorders, 21</em>, 65-73.</td>
<td>776 people without dementia, aged 75 years and above without dementia</td>
<td>To verify the effect of mental, physical and social leisure engagement on the dementia risk, as well as their combined effect.</td>
<td>A longitudinal observational study: 776 people without dementia, aged 75 years and above, who were still nondemented after 3 years and were followed for 3 more years to detect incident dementia</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Study</td>
<td>Participants/Method</td>
<td>Objective</td>
<td>Evidence Strength</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Repeated interviews with six people living with Alzheimer’s disease and observations focusing on their motives for their self-chosen occupational engagement and the significance of the daily occupations.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author(s)</td>
<td>N/A</td>
<td>To review the available literature on the effectiveness of physical activity, intellectual stimulation, and socialization on the incidence of dementia and on the course of dementia itself.</td>
<td>A review of the existing literature.</td>
</tr>
<tr>
<td>-----------</td>
<td>-----</td>
<td>---------------------------------------------------------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Ruthirakuhan, M, Luedke, A.C., Tam, A, Goel, A., Kurji, A., &amp; Garcia, A. (2012). Use of physical and intellectual activities and socialization in the management of cognitive decline of aging and in dementia: A review. <em>Journal of Aging Research</em>, Article ID 384875.</td>
<td>N/A</td>
<td>To explore what characterised the implementation process when the assistive technology was experienced as beneficial to the younger people living with dementia and the family carer in their daily life.</td>
<td>A qualitative longitudinal study with 12 younger people living with dementia and 14 family carers through in-depth interviews and observations.</td>
</tr>
</tbody>
</table>

**Supportive resources**

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>12 younger people living with dementia and 14 of their family carers</th>
<th>To explore what characterised the implementation process when the assistive technology was experienced as beneficial to the younger people living with dementia and the family carer in their daily life.</th>
<th>A qualitative longitudinal study with 12 younger people living with dementia and 14 family carers through in-depth interviews and observations.</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arntzen, C., Holthe, T., &amp; Jentoft, R. (2014). Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family carers. <em>Dementia</em>, 0(0), 1-17.</td>
<td>12 younger people living with dementia and 14 of their family carers</td>
<td>To explore what characterised the implementation process when the assistive technology was experienced as beneficial to the younger people living with dementia and the family carer in their daily life.</td>
<td>A qualitative longitudinal study with 12 younger people living with dementia and 14 family carers through in-depth interviews and observations.</td>
<td>High</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>62 family carers of people living with Alzheimer’s disease</td>
<td>To determine how community-based interventions such as adult day programs and caregiver support groups affected the quality of life (QOL) of caregivers of Alzheimer’s disease clients.</td>
<td>A pilot study employing a cross-sectional comparative design involving 62 caregivers with data collection consisting of a self-report questionnaire and a 13-item QOL scale.</td>
<td>High</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>169 family carers of people living Alzheimer’s disease</td>
<td>To examine the impact of social support on the health and well-being of caregivers of people living with Alzheimer’s disease.</td>
<td>A modified version of Antonucci and Jackson’s 1987 interpersonal support/efficacy framework to data on caregiver-care recipient dyads from a convenience sample of 169 family caregivers.</td>
<td>Medium</td>
</tr>
</tbody>
</table>
Cahill, S., Begley, E., Topo, P., Saarikalle, K., Macijauskiene, J., Budraitiene, A., ... Jones, K. (2004). ‘I know where this is going and I know it won’t go back’: Hearing the individual’s voice in dementia quality of life assessments. *Dementia, 3*(3), 313-330.

92 people living with dementia
To examine the impact of assistive technology on persons with dementia and their family caregivers. A longitudinal study with mixed-methods: in-depth interviews with 92 people living with dementia; a questionnaire; and a quality of life assessment using DQoL.


People living with dementia
An evidenced-based approach to the evaluation, assessment, and counselling of older drivers with cognitive impairment. One case study and literature review.


119 respondents: the majority were people living with dementia
To systematically quantify the presence of abnormal driving behaviours as observed by the caregiver at or near the time of driving retirement. A cross-sectional study using mailed questionnaires.
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Seven people living with early dementia and one person’s wife</td>
</tr>
<tr>
<td>To describe how researchers, practitioners and technicians in West Sweden worked together with older people with early stage dementia and their family members to develop a user-friendly technology-based information, education and support service.</td>
</tr>
<tr>
<td>Partnership working and participatory design: ACTION involves a participatory approach to research and development and data collection using multiple methods.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
</tr>
<tr>
<td>To analyse surveillance technologies for older people with attention to issues of power and inequality, along with inquiry into the design of surveillance technologies for the oldest population.</td>
</tr>
<tr>
<td>Literature review.</td>
</tr>
</tbody>
</table>

<p>| Mediu |</p>
<table>
<thead>
<tr>
<th>Authors</th>
<th>Sample Size</th>
<th>Study Objective</th>
<th>Methodology</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glueckauf, L., Davis, W.S., Willis, F., Sharma, D., Gustafson, J., Hayes, J., ... &amp; Springer, J. (2012). Telephone-based, cognitive-behavioural therapy for African American dementia caregivers with depression: Initial findings. <em>Rehabilitation Psychology, 57</em>(2), 124-139.</td>
<td>14 carers of people living with dementia</td>
<td>To compare the effects of telephone-based and face-to-face (f-to-f) cognitive-behavioural therapy (CBT) on changes in caregiver (CG) burden, assistance support, depression, and health status for African American (AA) CGs with depression.</td>
<td>A pilot study using a prepost, two-group design with 14 enrolled and randomized participants.</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Participants</td>
<td>Research Question</td>
<td>Methodology</td>
<td>Design</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Participants</td>
<td>Description</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>--------------</td>
<td>-----------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2. REC Approval

23 February 2011

Mrs Xia Li
Research Associate NHS Northamptonshire Francis Crick House
Summerhouse Road, Moulton Park
Northampton
NN3 6BF Dear Mrs Li

Study Title: REC reference number:
The Meaning, Construction and Place of Neighbourhood in the Lives of People with Dementia and their Carers: A Longitudinal Mapping Study
10/H0403/100

Thank you for your letter of 20 February 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).
The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does therefore apply to any non-NHS site at present. I will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation’s involvement. Guidance on procedures for PIGs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protocol</td>
<td>5</td>
<td>09 November 2010</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant Information Sheet: Carers</td>
<td>3</td>
<td>13 January 2011</td>
</tr>
<tr>
<td>REC application</td>
<td></td>
<td>11 November 2010</td>
</tr>
<tr>
<td>Questionnaire: DEMQOL carer</td>
<td>4</td>
<td>20 February 2011</td>
</tr>
<tr>
<td>Questionnaire: Non validated Demographic Information</td>
<td>2</td>
<td>05 November 2010</td>
</tr>
<tr>
<td>Summary CV for academic supervisor</td>
<td></td>
<td>09 November 2010</td>
</tr>
<tr>
<td>Participant Information Sheet: People with Dementia</td>
<td>6</td>
<td>17 January 2011</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>1</td>
<td>17 January 2011</td>
</tr>
<tr>
<td>Questionnaire: DEMQOL</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evidence of insurance or indemnity</td>
<td>16</td>
<td>November 2010</td>
</tr>
<tr>
<td>Covering Letter</td>
<td></td>
<td>11 November 2010</td>
</tr>
<tr>
<td>CV for student</td>
<td></td>
<td>11 November 2010</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td>11 November 2010</td>
</tr>
<tr>
<td>Participant Information Sheet: Clinicians</td>
<td>5</td>
<td>17 January 2011</td>
</tr>
<tr>
<td>Participant Consent Form: Carer</td>
<td>4</td>
<td>20 February 2011</td>
</tr>
<tr>
<td>Participant Consent Form: People with dementia</td>
<td>7</td>
<td>20 February 2011</td>
</tr>
</tbody>
</table>

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review—guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

---

| O/H0403/100 | Please quote this number on all correspondence |

With the Committee’s best wishes for the success of this project

Mr Robert Johnson  
Chair  
Yours sincerely

Email: heather.harrison@nottspct.nhs.uk

Enclosures:  
*After ethical review—guidance for researchers* SL-AR1 for CTIMPs, SL-AR2 for other studies

Copy to:  
Sponsor: Mr Mohammed Zubair  
R&D office for NHS care organisation at lead site: Northamptonshire Healthcare NHS Foundation Trust

328
Appendix 3. R&D Approval

Northamptonshire Healthcare
NHS Foundation Trust

Research and Development
Sudborough House,
St. Mary's Hospital,
London Road,
Kettering,
Northamptonshire,
NN15 7PW

Direct Dial: (01536) 494173
Fax No: (01536) 494216

Associate Medical Director: Dr Sean Scanlon
Head of Quality Support: Ruth Clarke
R&D Manager: Lauren Sayers

Mrs Xia Li
Research Associate,
NHS Northamptonshire,
Francis Crick House,
Summerhouse Road,
Moulton Park,
Northampton.
NN3 6BF
20.03.2011

Dear Xia,

Ref: R.113.11
Title: A Neighbourhood mapping study of people with Dementia.
Project Status: Approved
End Date: 30.09.2012

I am pleased to confirm that with effect from the date of this letter, the above study now has
Trust Research & Development permission to commence at Northamptonshire Healthcare NHS
Foundation Trust.

All documents received by this office have been reviewed and form part of the approval. The
documents received and approved are as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protocol</td>
<td>5</td>
<td>09 November 2010</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>17 January 2011</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>20 February 2011</td>
</tr>
<tr>
<td>Participant Information Sheet: Carers</td>
<td>3</td>
<td>13 January 2011</td>
</tr>
<tr>
<td>REC application</td>
<td></td>
<td>11 November 2010</td>
</tr>
<tr>
<td>Participant Consent Form: Clinician</td>
<td>4</td>
<td>20 February 2011</td>
</tr>
<tr>
<td>Questionnaire: DEMQOL - carer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaire: Non-validated Demographic Information</td>
<td>2</td>
<td>05 November 2010</td>
</tr>
<tr>
<td>Summary CV for academic supervisor</td>
<td></td>
<td>09 November 2010</td>
</tr>
<tr>
<td>Participant Information Sheet: People with Dementia</td>
<td>6</td>
<td>17 January 2011</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>1</td>
<td>17 January 2011</td>
</tr>
</tbody>
</table>
We are aware that undertaking research in the NHS comes with a range of regulatory responsibilities. Attached to this letter is a reminder of your responsibilities during the course of the research. Please ensure that you and the research team are familiar with and understand the roles and responsibilities both collectively and individually.

You are required to submit an annual progress report to the R&D Office and to the Research Ethics Committee. We will remind you when this is due.

The R&D Office is keen to support research, researchers and to facilitate approval. If you have any questions regarding this, or other research you wish to undertake in the Trust, please contact this office.

We wish you every success with your research.

Yours sincerely

Lauren Sayers  
Research and Development Manager

Encs: Researcher Information Sheet
Appendix 4. Information Sheets

PARTICIPANT INFORMATION SHEET (PEOPLE LIVING WITH DEMENTIA) - Part 1

A Neighbourhood Mapping Study of People Living with Dementia

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Part 1 tells you the purpose of the study and what will happen if you take part.
Part 2 gives you more detailed information about the study.
Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
The main purpose of this study is to develop a better understanding about the meaning of ‘neighbourhood’ in the day to day lives of you and your families in order to identify what are the important aspects for you and how you use community services and resources. This study is also to explore how neighbourhood impacts on your quality of life and to expand the knowledge and the understanding from you to help improve services that are aimed at supporting people living with dementia living in the community. To gain an in-depth understanding of your experiences, we would like to invite you to participate in this study to explore your experiences and views about this topic.

Why have I been invited to take part?
You have been invited to take part because you have been nominated through a Community Psychiatric Nurse in the memory assessment clinic as a person with dementia.

Do I have to take part?
No, taking part is entirely up to you. If you don’t want to take part you do not have to give a reason. If you choose to take part but later change your mind you can withdraw from the study. Your care and support will not be affected in any way if you do not wish to take part.
What will happen to me if I take part?

First, I will phone you to give you an opportunity to learn more about the study and ask any questions.

If you are happy to take part, we will need you to sign a consent form and nominate a person cohabiting with you (e.g. the primary carer) to take part along with you. The person must be aware of your diagnosis of dementia and aged 18 and above in order to take part. It is quite alright if you would like to discuss the study with the person before nominating him/her, and not he/she you nominate has to agree to participate. When I come to meet you, you may bring the person who is living with you if you wish and I can tell him/her more about the study at this time, too. If you’d rather talk about the study by yourself first we will arrange a meeting where you can ask questions and then give me the names and addresses of the person you wish to nominate. I can then send the person more information about the study and arrange to meet him/her if he/she wants to learn more about it. When the person who does agree to take part has given his/her consent, I will arrange a time and place that is suitable for you and him/her to talk to me. It will always be the same person coming to speak to you. This will usually take about one hour per visit and I will visit fortnightly the course of 12 months (about 24 visits).

I plan to support you in creating your own maps (e.g. your physical neighbourhood, important activities) to explore what ‘neighbourhood’ means to you and how you use and access your neighbourhood. Through our conversations, we will look at those factors that are important to you; an important part of this study is to ensure that your views and experiences form the main focus of this study. You may wish to take photographs to illustrate what you think is important. These photographs will also form part of our conversations so that you can explain why it is important and what it means to you. I will supply you with disposable cameras and pay for the developing costs. This is completely up to you and you do not have to include any photographs or pictures if you do not wish to. You may also wish to keep diaries to record your important activities so that we can discuss it to explore how you interact with your neighbourhood and engage in your networks and communities. I am also open to any suggestions that you might have with regard to this part of the study.
Our conversation will be tape-recorded. These tapes will be securely stored in the NHS premises and destroyed when the project is finished. This will help me compare the experiences of different people living with dementia and help me to understand what your life likes after diagnosing with dementia, how you adjust to the changes you experience and what your needs are.

I will ask you to fill out a questionnaire at the first, middle and the last visit; these should not take more than a few minutes. I will also ask you to spend a few minutes to complete a demographic information sheet at the first visit.

All information about you will be kept completely confidential. If we publish any data from the study, no individual will be able to be identified at any time. No one involved with your care will have access to what you say during the visits.

What are the possible risks and benefits of taking part?
There are no known risks associated with this type of interview. All information about you will be kept completely confidential.

Interviews are a common way of finding out about people’s experiences, and do not have any known risks. The study is insured by the University of Manchester.

What if there is a problem?
Any complaint about the way you have been treated during the study will be dealt with. Detailed information on this is given in Part 2.

What do I do now?
If the information in Part 1 has interested you and you are thinking about taking part, you may wish to read the additional information in Part 2 before making any decision. Please feel free to discuss this information with your family, friends or care providers.

If you wish to take part, please complete the reply slip and return in the enclosed self-addressed, stamped envelope.
PARTICIPANT INFORMATION SHEET (PEOPLE LIVING WITH DEMENTIA) – PART 2

What will happen if I don’t want to carry on with the study?
You withdraw from the study at any point. You do not have to give a reason, and it will not affect the care you receive. Simply inform the researcher that you no longer wish to take part.

What if something goes wrong?
We are confident that our methods are safe. However, should you have any cause for complaint about the way you have been treated, or indeed about any aspect of the study, you should inform the researcher (see contact details at end of this leaflet). Any such complaints will be noted in writing and passed on to the independent committee which is overseeing this study. You will then receive a written response to your complaint within a reasonable period of time. You may also wish to contact the University Research Office or independent Ethics Committee directly using the contact details at the end of this sheet.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk.

Will my taking part in this study be kept confidential?
All the information which we collect about you during the course of the study will remain completely confidential, and will not be discussed with anyone else. If you choose to take part, but later change your mind, you can withdraw from the study without your care or support being affected in any way.

Data collected on you will be stored, handled and destroyed in accordance with the Data Protection Act 1998.
This study will adhere to NHS policy with regard to the reporting of any child protection or vulnerable adult issues that may be raised during the course of this research.

**Who is organising and funding the research?**
This research is being carried out by a PhD student at the University of Manchester. This is a student research study.

**Who has reviewed this study?**
This study has been reviewed by Nottingham REC 1 who checks that the study is useful, safe and acceptable to participants, especially people who have contact with the NHS.

**Contact for further information**
If you need more information before you decide whether to take part, or if you have any questions which you want to ask, you can contact us via post, telephone or email using the contact details given below:

Xia Li
Research Associate
NHS Northamptonshire
Francis Crick House, Summerhouse Road, Moulton Park, Northampton, NN3 6BF
Tel (office): +44 (0)160 4651 266
Email: Xia.Li@northants.nhs.uk

The Independent National Research Ethics Committee that reviewed this study:
Nottingham Research Ethics Committee 1
The Old Chapel, Royal Standard Place, Nottingham, NG1 6FS
Tel: 0115 8839 368
Research Reference Number: 10/H0403/100
A Neighbourhood Mapping Study of People Living with Dementia

What is the purpose of the study?
The main purpose of this study is to develop a better understanding about the meaning of ‘neighbourhood’ in the day to day lives of people living with dementia and yourself. To help gain an in-depth knowledge and understanding of what comprises a ‘neighbourhood’, we would like to invite you (along with the person with dementia who you are caring for) to participate in this study to explore your experience and views about this topic, which aims to help improve services which support people living with dementia living in the community.

Why have I been invited to take part?
You have been invited to take part because you have been nominated by the person with dementia who you are caring for.

Do I have to take part?
No, taking part is entirely up to you. If you don't want to take part you do not have to give a reason. If you choose to take part but later change your mind you can withdraw from the study. Your care and support will not be affected in any way if you do not wish to take part.

What will happen to me if I take part?
First, I will phone you to give you an opportunity to learn more about the study and ask any questions.
If you are happy to take part, we will need you to sign a consent form. When I come to meet you, you may bring the person with dementia with you if you wish and I can tell you more about the study at this time, too. If you would rather talk about the study by yourself first we will arrange a meeting where you can ask questions. It will always be the same person coming to speak to you. This will usually take about one hour per visit and I will visit fortnightly the course of 12 months (about 24 visits).

Your will support the person with dementia in participating in this study, e.g. taking photographs, keeping diaries, creating maps. During the interview, I will ask you the same questions which have been asked of the person with dementia to explore your experience and views of ‘neighbourhood’.

Our conversation will be tape-recorded. These tapes will be securely stored in the NHS premises and destroyed when the project is finished.

I will also ask you to spend a few minutes to complete a demographic information sheet at the first visit.

All information about you will be kept completely confidential. If we publish any data from the study, no individual will be able to be identified at any time.

**What are the possible risks and benefits of taking part?**

There are no known risks associated with this type of interview. All information about you will be kept completely confidential.

Interviews are a common way of finding out about people’s experiences, and do not have any known risks. The study is insured by the University of Manchester.

**What if there is a problem?**

Any complaint about the way you have been treated during the study will be dealt with. Detailed information on this is given in Part 2.

**What do I do now?**
If the information in Part 1 has interested you and you are thinking about taking part, you may wish to read the additional information in Part 2 before making any decision. Please feel free to discuss this information with your family or friends.

If you wish to take part, please complete the reply slip and return in the enclosed self-addressed, stamped envelope.
PARTICIPANT INFORMATION SHEET – PART 2

What will happen if I don’t want to carry on with the study?
You withdraw from the study at any point. You do not have to give a reason, and it will not affect the care you receive. Simply inform the researcher that you no longer wish to take part.

What if something goes wrong?
We are confident that our methods are safe. However, should you have any cause for complaint about the way you have been treated, or indeed about any aspect of the study, you should inform the researcher (see contact details at end of this leaflet). Any such complaints will be noted in writing and passed on to the independent committee which is overseeing this study. You will then receive a written response to your complaint within a reasonable period of time. You may also wish to contact the University Research Office or independent Ethics Committee directly using the contact details at the end of this sheet.

What if there is a problem?
Complaint: If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk.

Will my taking part in this study be kept confidential?
All the information which we collect about you during the course of the study will remain completely confidential, and will not be discussed with anyone else. If you choose to take part, but later change your mind, you can withdraw from the study without your care or support being affected in any way.

Data collected on you will be stored, handled and destroyed in accordance with the Data Protection Act 1998.
This study will adhere to NHS policy with regard to the reporting of any child protection or vulnerable adult issues that may be raised during the course of this research.

**Who is organising and funding the research?**
This research is being carried out by a PhD student at the University of Manchester. This is a student research study.

**Who has reviewed this study?**
This study has been reviewed by Nottingham REC 1 who checks that the study is useful, safe and acceptable to participants, especially people who have contact with the NHS.

**Contact for further information**
If you need more information before you decide whether to take part, or if you have any questions which you want to ask, you can contact us via post, telephone or email using the contact details given below:

Xia Li  
Research Associate  
NHS Northamptonshire  
Francis Crick House, Summerhouse Road, Moulton Park, Northampton, UK, NN3 6BF  
Tel (office): +44 (0)160 4651 266  
Email: Xia.Li@northants.nhs.uk

The Independent National Research Ethics Committee that reviewed this study:  
Nottingham Research Ethics Committee 1  
The Old Chapel, Royal Standard Place, Nottingham, NG1 6FS  
Tel: 01158839368  
Research Reference Number: 10/H0403/100
Appendix 5. Consent Forms

PARTICIPANT CONSENT FORM – PEOPLE LIVING WITH DEMENTIA

Title of Project: A Neighbourhood Mapping Study of People Living with Dementia

Name of Researcher: Xia Li

Please initial box

1. I confirm that I have read and understand the information sheet dated ________ version ______ for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that during the visits with the researcher, our conversations will be audio-taped and listened to by responsible individuals from the University of Manchester. I give permission for these individuals to listen to the tape recordings of our discussions. I understand that before anything that I say is used in published work, it will be completely anonymised and I will not be able to be identified.

Please tick one of the following options:

1. I am happy for direct quotations to be used
2. I wish to see any quotations before agreeing to their use
3. I do not agree to quotations being used

4. If at any time I am unable to continue to participate in the research study for whatever reason, I agree for the person I nominated to continue to take part in the study, if he/she wishes to at that time.
5. I agree to take photographs to demonstrate what I think is important to me and/or I am happy for the person I nominated to help me take photographs to be used in order to supplement the interview data.

6. I agree to keep my diary on my weekly activities and/or I am happy for the person I nominated to help me keep the diary being used.

7. I agree to create maps and/or I am happy for the person I nominated to help me create maps to be used.

8. I agree that Xia Li can photograph the maps created by me and/or the person I nominated.

9. I agree to complete the DEMQOL questionnaire to be used.

10. I agree to complete the demographic information sheet.

11. I agree that Xia Li can photograph the maps created by me and my carer.

12. I agree to take part in the above study.

13. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

________________________  ______________  ______________
Name of participant         Date              Signature

________________________  ______________  ______________
Name of person taking consent  Date              Signature

________________________  ______________  ______________
Researcher                  Date              Signature

Copy 1 – for participant, Copy 2 – for researcher
PARTICIPANT CONSENT FORM - CARER

Title of Project: A Neighbourhood Mapping Study of People Living with Dementia

Name of Researcher: Xia Li

Please initial box

1. I confirm that I have read and understand the information sheet dated ________ version ______ for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that during the visits with the researcher, our conversations will be audio-taped and listened to by responsible individuals from the University of Manchester. I give permission for these individuals to listen to the tape recordings of our discussions. I understand that before anything that I say is used in published work, it will be completely anonymised and I will not be able to be identified.

Please tick one of the following options:

1. I am happy for direct quotations to be used

2. I wish to see any quotations before agreeing to their use

3. I do not agree to quotations being used

4. If at any time the person with dementia is unable to continue to participate in the research study for whatever reason, I agree to continue to take part in the study, if he/she has agreed at the commencement of the study.
5. I agree to help the person with dementia to take photographs in order to demonstrate what he/she thinks is important to him/her, I am also happy for those photographs to be used/in order to supplement the interview data.

6. I agree to help the person with dementia to keep his/her diary on the weekly activities being used.
7. I agree to help the person with dementia to create maps to be used.

8. I agree to complete the DEMQOL questionnaire to be used.

9. I agree that Xia Li can photograph the maps created by me and/or the person with dementia.

10. I agree to take part in the above study.

11. I understand that relevant sections of data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

________________________  _______________  ____________________
Name of participant       Date                  Signature

________________________  _______________  ____________________
Name of person taking consent Date                  Signature

________________________  _______________  ____________________
Researcher                 Date                  Signature

Copy 1 – for participant, Copy 2 – for researcher
Appendix 6. Summary of the Main Activities with Mary and Steve

<table>
<thead>
<tr>
<th>Session</th>
<th>Date</th>
<th>Main activity</th>
<th>Duration (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>03/06/2011</td>
<td>Initial meeting to explain research, answered questions, obtained consent, conducted interview, and completed demographic to gather background information</td>
<td>72</td>
</tr>
<tr>
<td>2</td>
<td>24/06/2011</td>
<td>Obtained consent, undertook interview to understand the meaning of the neighbourhood</td>
<td>135</td>
</tr>
<tr>
<td>3</td>
<td>22/07/2011</td>
<td>Obtained consent, undertook interview to deeply explore the meaning of the neighbourhood, explored the diary and complete the DEMQOL questionnaire to gather information about Mary’s quality of life</td>
<td>81</td>
</tr>
<tr>
<td>4</td>
<td>16/08/2011</td>
<td>Obtained consent, conducted interview to deeply explore the meaning of the neighbourhood and the important aspects of their lives and of the neighbourhood</td>
<td>92</td>
</tr>
<tr>
<td>5</td>
<td>05/09/2011</td>
<td>Obtained consent, conducted interview to understand their relationships with the neighbours and deeply explore the important aspects of their lives.</td>
<td>81</td>
</tr>
<tr>
<td>6</td>
<td>21/10/2011</td>
<td>Obtained consent, undertook interview, and co-constructed a neighbourhood map to illustrate the physical landmarks</td>
<td>57</td>
</tr>
<tr>
<td>7</td>
<td>25/11/2011</td>
<td>Obtained consent, undertook interview to deeply explore the meaning of the neighbourhood, their social network, and co-constructed a neighbourhood map to illustrate the physical landmarks</td>
<td>45</td>
</tr>
<tr>
<td>8</td>
<td>12/01/2012</td>
<td>Obtained consent, conducted interview to further explore the neighbourhood map and understand their social network and social activities.</td>
<td>38</td>
</tr>
<tr>
<td>9</td>
<td>24/02/2012</td>
<td>Obtained consent, conducted interview to further explore their social network and social activities.</td>
<td>48</td>
</tr>
<tr>
<td>---</td>
<td>------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>----</td>
</tr>
<tr>
<td>10</td>
<td>23/03/2012</td>
<td>Obtained consent, undertook interview to discuss the photographs, finalised the neighbourhood map and further explore the emergent themes of the neighbourhood map</td>
<td>48</td>
</tr>
<tr>
<td>11</td>
<td>20/04/2012</td>
<td>Obtained consent, undertook interview, finalised and further explored their connection with their neighbourhood and family dynamic, complete DEMQOL question</td>
<td>69</td>
</tr>
<tr>
<td>12</td>
<td>25/05/2012</td>
<td>Obtained consent, conducted interview, ended relationship, and gave family a thank you card and a bunch of flowers</td>
<td>55</td>
</tr>
<tr>
<td></td>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>821 (13 hours, 41 minutes)</strong></td>
</tr>
</tbody>
</table>
## Appendix 7. Summary of the Main Activities with Patricia and Brian

<table>
<thead>
<tr>
<th>Session</th>
<th>Date</th>
<th>Main activity</th>
<th>Duration (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>14/08/2011</td>
<td>Initial meeting to explain research, answered questions, obtained consent, facilitated interview, and completed demographic to gather background information</td>
<td>94</td>
</tr>
<tr>
<td>2</td>
<td>28/08/2011</td>
<td>Obtained consent, facilitated interview to build up relationship, understand family dynamics and explored the dairy</td>
<td>92</td>
</tr>
<tr>
<td>3</td>
<td>25/09/2011</td>
<td>Obtained consent, facilitated interview, completed the DEMQOL questionnaire to gather information about Patricia’s quality of life (interviewed the couple together)</td>
<td>97</td>
</tr>
<tr>
<td>4</td>
<td>16/10/2011</td>
<td>Obtained consent, facilitated interview to explore the meaning of the neighbourhood and the important aspects of their lives and of the neighbourhood</td>
<td>77</td>
</tr>
<tr>
<td>5</td>
<td>06/11/2011</td>
<td>Obtained consent, facilitated interview to further explore their neighbourhood and deeply explore the impact of dementia on their lives.</td>
<td>84</td>
</tr>
<tr>
<td>6</td>
<td>04/12/2011</td>
<td>Obtained consent, facilitated interview, and co-constructed a neighbourhood map to illustrate the physical landmarks, social network and social activities (interviewed the couple together)</td>
<td>58</td>
</tr>
<tr>
<td>7</td>
<td>08/01/2012</td>
<td>Obtained consent, facilitated interview to further explore the meaning of the neighbourhood, their social activities and daily life (interviewed the couple together)</td>
<td>73</td>
</tr>
<tr>
<td>8</td>
<td>19/02/2012</td>
<td>Obtained consent, facilitated interview to further explore the neighbourhood map and understand their social network and social activities.</td>
<td>78</td>
</tr>
<tr>
<td>Date</td>
<td>Date Obtained</td>
<td>Details</td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>---------------</td>
<td>-------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>25/03/2012</td>
<td>9</td>
<td>Obtained consent, facilitated interview to in-depth discuss the emergent themes</td>
<td></td>
</tr>
<tr>
<td>29/04/2012</td>
<td>10</td>
<td>Obtained consent, facilitated interview to deeply understand their neighbourhood, landmarks and their connection with their neighbourhood, and discussed the photographs (interviewed the couple together)</td>
<td></td>
</tr>
<tr>
<td>26/05/2012</td>
<td>11</td>
<td>Obtained consent, facilitated interview to further explore the emergent themes, particularly focused on their lived experiences</td>
<td></td>
</tr>
<tr>
<td>24/06/2012</td>
<td>12</td>
<td>Obtained consent, facilitated interview to select and discuss the photographs, and completed the DEMQOL questionnaire to gather information about Patricia’s quality of life (Brian alone as Patricia was feeling unwell)</td>
<td></td>
</tr>
<tr>
<td>08/07/2012</td>
<td>13</td>
<td>Obtained consent, facilitated interview, ended relationship, and gave family a thank you card and a bunch of flowers</td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL** 944 (15 hours and 44 minutes)
### Appendix 8. Summary of the Main Activities with Diane and Dave

<table>
<thead>
<tr>
<th>Session</th>
<th>Date</th>
<th>Main activities</th>
<th>Duration (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>22/08/2011</td>
<td>Initial meeting to explain research, answered questions, obtained consent, facilitated interview, and completed demographic questionnaire to gather background information</td>
<td>77</td>
</tr>
<tr>
<td>2</td>
<td>02/09/2011</td>
<td>Obtained consent and facilitated interview to explore the family dynamics and build up relationship</td>
<td>72</td>
</tr>
<tr>
<td>3</td>
<td>17/10/2011</td>
<td>Obtained consent, facilitated interview to understand the meaning of the neighbourhood, and completed the DEMQOL questionnaire</td>
<td>78</td>
</tr>
<tr>
<td>4</td>
<td>14/11/2011</td>
<td>Obtained consent, facilitated interview to deeply explore the meaning of the neighbourhood, and co-constructed a neighbourhood map to illustrate the physical landmarks</td>
<td>77</td>
</tr>
<tr>
<td>5</td>
<td>26/01/2012</td>
<td>Obtained consent, facilitated interview to discover the social network of this couple, and co-constructed a neighbourhood map, including the social network</td>
<td>60</td>
</tr>
<tr>
<td>6</td>
<td>02/03/2012</td>
<td>Obtained consent, facilitated interview, and discussed photographs to further uncover the construction of the neighbourhood</td>
<td>78</td>
</tr>
<tr>
<td>7</td>
<td>22/03/2012</td>
<td>Obtained consent, facilitated interview to explore the connection between the person and place</td>
<td>55</td>
</tr>
<tr>
<td>8</td>
<td>13/04/2012</td>
<td>Obtained consent, facilitated interview, and finalised the neighbourhood map and associated social network</td>
<td>56</td>
</tr>
<tr>
<td>9</td>
<td>04/05/2012</td>
<td>Obtained consent and facilitated interview to further explore the emergent themes and the map</td>
<td>57</td>
</tr>
<tr>
<td>10</td>
<td>22/06/2012</td>
<td>Obtained consent, facilitated interview, finalised and further understand the chosen photographs and completed DEMQOL questionnaire</td>
<td>53</td>
</tr>
<tr>
<td></td>
<td>Date</td>
<td>Description</td>
<td>Duration</td>
</tr>
<tr>
<td>----</td>
<td>-----------</td>
<td>-----------------------------------------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>11</td>
<td>06/07/2012</td>
<td>Obtained consent, facilitated interview, ended relationship, and gave family a thank you card and a bunch of flowers</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td></td>
<td><strong>703 (11 hours, 43 minutes)</strong></td>
</tr>
</tbody>
</table>
## Appendix 9. Summary of the Main Activities with Jonathan and Jackie

<table>
<thead>
<tr>
<th>Session</th>
<th>Date</th>
<th>Main activity</th>
<th>Duration (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>04/12/2011</td>
<td>Initial meeting to explain research, obtained consent, facilitated interview,</td>
<td>56</td>
</tr>
<tr>
<td></td>
<td></td>
<td>completed demographic and DEMQOL questionnaire</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>29/01/2012</td>
<td>Obtained consent, undertook interview to understand the meaning of the</td>
<td>37</td>
</tr>
<tr>
<td></td>
<td></td>
<td>neighbourhood</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>19/02/2012</td>
<td>Obtained consent, conducted interview to deeply explore the meaning of the</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td></td>
<td>neighbourhood</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>25/03/2012</td>
<td>Obtained consent, conducted interview to explore their relationships with the</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td></td>
<td>neighbours and deeply explore the important aspects of their lives</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>27/04/2012</td>
<td>Obtained consent, undertook interview to explore their relationships with</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td></td>
<td>their families and in depth exploration of the important aspects of their</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>lives</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>24/05/2012</td>
<td>Obtained consent, conducted interview, and co-constructed a neighbourhood</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td></td>
<td>map to illustrate the physical landmarks</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>15/06/2012</td>
<td>Obtained consent, conducted interview to further explore the neighbourhood</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td></td>
<td>map and understand their social network and social activities.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>24/06/2012</td>
<td>Obtained consent, conducted interview to discuss the photographs, finalised</td>
<td>48</td>
</tr>
<tr>
<td></td>
<td></td>
<td>the neighbourhood map and further explore the emergent themes of the</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>neighbourhood map</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>15/07/2012</td>
<td>Obtained consent, undertook interview, and completed DEMQOL question</td>
<td>70</td>
</tr>
<tr>
<td>10</td>
<td>17/07/2012</td>
<td>Obtained consent, conducted interview, ended relationship, and gave family a</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td></td>
<td>thank you card and a bunch of flowers</td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>480 (eight hours)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 10. Summary of the Main Activities with Emily and Tim

<table>
<thead>
<tr>
<th>Session</th>
<th>Date</th>
<th>Main activity</th>
<th>Duration (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>06/06/2012</td>
<td>Initial meeting to explain research, obtained consent, facilitated interview to gain background information and establish rapport, Emily gave me a book she wrote</td>
<td>43</td>
</tr>
<tr>
<td>2</td>
<td>14/06/2012</td>
<td>Obtained consent, conducted interview to gain information on their family relationships, completed demographic questionnaire</td>
<td>62</td>
</tr>
<tr>
<td>3</td>
<td>20/06/2012</td>
<td>Obtained consent, undertook interview to understand the meaning of the neighbourhood, completed DEMQOL questionnaire</td>
<td>66</td>
</tr>
<tr>
<td>4</td>
<td>25/06/2012</td>
<td>Obtained consent, conducted interview to explore their relationships with the neighbours and the important aspects of their lives, and co-constructed a neighbourhood map to illustrate the physical landmarks</td>
<td>56</td>
</tr>
<tr>
<td>5</td>
<td>29/06/2012</td>
<td>Obtained consent, conducted interview to further explore the neighbourhood map and understand their relationships with their families and their social networks</td>
<td>55</td>
</tr>
<tr>
<td>6</td>
<td>03/07/2012</td>
<td>Obtained consent, undertook interview, and further explore the emergent themes and finalised the neighbourhood map</td>
<td>60</td>
</tr>
<tr>
<td>7</td>
<td>10/07/2012</td>
<td>Obtained consent, conducted interview to further explore the emergent themes relating to their social activities and lived experience.</td>
<td>54</td>
</tr>
<tr>
<td>8</td>
<td>13/07/2012</td>
<td>Obtained consent, conducted interview to select and discuss the photographs, and further explore the important aspects of their neighbourhood</td>
<td>47</td>
</tr>
<tr>
<td>Date</td>
<td>Action Description</td>
<td>Duration</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>------------------------------------------------------------------------------------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td>20/07/2012</td>
<td>Obtained consent, undertook interview, completed DEMQOL questionnaire, ended relationship, and gave family a thank you card and a bunch of flowers</td>
<td>40</td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL** | 484 (eight hours and four mins) |
Appendix 11. Diary Template

<table>
<thead>
<tr>
<th>Date</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>When</td>
<td></td>
</tr>
<tr>
<td>Where</td>
<td></td>
</tr>
<tr>
<td>Whose suggestion or idea, e.g. people living with dementia’s idea, carer’s idea</td>
<td></td>
</tr>
<tr>
<td>With whom, e.g. paid/unpaid carer, family member, etc.</td>
<td></td>
</tr>
<tr>
<td>How long it takes to get there?</td>
<td></td>
</tr>
<tr>
<td>Distance (mileage)</td>
<td></td>
</tr>
<tr>
<td>How did you get there, e.g. by car, by bus?</td>
<td></td>
</tr>
<tr>
<td>How long did you stay?</td>
<td></td>
</tr>
<tr>
<td>What did you do?</td>
<td></td>
</tr>
<tr>
<td>How did you feel or how did it impact on you, e.g. well-being, mood, engagement and occupation?</td>
<td></td>
</tr>
<tr>
<td>Positive or negative impact?</td>
<td></td>
</tr>
</tbody>
</table>

Note: please state if you have additional support or any service change impacts on you, e.g. what support, what service change, when, how
### Appendix 12. Demographic Questionnaire

**Demographic Information – Person with dementia**

<table>
<thead>
<tr>
<th>ID:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Service</td>
<td>Diagnosis</td>
</tr>
<tr>
<td><strong>Time since diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Time until diagnosis (from changes being noticed)</strong></td>
<td></td>
</tr>
<tr>
<td>**Age (now)</td>
<td><strong>Age (at diagnosis)</strong></td>
</tr>
<tr>
<td>Sex (Tick)</td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>F</td>
</tr>
</tbody>
</table>

**Employment** including any changes since diagnosis? (Tick)
- F/T
- P/T
- Unemployed
- Self-employed
- Retired
- Other

**Housing tenure** (Tick)
- Owned
- Rented

Length of time in the property (years)

**What is the highest level of education qualification you have obtained?** (Tick)
- Degree or higher degree
- Higher education qualification below degree level
- A-Level or higher
- Level or GCSE
- No formal qualification
- Other

**Which of these best describes your ethnic group?** (Tick)
- White British
- White Irish
- Any other White Background
- Mixed White and Black Caribbean
- Mixed White and Black African
- Mixed White and Asian
• Any other mixed background
• Asian or Asian British – Indian
• Asian or Asian British – Pakistani
• Asian or Asian British – Bangladeshi
• Any other Asian background
• Black or Black British - Caribbean
• Black or Black British - African
• Any other Black background
• Chinese
• Not stated
• Any other
Demographic Information – Carer

Relationship to Person with dementia:

Length of time living Person with dementia:

Age (now)

Sex M F

Employment including any changes since diagnosis? (Tick)

• F/T
• P/T
• Unemployed
• Self-employed
• Retired
• Other

Housing tenure (Tick) Owned Rented

Length of time in the property (years)

What is the highest level of education qualification you have obtained? (Tick)

• Degree or higher degree
• Higher education qualification below degree level
• A-Level or higher
• Level or GCSE
• No formal qualification
• Other

Which of these best describes your ethnic group? (Tick)

• White British
• White Irish
• Any other White Background
• Mixed White and Black Caribbean
• Mixed White and Black African
• Mixed White and Asian
• Any other mixed background
• Asian or Asian British – Indian
- Asian or Asian British – Pakistani
- Asian or Asian British – Bangladeshi
- Any other Asian background
- Black or Black British - Caribbean
- Black or Black British - African
- Any other Black background
- Chinese
- Not stated
- Any other