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People with Dementia Living in Extra Care Housing

An exploration of the practicalities and possibilities

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ABSTRACT

Current understanding of housing need in later life is shaped by demographics, social policy, legislative responsibilities, and a growing, but limited body of research and guidance on supporting individuals with dementia to maintain independence with appropriate levels of care.

Informed by a survey of extra care housing provision and adopting a grounded theory approach, this study aimed to consider the appropriateness of extra care housing for people with dementia based on the experiences of those living and working in two extra care schemes. Focus groups and interviews revealed four themes to living well with dementia in extra care; a clear understanding of what extra care is and is not; a physical environment that helps people feel safe and find their way easily; a friendly, skilled and competent support team; and a well-developed community where residents can take part, develop friendships, and reduce unwanted isolation.

Set within two current discourses of care and support and management, the juxtaposition of social worlds theory and total quality and operational excellence theory helped to frame the issues raised by participants, offering a new model of extra care. The addition of 'place' in the new approach highlights the need to manage the spatial environment in extra care to ensure a cohesive and inclusive community. What mattered to residents, staff and managers was having a personalised and flexible service with the right processes and people in place to support people with dementia. Combining sociological and managerial perspectives puts residents and staff at the heart of establishing an approach that delivers.

This study contributes to knowledge development in three areas; understanding of extra care housing for people with dementia; interdisciplinary approaches to models of extra care provision; and methodology on researching living with dementia in a supported housing environment. Future research could evaluate the new approach to extra care proposed in this thesis.

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TABLE OF CONTENTS

ABSTRACT.....	3
ACKNOWLEDGEMENTS.....	4
TABLE OF CONTENTS.....	7
LIST OF FIGURES.....	11
LIST OF TABLES.....	14
1. CHAPTER 1: INTRODUCTION TO THE THESIS	15
1.1 INTRODUCTION	15
1.2 PERSONAL BACKGROUND AND COMMITMENT TO THE RESEARCH.....	15
1.3 CONTEXT FOR THE STUDY.....	18
1.4 RESEARCH AIM AND QUESTIONS.....	20
1.5 ORGANISATION OF THE THESIS.....	22
2. CHAPTER 2: INITIAL LITERATURE REVIEW TO UNDERSTAND THE CONTEXT OF AGEING WELL WITH DEMENTIA IN EXTRA CARE IN THE UK.....	25
2.1 INTRODUCTION	25
2.2 DEVELOPMENT OF EXTRA CARE IN THE UK	28
2.3 AGEING AND LIVING WELL.....	33
2.4 DEMENTIA: WHAT IS IT AND HOW PREVALENT IS IT?.....	36
2.5 THE POLICY OF DEMENTIA CARE.....	39
2.6 BELONGING, IDENTITY, ATTACHMENT AND PERSONHOOD	45
2.7 AGEING IN PLACE AND DEMENTIA FRIENDLY DESIGN.....	51
2.8 CONCLUSION	59
3. CHAPTER 3: METHODOLOGY AND ETHICAL CONSIDERATIONS.....	61
3.1 INTRODUCTION AND BACKGROUND TO THE RESEARCH.....	61
3.2 CONCEPTUAL FRAMEWORK AND METHODS	61
3.3 RESEARCH SITES AND PARTICIPANT INVOLVEMENT	74
3.4 ETHICAL ISSUES AND THEIR GOVERNANCE.....	84
3.5 DEVELOPING THE DATA.....	87
3.6 REFLEXIVITY BETWEEN THE RESEARCHER AND PARTICIPANTS.....	89
3.7 DISCUSSION OF THE METHODOLOGY	91

3.8	DISCUSSION OF THE METHODS	97
3.9	GENERALISING FROM THE FINDINGS	113
3.10	CONCLUSION	114
4.	CHAPTER 4: LIVING WELL IN A CLEARLY DEFINED EXTRA CARE SCHEME	116
4.1	INTRODUCTION TO DATA ANALYSIS AND THE FINDINGS	116
4.2	A PEN PICTURE OF EXTRA CARE RESIDENTS.....	117
4.3	WHAT PARTICIPANTS SAID ABOUT EXTRA CARE.....	120
4.4	DEFINING EXTRA CARE	122
4.5	LIVING WELL	131
5.	CHAPTER 5: DEVELOPING A COMMUNITY AND SUPPORTING INDIVIDUALS....	144
5.1	DEVELOPING THE COMMUNITY.....	144
5.2	HAVING AN EFFECTIVE TEAM	153
5.3	CONCLUSION	177
6.	CHAPTER 6: THE LIVED EXPERIENCE EXAMINED	179
6.1	INTRODUCTION	179
6.2	PLANNING THE SERVICE: THE IMPORTANCE OF A VISION OF EXTRA CARE...180	
6.3	LIVING WELL: SUPPORTIVE RELATIONSHIPS, RIGHTS, RISKS AND SAFETY184	
6.4	RECOGNISING AND DEVELOPING THE COMMUNITY.....	197
6.5	BEING AN EFFECTIVE TEAM WITH THE RIGHT PEOPLE	203
6.6	SUPPORTING AN EFFECTIVE TEAM WITH THE RIGHT PROCESSES AND RESOURCES.....	211
6.7	CONCLUSION	216
7.	CHAPTER 7: INSIGHTS INTO EXTRA CARE AS A SOCIAL WORLD – CONTRIBUTIONS FROM A FURTHER LITERATURE REVIEW	218
7.1	AN INTRODUCTION TO SOCIAL WORLDS THEORY AND ITS RELEVANCE TO EXTRA CARE HOUSING.....	218
7.2	SOCIAL GROUPS AND SOCIAL WORLDS IN EXTRA CARE.....	227
7.3	MOVING INTO AND BEING ACCEPTED IN EXTRA CARE	238
7.4	THE IMPORTANCE OF SPACE FOR SOCIAL INTERACTIONS AND FORMING GROUPS	245
7.5	CONCLUSION TO THE INSIGHTS OF EXTRA CARE AS A SOCIAL WORLD	254

8.	CHAPTER 8: INSIGHTS INTO MANAGING QUALITY AND OPERATIONAL EXCELLENCE IN EXTRA CARE – CONTRIBUTIONS FROM A FURTHER LITERATURE REVIEW	257
8.1	APPROACHES TO QUALITY MANAGEMENT AND OPERATIONAL EXCELLENCE	259
8.2	AN INTRODUCTION TO TOTAL QUALITY MANAGEMENT (TQM)	264
8.3	THE EUROPEAN FOUNDATION FOR QUALITY MANAGEMENT (EFQM) EXCELLENCE MODEL	269
8.4	FRAMEWORKS, DIAGNOSTIC TOOLS AND PERFORMANCE MEASUREMENT	273
8.5	IMPLEMENTING QUALITY MANAGEMENT IN EXTRA CARE HOUSING.....	276
8.6	CONCLUSION TO THE INSIGHTS TO EXTRA CARE AS A COMPLEX ORGANISATION	289
9.	CHAPTER 9: A FRAMEWORK FOR EXTRA CARE DEVELOPMENT.....	291
9.1	INTEGRATING SOCIAL WORLDS THEORY AND ORGANISATIONAL EXCELLENCE WITHIN THE EXTRA CARE MODEL.....	295
9.2	DELIVERING EXCELLENCE WITHIN THE EXTRA CARE MODEL	301
9.3	A FRAMEWORK FOR ACTION	306
9.4	FROM THE SPECIFIC TO THE GENERAL: A MODEL FOR OPERATIONAL EXCELLENCE WITHIN EXTRA CARE HOUSING	326
9.5	CONCLUSION TO A MODEL FOR EXTRA CARE DEVELOPMENT	328
10.	CHAPTER 10: CONCLUSIONS.....	332
10.1	INTRODUCTION	332
10.2	RESEARCH QUESTION REVISITED	334
10.3	RESEARCH IMPLICATIONS AND CONTRIBUTION TO KNOWLEDGE	335
10.4	REFLECTIONS ON STRENGTHS AND LIMITATIONS OF THE RESEARCH	339
10.5	IMPLICATIONS FOR POLICY AND PRACTICE	344
10.6	DIRECTIONS FOR FUTURE RESEARCH.....	349
10.7	CONCLUDING REMARKS	351
	BIBLIOGRAPHY	353
	APPENDICES	393
	APPENDIX 1: PICOT FORMULATION OF ISSUES FOR LITERATURE SEARCH.....	393
	APPENDIX 2: THE HISTORY OF ACCOMMODATION AND CARE IN ENGLAND.....	397
	APPENDIX 3: LEVELS OF HOUSING WITH CARE IN 2017	399

APPENDIX 4: PILOT QUESTIONNAIRE	400
APPENDIX 5: ACTIVITIES IN PHASES 1 AND 2 OF THE EXTRA CARE RESEARCH PROGRAMME.....	414
APPENDIX 6: PRACTICAL ISSUES EXPERIENCED DURING RESEARCH FIELD WORK	416
APPENDIX 7: CASE STUDY SITES.....	420
APPENDIX 8: CRITERION FOR SELECTING PARTICIPANTS FOR INDIVIDUAL INTERVIEWS WITHIN THE EXTRA CARE RESEARCH.....	425
APPENDIX 9: REVIEW OF LEVEL OF PARTICIPANT INVOLVEMENT AND COLLABORATION ACHIEVED IN THE EXTRA CARE RESEARCH.....	426
APPENDIX 10: EXTRA CARE HOUSING RESEARCH: ETHICAL ISSUES COVERED BY THE NATIONAL SOCIAL CARE RESEARCH ETHICS COMMITTEE	429
APPENDIX 11: ETHICAL ISSUES, POTENTIAL RISKS AND BURDENS FOR RESEARCH PARTICIPANTS	434
APPENDIX 12: MATCHING GROUNDED THEORY TO THE CORE ASPECTS OF CRITICAL REALISM	438
APPENDIX 13: DEMENTIA DECLARATION OUTCOMES MATCHED TO CONCEPTS FROM EXTRA CARE RESEARCH THEMATIC ANALYSIS	439
APPENDIX 14: CONCEPTS WITHIN EACH OF THE CATEGORIES IDENTIFIED IN THE EXTRA CARE RESEARCH.....	440
APPENDIX 15: THE DEVELOPMENT OF THE QUALITY MOVEMENT.....	442
APPENDIX 16: EXTRA CARE HOUSING MODEL COMPONENTS MAPPED TO EFQM ENABLERS.....	446
APPENDIX 17: CRITICISMS OF THE BALANCED SCORECARD	449
APPENDIX 18: POTENTIAL BENEFITS AND DISADVANTAGES OF TQM,EFQM AND BALANCED SCORECARDS WITHIN EXTRA CARE HOUSING SCHEMES	452

LIST OF FIGURES

Figure 2-1: Extra care within a range of housing with care options	29
Figure 2-2: Models of extra care for people with dementia	32
Figure 2-3: Approaches to life course and ageing.....	35
Figure 2-4: World Health Organization "Six Stages of Acceptance of Dementia" model from Dementia: A Public Health Priority.....	40
Figure 2-5: A web of understanding of dementia in extra care from a gerontological perspective.....	43
Figure 2-6: A framework for conceptualizing research focused on personhood in dementia	51
Figure 2-7: Ageing in place with well-designed housing.....	57
Figure 3-1: Members of an extra care community	62
Figure 3-2: Overview of the extra care research methodology	64
Figure 3-3: Influences on the research approach	74
Figure 3-4: Grounded theory research as a continuum of efforts with varying degrees of involvement and collaboration in the extra care research	82
Figure 3-5: Plan Act Check Review model of participant involvement in extra care grounded theory research.....	83
Figure 3-6: High level data collection and data analysis process.....	88
Figure 3-7: Mapping four hyphen Spaces	90
Figure 3-8: Extra care researcher positioning using.....	91
Figure 3-9: Researcher assumptions of positioning by participant groups	93
Figure 3-10: Thematic analysis - from data to core categories.....	105
Figure 3-11: Relationship between categories, concepts and codes within thematic analysis	108
Figure 3-12: Four linked categories that emerged from extra care focus groups and interviews	109
Figure 3-13: Stages in Extra Care Research Thematic Analysis.....	112

Figure 4-1: Four inter-related themes constructed from participant discussions	121
Figure 4-2: Elements that contribute to a clear vision of extra care housing	123
Figure 4-3: Features that help individuals to live well.....	133
Figure 5-1: Characteristics described as essential to a well-developed community	146
Figure 5-2: An effective team to support individuals in extra care	154
Figure 5-3: Typical structure of case-study extra care schemes	162
Figure 6-1: Model of extra care housing.....	179
Figure 6-2: Having a clear vision that describes the service.....	181
Figure 6-3: Characteristics that help individuals to live well	185
Figure 6-4: Minimising potential problems of an unlocked environment for people who become disorientated.....	193
Figure 6-5: Matrix of factors influencing acceptance and risk taking in relationships with people with dementia.....	195
Figure 6-6: Characteristics described as essential to a well-developed community.....	198
Figure 6-7: Concentric circles of community	200
Figure 6-8: An effective team to support individuals in extra care	204
Figure 6-9: Designing processes for delivering extra care services with suppliers and customers	212
Figure 7-1: A framework for the emergence of a social world of extra care	221
Figure 7-2: Model of Extra Care	225
Figure 7-3: Symbolic interaction processes	226
Figure 7-4: Social world of extra with examples of possible sub-worlds	228
Figure 7-5: Moving from external social worlds into the social world of extra care	230
Figure 7-6: Being a member of different resident social sub-worlds	232
Figure 7-7: Floating support worker crossing the boundary at the intersection of social sub-worlds	240
Figure 7-8: Progressive privacy design principles	246
Figure 7-9: Boundary objects used to negotiate order	252

Figure 8-1: Model of Extra Care	257
Figure 8-2: Oakland TQM model	266
Figure 8-3: The European Foundation for Quality Management (EFQM) Excellence Model (Copyright EFQM (2012))	269
Figure 8-4: The Balanced Scorecard	274
Figure 8-5: Regulation of extra care housing	278
Figure 8-6: Strategy framework for public performance management	280
Figure 8-7: Example of a strategic service process orientated approach to service delivery in extra care	281
Figure 8-8: Example of a bottom up performance measurement approach in Extra Care schemes	282
Figure 8-9: 5D Approach to operational excellence in extra care.....	285
Figure 9-1: Model of extra care housing agreed with research participants.....	291
Figure 9-2: Model 1: Contextualising the model of extra care housing within an approach to quality and operational excellence.....	296
Figure 9-3: The development and delivery of extra care housing seen through the lenses of social worlds and quality management	300
Figure 9-4: Providing an excellent extra care service to meet stakeholder expectations	303
Figure 9-5: 5D Approach to operational excellence in extra care using social worlds theory	305
Figure 9-6: Total Quality Management for extra care housing.....	309
Figure 9-7: Convergence of service delivery styles within extra care.....	311
Figure 9-8: EFQM Excellence Model	314
Figure 9-9: Extra care quality management model 1.....	317
Figure 9-10: Extra care quality management model 2.....	319
Figure 9-11: Similarities and differences between the Balanced Scorecard	323
Figure 9-12: Model of extra care run by organisations operating a total quality approach to excellence with a social worlds perspective	327
Figure 10-1: Putting older people at the heart of the extra care service model	345
Figure 10-2: Implications of the research for commissioners, designers and developers of extra care.....	346

Figure 10-3: Implications of the research for commissioners, contractors and allocation panels	347
Figure 10-4: Implications of the research for operational providers of extra care	348

LIST OF TABLES

Table 2-1: Enhancing the Healing Environment benefits to people with dementia and carers	59
Table 3-1: Age of participating residents.....	77
Table 3-2: Resident participant experience of living with dementia.....	77
Table 3-3: Number of allocation panel and scheme manager	78
Table 3-4: Number and gender of staff group participants by scheme	79
Table 3-5: Consistency and variation in environmental assessments of extra care communal areas	99
Table 3-6: Comparison of three approaches to thematic analysis.....	104
Table 6-1: Elements of the extra care model supporting Grimshaw et al’s attributes of relational value	187
Table 8-1: Quality and operational excellence issues arising from the research findings.....	261
Table 8-2: Issues arising from the extra care research mapped to the EFQM criteria.....	270
Table 8-3 : 5D approach questions mapped to issues from the research.....	287

1. CHAPTER ONE: INTRODUCTION TO THE THESIS

1.1 INTRODUCTION

This introductory chapter sets out the context for the study on the possibilities and practicalities of people with dementia living in extra care, including a reflection on the researcher's personal background and commitment to the research.

An inductive approach was taken for the research as championed by grounded theory (discussed in Chapter 3), which has influenced how the research aims and questions were formulated, and the thesis structured. This chapter sets out the research aim and questions, informed by an initial pilot questionnaire used to gather the views of those working in the extra care housing sector about the prevailing extra care models and their ability to support people living with dementia. It will conclude with a description of the structure of the thesis to help the reader navigate their way around.

1.2 PERSONAL BACKGROUND AND COMMITMENT TO THE RESEARCH

My journey toward this research started in the late 1980s, some twenty years after Peter Townsend's (1962) seminal study of residential care homes and institutions. Townsend's study of a wide range of different types of accommodation and institutions provided insight into the life of those living in the institutions, why they entered the homes and the adequacy of the services provided. The report tentatively defined 'quality' to include physical facilities, staffing, services, means of occupation, freedom in daily life, and social provision. Townsend's work argued that approaches to providing care were not satisfactory and concluded that

...the solution could be to abandon institutions as an instrument of social policy, reduce progressively the number of communal homes (especially all former workhouses), extend the responsibility of hospital management committees to the management and supervision of all institutions and

communal homes, create a comprehensive local family help service, increase the amount of 'sheltered' housing and encourage the development of general practitioner services. (British Geriatrics Society, 2014, p. 1)

In the late 1980s, residential homes for older people had not been abandoned, rather they comprised a growing part of the long-term care sector for older people. Provision overtook demand in the 1980s, stimulated by the privatisation of residential care in response to the introduction of the 1980 Supplementary Benefits (Requirement) Regulations, which allowed people to use board and lodging payments to pay for the private care home fees. As a manager of a residential care home I witnessed the changes brought about by the implementation in 1993 of the NHS and Community Care Act (1990) reforms, the introduction of care management, and the introduction of National Minimum Standards for residential care home provision. A key priority for me was to ensure that residents were satisfied by being involved in the day to day running of the home, which was consistent with the findings of research into the cost and quality of residential care by Bland et al (1992). One of my driving forces throughout that period was to make sure that people with dementia were supported in a homely environment by the best team of people possible. To support staff in the residential home I became an NVQ assessor for one of the first pilots in the care sector, and part of the team for the Training for Care Staff Programme within the Department of Health's Caring in Homes Initiative (Payne, 1993).

I then became a training and development officer working with social workers to develop the care management training in response to the NHS and Community Care Act 1990. Throughout that period my commitment remained to putting the individual first and focussing on their strengths and networks to offer appropriate care and support in the best possible environment. I continued to place the service user at the centre in subsequent health and social care projects and programmes that I developed, often in the face of disconnected professionals working across different organisations.

In the ten years prior to undertaking this PhD I was responsible for procuring and developing accommodation with care¹ and support for people with and without dementia in a large local authority. The local authority strategy was reminiscent of Townsend's recommendations; it set out to reduce the large volume of residential home accommodation and instead offer a combination of specialist centres for people with dementia, specialist housing options in the form of extra care, with a residual amount of residential care (Robertson, 2012). The procurement supported the local authority's dementia strategy placing a high priority on enabling people to stay in their own home, whilst offering an opportunity for that home to be in a more supported environment, such as extra care or a specialist residential and community care centre designed specifically for people with dementia, when appropriate. It aimed to provide individuals with an alternative model that facilitated a real choice between supported living at home and living in residential care, which was to be retained for those with the most complex needs (Robertson, 2012, p. 2).

My interest in this research topic started as it became apparent that more people living with dementia were moving into generic models of extra care, and more people were developing dementia after they had moved into extra care. Throughout my career I have been passionate about delivering person-centred services to people by having well trained and equipped staff supported by appropriate policies and procedures. My work in procuring accommodation with care and support drew my attention to how far the design of the environment could further help or hinder people with dementia to live well in extra care. The combined effect of the design of the care environment, different staffing models, and a framework of national and local policies and procedures on the wellbeing of people with dementia appeared to be an under-researched area. This research set out to confirm there was a research gap and to fill it.

¹ Accommodation with care in the local authority was defined as including both individual housing and residential homes

My involvement at an early stage of my career in a pilot for a Quality of Life programme in residential care involved focus groups with residents, their families, and staff. The purpose was to hear the voices of those living, working in and visiting residential homes to help develop and implement plans to improve the quality of the residential care. The work showed how powerful the voice of the lived experience can be. It has been central to all my work since then, has included the development of models of co-delivery and co-production, and influenced my choice of research approach for this study.

During the three years of this research study I have moved from being a senior professional within a large authority to be a doctoral researcher. The transition has required me to change my approach or epistemological stance as described later in Chapter 3. It was essential for me to see beyond the professional viewpoint and embrace the views of those living and working in extra care to gain a better sense of the possibilities and practicalities of people with dementia living in extra care. There was another significant change to my viewpoint; during the period of the research I became the daughter of a father living with advancing dementia. The challenges we started and continue to face influenced my position as researcher; they helped me to have different perspectives on the findings; as a professional, as a researcher, and as a carer of a potential service user. I believe this thesis has become richer as a result.

1.3 CONTEXT FOR THE STUDY

The number of older people in the UK is set to rise over the next two decades. In England the number of people aged 65 and over is predicted to grow from 10 million to 14.5 million between 2017 and 2035 (POPPI, 2017)². Of those, 36% are predicted to live alone in 2017 and 37.5% in 2035.

The number of older people with some form of care need is significant, with almost half of people over 65 living with a limiting long-term illness or disability

² Based on Office of National Statistics published 23 May 2016 which are full 2014-based and project forward the population to 2039.

(POPPI, 2017). By 2035 there are expected to be over 7 million people over the age of 65 whose day-to-day activities are limited by their long-term illness, a rise of almost 50 per cent. It is also expected that the number of people aged over 65 living with dementia in England will rise by 70% from the current 702,000 people to 1.2 million in 2035.

There is a long history of Government commitment to meeting the challenges of demographic change, the latest of which is that Government has recognised the need for, and committed to establish, a fair and more sustainable basis for adult social care in the face of the future demographic challenges (HM Treasury, 8 March 2017, pp. 47, para 5.6). In his March 2017 Budget Statement, the Chancellor of the Exchequer, Philip Hammond, announced that “the Government will set out their thinking on the options for the future financing of social care in a Green Paper later this year” (Hammond, 2017). The Government confirmed that the contents of the green paper would be holistic and person-centred saying “the whole purpose of having a Green Paper and a debate is to make sure that we consider this issue not in a silo, but holistically [e.g. with housing], with a person-centred approach” (Doyle-Price, 2017).

There is growing evidence of the role of housing in relation to improving health and wellbeing, reducing the need for adult social care and demand on NHS services (Vallelly, et al., 2006; Darton, et al., 2008; Dutton, 2010; Netten, et al., 2011; Garrett & Burris, 2015; Holland, 2015; Nicol, et al., 2015). The Local Government Association (2016) reported that there was a distinct and urgent need to better provide a range of housing options to meet the wide variety of housing circumstances, aspirations and needs of people as they age. Although housing quality and suitability has a direct impact on the health and wellbeing of the occupants of a home (Local Government Association, 2017), currently most people over the age of 65 live in mainstream housing.

As few as 0.6 per cent of the people aged over 65 live in housing with care³, including extra care housing, which is a significantly smaller proportion than in other countries with more mature retirement housing markets such as the US and Australia (Local Government Association, 2017). In the context of notable health changes in the English population, a suitably designed home could help extend independent, safe living in later life. Given the significant numbers of older people in the population who are limited by a long-term health condition and the increasing number of people living with dementia, it is important to look at the possibilities and practicalities of extra care being able to provide a holistic and person-centred approach to accommodation options with care.

1.4 RESEARCH AIM AND QUESTIONS

In early 2016 when this research proposal was being considered, there was a perceived gap in knowledge about the profile of extra care schemes across the country, and little conclusive evidence about how best individuals with dementia could be supported in extra care. There appeared to be little shared understanding of the prevalence of the different models of extra care for people with dementia; how far extra care housing schemes had adopted design elements that may help an individual with dementia; and whether or how individuals with dementia were supported to move into and stay within extra care schemes.

Given this, a pilot questionnaire (described in Section 3.8.1) was developed to find out from extra care housing providers the variety and types of extra care housing schemes in use, and how well the housing providers believed they supported individuals with dementia (Twyford, 2016). The pilot revealed that development of extra care schemes has often been opportunistic dependent on local or grant funding. Sizes varied with typically between 50 and 100

³ Housing with care is known variously as extra care, assisted living, very sheltered housing, close care and others. Typically, it includes personal and domestic support, a dining service, communal facilities and usually 24-hour staff on site. The term extra care has been adopted for this thesis as it is the name given to the two case studies used in the research.

apartments (apart from in the larger retirement villages). There was a variable knowledge base about dementia design. Although there was a strong commitment from individual managers and schemes that took part in the survey to do their best for people with dementia, there was also a perceived tension between creating dementia friendly environments and having an environment that was also attractive to the public and people not living with dementia. There was no explicit exclusion of people with dementia from the schemes (depending instead on allocation panel interpretations of being able to meet needs), and integrated models of support reflected local arrangements between housing providers, housing authorities and social services.

The pilot study concluded that further research could usefully explore the impact upon the individual of when and at what stage of their individual dementia journey they move into an extra care scheme and triggers that might cause someone with dementia to leave extra care, and how they might be overcome through integrated working and/or environmental design. The interplay between policy frameworks, the immediate interactional environment, and the broader culture within extra care housing and whether it constrains or enhances the experience of an individual living with dementia was also highlighted as an area for further research.

Although the preliminary study was limited in its design and application (Twyford, 2016, p. 14) it nevertheless provided a useful baseline picture for the main research study into individuals with dementia living in extra care. The findings supported the aim of the research. That is, to explore the appropriateness of extra care housing provision for people with dementia, including the opportunities it offers, the barriers it creates, and whether there is an affordable model of extra care which can be inclusive of people with dementia.

The research questions were:

- What is extra care, and what does it mean for those who live and work there?

- Is this model of extra care appropriate for a person with dementia?
- What modifications to the extra care model might make it more appropriate for individuals with dementia and their carers?

Ethical issues surrounding personhood, dementia and maximising the inclusion of people with dementia in research underpinned the way in which the study was undertaken (Sherratt, et al., 2007; O'Connor & Purves, 2009; Murphy, et al., 2015), and are more fully discussed in Section 3.4.

1.5 ORGANISATION OF THE THESIS

This chapter (1) introduces the study. A short summary of the researcher's background and commitment to the study is included before setting out the context for the research and why it is pertinent at this time. It then describes the research aim and questions, informed by a pilot questionnaire devised to ascertain the types of extra care housing schemes in the UK and their support for individuals with dementia. The remaining chapters of the thesis are organised as follows:

Chapter 2 sets out an initial review of the literature as part of the grounded theory approach to the research (discussed more fully in Chapter 3). The literature review provides a systematic assessment of the existing body of knowledge relevant to the care and support for individuals with dementia living in extra care housing. Together with the pilot questionnaire, the initial literature review provides justification for the research aim and questions.

Chapter 3 sets out the methodology and ethical considerations of the research. It establishes that an objective of the research was to involve residents with and without dementia, their carers, front line staff, managers, and policy makers in considering whether extra care can provide a sustainable model of housing with care for people with dementia. It details how a grounded theory approach was used with qualitative research methods including questionnaires, focus groups, individual interviews, observation and secondary literature searches. The

chapter describes how the methods were selected to explore individuals' experiences, understanding, and interpretation of social practices and the processes involved in extra care delivery at two case study extra care schemes in the East Midlands, with comparisons to other schemes to see how generalisable the findings might be. The grounded theory research process involved interaction and organisation of data in a way that allowed the data to be interpreted without the researcher being constrained by previously held assumptions or preconceptions. The chapter describes how literature is used throughout the thesis to support and extend a theoretical model of extra care housing for people living with dementia. It concludes with a summary of influences on the research approach that has been adopted.

Chapters 4 provides a pen picture of the residents who took part in the research before setting out the findings from the participant accounts of living and working in extra care. The participant accounts are themed to identify what would ideally underpin a model of extra care housing to support people living with dementia. **Chapters 4 and 5** set out the complex inter-relationships between the themes described and puts forward a model of extra care with four components.

Chapter 6 scrutinises the concepts and themes that were raised by participants and described in Chapter 4 and 5, setting out and discussing the lines of enquiry arising from them. The chapter highlights the emergent fit between the initial literature review and issues raised by participants, which adds to their interpretation within the theoretical model of extra care housing. As part of the grounded theory approach used for the research, the analysis of data in this chapter points towards two theories that are explored to help understand whether there is an appropriate model of extra care for people with dementia; social worlds theory and quality and operational excellence theory.

Chapters 7 and 8 provide insights from further literature searches on social worlds theory and the theory of quality and operational excellence. The secondary data provided by the literature are critically appraised to see how it

contributes to better understanding the experience of people with dementia living in extra care housing. The insights from the literature are integrated with the earlier findings to ensure the concepts are well-developed and fully grounded in readiness to modify them into the theoretical model of extra care in Chapter 9. Chapters 7 and 8 also suggest where there are gaps in the current body of knowledge that future research might address.

Chapter 9 proposes a theoretical model that can be used to commission, develop and operate extra care housing. It uses the concept of people with dementia living as well as possible as a central reference point for the theoretical model. The chapter offers a framework that integrates social worlds theory and quality and operational excellence theory to ensure that the four components of the extra care model effectively support people with dementia to live as well as possible. The chapter goes on to consider how generalisable the theoretical model and framework might be to other settings and makes suggestions for best practice to implement them.

Chapter 10 concludes the thesis by summarising and reflecting on the research. The key findings of the research are drawn together, and an argument put forward for their relevance and usefulness in contributing to research and practice. It is suggested that this research has made a unique contribution to the field of extra care housing spanning across sociological and management disciplines. This concluding chapter sets out the limitations of the research and how they might impact on the original aim of the research to provide an example of best practice that could be applicable beyond the immediate research sites. The implications of the research findings for the commissioning, development and operation of extra care schemes are summarised, as are recommendations for future research.

The thesis has been written so that it can be used as a resource for those who have an interest in the development of extra care. To enable the thesis to be used as a body of reference materials the introduction to each chapter sets out its content in the context of the overall thesis.

2. CHAPTER TWO: INITIAL LITERATURE REVIEW TO UNDERSTAND THE CONTEXT OF AGEING WELL WITH DEMENTIA IN EXTRA CARE IN THE UK

INTRODUCTION

Consistent with a grounded theory approach (explained in more depth in Chapter 3), this section presents the findings of an initial literature review which aimed to identify, critically appraise, and synthesise studies relevant to the care and support for individuals with dementia through the provision of extra care housing. The purpose of this initial literature review was to explore the researcher's epistemological framework and sensitise the researcher to the current knowledge available.

Systematic literature reviews have been variously described by different authors including Mulrow et al (1997), Tranfield et al (2003), and Aveyard (2014). Aveyard (2014) emphasised the link between a robust literature search and evidence-based practice which was helpful in placing this initial literature review within the grounded theory approach used for the study of extra care. Set within health and social care, Aveyard's approach was consistent with those of other authors in the field. She asserted that

A good quality literature review, ... is one that attempts to incorporate a systematic approach to literature searching, appraisal and re-analysis, even though the final review might fall short of a full and detailed systematic approach. (Aveyard, 2014, p. 16).

In undertaking a 'good quality literature review' an attempt was made to avoid bias or inaccurate conclusions which could have occurred if no defined method or systematic approach was undertaken. The preliminary literature review for this research was not a full and detailed systematic review. Rather, it took the format of a comprehensive review over an extended period from the start of the PhD study in September 2015 to the summer of 2016, when the field work phase of the research began. The aim was to produce a review that highlighted the key

findings and debates relating to extra care housing and its appropriateness for people living with dementia, providing the context and rationale for the PhD study. It was also undertaken to meet an ethical obligation that participants are not asked to contribute to unnecessary research⁴.

A PICOT format⁵ (Fineout-Overholt & Johnston, 2005) was adapted to develop literature searches for the three questions contained in the research proposal

- What is extra care, and what does it mean to you?
- Is this model of extra care appropriate for a person with dementia?
- What modifications to the extra care model might make it more appropriate for individuals with dementia?

Fineout-Overholt's PICOT format focused on clinical health evidence reviews, whereas the PICOT search for this extra care research were more generic, including a range of search terms set out in Appendix 1. The search used three theoretical frameworks, across different disciplines, relating to community, belonging and ageing in place; dementia, dementia care and personhood; and dementia friendly design and ageing well.

Care was taken to ensure that any focus resulting from the use of specific theoretical frameworks did not restrict the breadth of the review or introduce bias (Aveyard, 2014). This was particularly important as the grounded theory approach used in this research required the researcher not to have pre-conceived ideas about the research questions and where they might lead. Main concepts were searched for separately, with search criterion included or excluded according to each concept (see Appendix 1). Six main areas were explored in the literature search, which were:

1. What have been the political, economic, social and legal drivers to the development of housing for older people and how are they relevant?

⁴ In this context research would be unnecessary if there was already a body of knowledge that covered the subject area, that is, if it did not contribute original or new knowledge to the field of extra care provision for people living with dementia.

⁵ PICOT is an acronym for Population or subject of interest, Issue of interest, Comparisons of interest, Outcome of interest and Timeframe.

2. What is extra care and is there one or multiple models?
3. Is there enough extra care to meet demand from older people in the UK?
4. What causes older people to move to a new house?
5. What factors are important in enabling an individual with dementia to successfully move and live well in extra care, and are they in place?
6. How does a sense of identity and personhood impact on a person with dementia living as well as possible in extra care?

Electronic searches were undertaken using a range of tools and databases including STAR, Google Scholar, ISI Web of Science and JSTOR. The searches included books and peer reviewed journals relating to ageing and society, disability and human development, social work and development, mental health, health and social care, dementia, research development, quality, nursing and residential care, housing care and support.

Professional literature sources were also used. They comprised research foundations and charitable organisation publications including the Centre for Policy on Ageing, Centre for Ageing Better, Joseph Rowntree, Alzheimer's Society, Housing Learning Improvement Network, King's Fund, and National Care Forum. Such reports were not always peer reviewed, but provided complementary perspectives or viewpoints based on practice examples. Grey literature including unpublished research findings from related research projects was used.

The period from the 1980s onwards was used as the timeframe for the literature search because it was the period in which specialist extra care housing started to be developed through Government funded schemes. It was also the time in which much seminal work on capacity based and other approaches to personhood were developed (Kitwood, 1993; Higgs & Gilleard, 2015; Alzheimer Europe, 2017). Where possible, examples of UK research were used in the review because they were specific to the context of extra care housing in the UK. Other international research examples were included where they offered

complementary perspectives. The preliminary literature review focused on 266 items which were catalogued according to the subject of interest. They were drawn from a range of books, blogs, briefing papers, codes of practice, conference proceedings, on-line databases, discussion papers, good practice or guidance papers, journal articles, PhD papers, press releases, radio reports, review papers, statutory guidance, toolkits, and websites. Further literature was reviewed if indicated as of interest in the original 266 items. The findings of the search were presented as themes that emerged from the appraisal and synthesis of the literature.

DEVELOPMENT OF EXTRA CARE IN THE UK

Anticipating the housing needs of older people in the UK is a requirement of current governmental social policy and a legislative responsibility for local authorities and partner agencies under a number of Acts of Parliament, including the Health and Social Care Act (2012) and the Care Act (2014). There is a growing body of guidance on responding to housing needs and assisting older people to maintain independence with appropriate levels of care and support within limited available resources including Lifetime Homes, Lifetime Neighbourhoods (Department for Communities and Local Government, 2008) and Housing our Ageing Population (Barac & Park, 2009; Porteus, 2012; Best & Porteus, 2016).

Provision of accommodation for vulnerable people started in the 16th Century and continues to develop and change today. An overview of the historical timeline is set out in Appendix 2, charting the changes over the last five centuries including the development of alms-houses, workhouses, residential homes, sheltered housing, and extra care housing. Today there is a range of housing with care⁶ options, broadly classified by Valins (1988), Salmon (1994), and Robson et al (1997), and described in Appendix 3 . Although there is still no

⁶ Housing with care includes individual dwellings, groups of individual dwellings, and residential homes for groups of people

single national classification system, there is consensus that the spectrum of housing consists of individual familial dwellings in the community, general sheltered housing, extra care housing for older people (specialist housing with care), and residential, nursing and specialist or hybrid care homes, see Figure 2-1.

Each form of housing has the potential to be enhanced by assistive technology including equipment and devices which promote greater independence by enabling people to perform tasks that they were formerly unable to accomplish, or had great difficulty accomplishing.

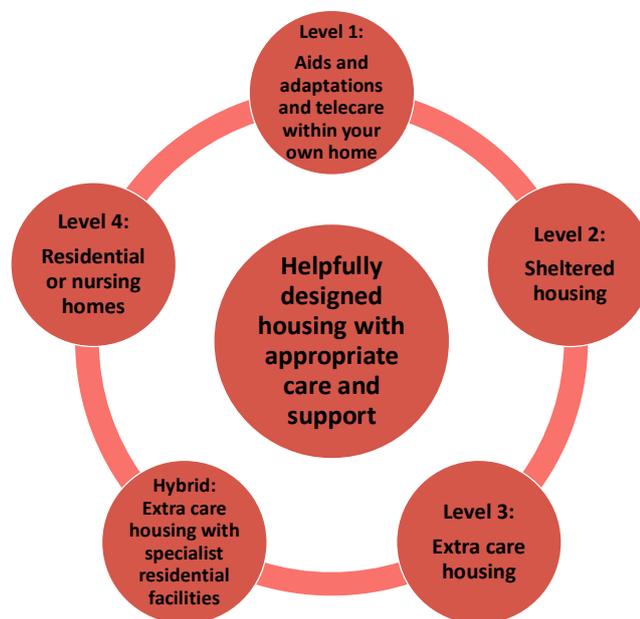


Figure 2-1: Extra care within a range of housing with care options

Extra Care Housing and other specialist supported housing models are relatively modern concepts in the UK, emerging from the late 1980s and early 1990s (McCafferty, 1995). There was little early consensus on what extra care was and its development was opportunistic and piecemeal (Tinker, et al., 2007). The key elements of extra care housing have been described through a number of research studies and reports such as those by Robson et al's (1997), Dutton (2010), Baumker et al (2012), Laing and Buisson (2015), and (Riseborough, et al., 2015).

Consistent across all the definitions is that extra care is primarily for older people (although many schemes do also accept appropriate younger adults) with individual dwellings or self-contained accommodation. The schemes are usually purpose designed with access to assistive technology and with safety and security built into the design of the building. There is often a mix of dwellings with one or two bedrooms offering an opportunity for individuals or couples to live alone or together. The independent nature of the dwellings is ideal to accommodate couples of all descriptions, be they married, in a registered relationship or other type of relationship, and be they of the same or opposite sex. Care is delivered flexibly tailored to each person's individual needs by a team of support staff who are usually based on the premises and available 24 hours a day. Communal facilities and services are available, and normally includes meal provision. Extra care often aims to provide a home for life, but it is increasingly recognised that this cannot always be achieved for a minority of residents.

Common themes important to residents considering moving into extra care emerged from the literature above. They include promoting independence, reducing social isolation, and achieving the best possible quality of life⁷ for residents. The combination of security and independence is highly valued. Achieving the best quality of life for residents is recognised as potentially challenging when individuals have chronic, progressing or life-limiting conditions, including dementia.

Unlike residential care homes, many extra care schemes do not require residents to obtain their care services from a specific provider. Costs for non-care services such as some domestic services, and for communal areas including a catering

⁷ Quality of life is described as "an individual's perception of his or her position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way a person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features in the environment." (WHO, 1994). As people age, their quality of life is largely determined by their ability to maintain autonomy and independence. (World Health Organisation, 2002, p. 13)

kitchen, and in some cases meals, might be built into a charge to residents. In some schemes residents prefer to receive their care and non-care services from the same provider or providers who work together, and so opt to have a complete package from the on-site providers.

National government has been instrumental in supporting the growth of extra care by providing policy direction, by supporting funding of extra care schemes⁸, and by encouraging commissioning guidelines (Housing LIN, 2010). Extra care housing in the not-for-profit, or public sector, is usually delivered through partnerships involving, but not limited to, local authorities, housing organisations, investors and commercial developers, domiciliary care providers, health services, voluntary services and other commercial businesses. The complexity of such partnership arrangements can lead to differing requirements. Although there is no one defined model of extra care, broad approaches to extra care supporting people with dementia have emerged (Barrett, 2012), described as integrated, separated, hybrid and specialist, as illustrated below in Figure 2-2.

Much of the earlier research has sought to gain a positive evidence base for the further development and use of extra care by exploring the relative costs and outcomes for people in extra care (Vallelly, et al., 2006; Dutton, 2010). Until recently, practice suggested that a vibrant and viable extra care scheme could be sustained if the population of residents⁹ had well balanced levels of need.

Current resource tensions within the care sector are challenging that premise, with anecdotal reports that local authorities are increasingly wanting to place a greater proportion of people with higher levels of need in extra care.

⁸ Government capital funds such as the Extra Care Housing Capital Fund (2004-2010), Social Care Capital Grant, and the Care and Support Specialised Housing Support fund were intended to encourage Local Authorities to provide greater housing choice to older people and other people with disabilities or long-term conditions.

⁹ Resident will be used here to describe an occupier of an extra care scheme; people who live in Extra Care Housing have their own self-contained homes, their own front doors and a legal right to occupy the property. Some residents will be tenants of rented apartments, some will own their apartment outright, and some will share the ownership of the apartment with the Registered Social Landlord of the extra care scheme.

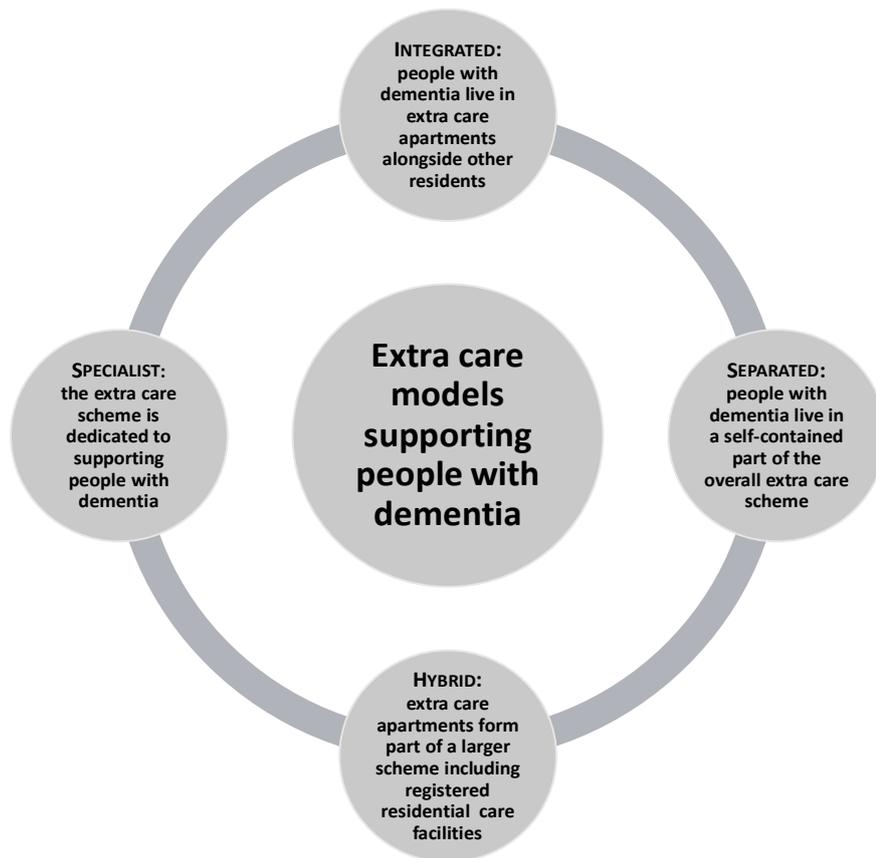


Figure 2-2: Models of extra care for people with dementia
(adapted from Barratt, 2012)

Shared learning around the potential of extra care to support people with dementia is happening, for example through the Housing LIN¹⁰ and the Housing and Dementia Research Consortium (HDRC)¹¹. With a growing population of people living with or likely to develop dementia (Alzheimer's Disease International, 2014; Prince, et al., 2014) and concern about poor suitability of existing housing for people with dementia (Alzheimer's Society, 2012) extra care housing is seen by some as an alternative to residential care. The role of extra care in providing a place in which to age, or a home for life, has been examined in several studies. Kneale and Smith (2013) stated that extra care could be a

¹⁰ Housing Learning and Improvement Network

¹¹ The Housing and Dementia Research Consortium (HDRC) is based at University of Worcester and is a membership group of organisations and individuals who are committed to research and knowledge exchange focusing on 'what works' for people living with dementia in housing with care and other forms of accommodation and care services in the UK and beyond. <https://www.worcester.ac.uk/discover/housing-and-dementia-research-consortium.html>

home for life for most residents, but Bernard et al (2007) and Croucher et al (2007) concluded that providing a home for life can prove a major challenge for people with dementia. Croucher et al (2007) reported that there was evidence that extra care could support people with mild to moderate dementia, and there appears to be increasing evidence and general agreement that moving to extra care is not the best option for people who already have advanced dementia (Dutton, 2010; Barrett, 2012).

Some of the themes set out in this introductory section on extra care will be explored in more detail in the remaining sections of the literature review.

AGEING AND LIVING WELL

The discourse on active ageing¹², positive ageing and positive living (World Health Organisation, 2002 & 2007; Fernández-Ballesteros, et al., 2013; Foster & Walker, 2015; Wealleans, 2015) provides a lens through which to consider the experience of living in extra care. It is outside the scope of this thesis to provide a full critique of active ageing, but it is important to acknowledge its relevance for extra care. Active ageing promotes mental health and social connections, consistent with the common themes identified as important to residents considering a move into extra care (see Section 0). Active ageing also supports the rights and responsibilities of people to participate in aspects of community life (World Health Organisation, 2002, p. 13), which is fundamental to people living well in extra care. The determinants of active ageing related to behaviour, personal factors, the physical and social environments, and economics all inter-relate in planning for active ageing in an extra care scheme, shaping who extra care is targeted at.

The primary criterion for access to most extra care schemes is that people are normally 55 years and older. Often there are secondary criteria such as 'has housing need' 'has care need' or 'has a local connection'. The primary criterion

¹² Active ageing is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age (World Health Organisation, 2002, p. 12)

focuses on a chronological definition of age, whilst the secondary criteria begin to stray into socially constructed meanings of age. There is no one numerical criterion with which to refer to the older population, although in the UK and many other developed countries the age of 60 to 65 has been used to define the beginning of old age, marked for many people by the age of retirement (Gorman, 1999).

Chronological old age is not a good marker for the housing care and support needs that one might have. Recognising that some people younger than 60-65 have housing needs, a lower age limit of 55 has been set for most housing developments specifically for older people. Similarly, a majority of older people are living for longer, and many of their additional years are free from disability (Carnegie Inquiry into the Third Age, 1993).

Concepts of the third and fourth ages emerged in the mid to late 1980s as the view of old age as a uniform period of life declined. Concepts of third and fourth ages were developed further by Laslett (1994; 1996). There is a consensus that the third age follows on from the period of adulthood, reproducing, working and earning to include more leisure time and opportunities for personal fulfilment. In contrast to previous paradigms of old age, Laslett (1996) sought to re-map the third age away from the fourth age which he saw as a period of decline and decrepitude. Previous negative representations of old age were rejected in the culture of the third age, which was portrayed as an era of successful ageing.

There are no hard and fast criteria that differentiate between ages. Figure 2-3 below sets out some of the different approaches to life course and ageing with concepts of age mapped against general bands based on chronological age. The bands do not directly map one to the other, for example middle age and old age can variously be considered third age or fourth age depending on the individual and their circumstances. The characteristics are perhaps more useful in showing the reference points between the ages across the life course, with an individual moving from dependence in childhood, through maturity and independence and then a return to dependence for some but not all. The measures or outcomes

are included to show how success or failure may be judged typically across the life-course.

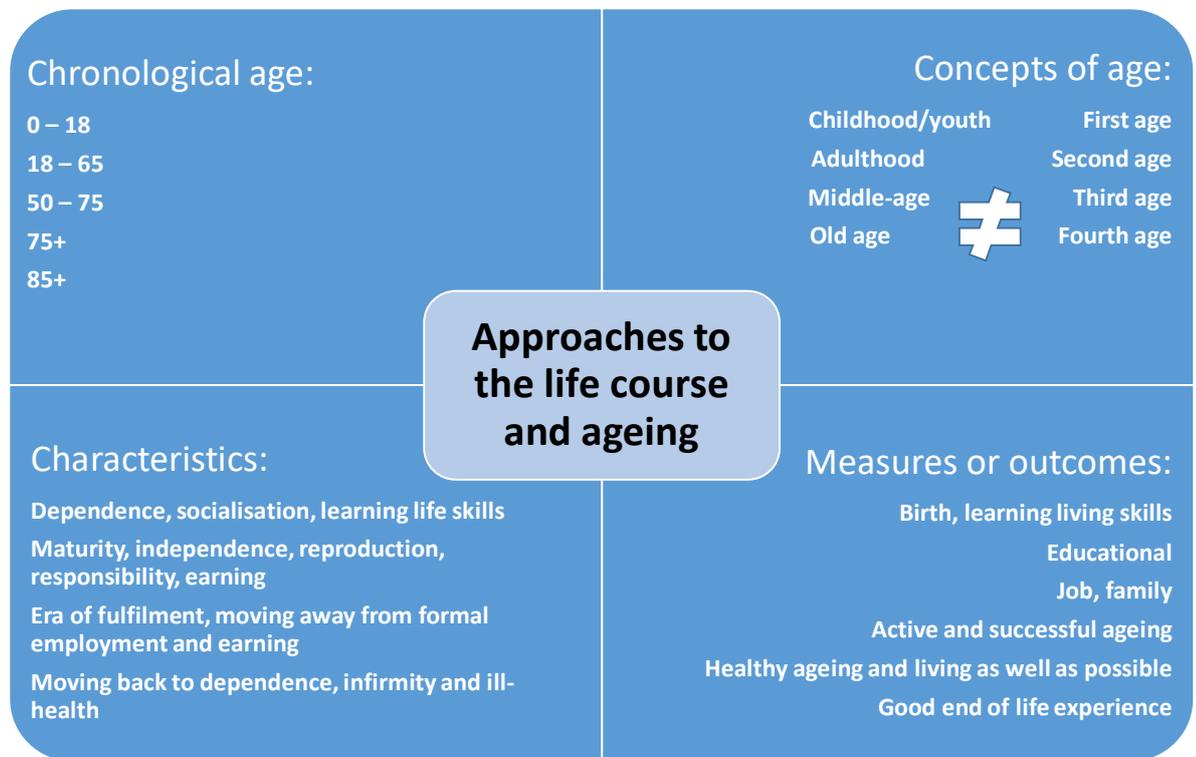


Figure 2-3: Approaches to life course and ageing

Separate to the third age, the fourth age started to be seen as ‘treading down’ older and more defenceless people (Margot Jeffreys and Michael Young quoted in (Laslett, 1994, p. 445). The fourth age is typified as the end of successful ageing and the transition period before dying; consisting of being less active, with increasing dependence, and increasing infirmity and ill-health. This division between the third and fourth age is not heralded by the achievement of a chronological age but lends itself more to a specific phase of life; some individuals make a transition straight from finishing work to ill-health and death even before they reach pension age.

Gilleard and Higgs (2010) argue that the fourth age is neither a particular age cohort nor a distinct phase of life, putting forward instead the idea of the fourth age as a metaphorical black hole with imagery which depicts choice, autonomy,

self-expression, and pleasure collapsing into a silent negativity (Gilleard & Higgs, 2010, p. 126). The work of Gilleard and Higgs, and other contrasting views on loss of agency and the fourth age including Heikkinnen (2000), Coleman and O'Hanlan (2004) and Twigg (2006), informed research by Lloyd et al (2014) which concluded that a great deal of physical, mental and emotional effort was required to maintain a sense of self in the fourth age, and that social relationships were essential in the maintenance of identity.

Discussion of the fourth age as a passage of decline and a closeness to death differentiates between social and biological death. The social imagery of Gilleard and Higgs symbolises social death by loss of autonomy, choice and independence, similar to that described by Lloyd (2000, p. 175) as 'an abyss into which each of us must avoid falling'. For this study on whether individuals with dementia can live well in extra care, the notion of social death becomes paramount in that social death could occur significantly earlier than the biological death of an individual with dementia.

Notions of belonging, identity, attachment and personhood are key players in advancing or delaying the social death of an individual living with dementia. These will be explored further in Section 0.

DEMENTIA: WHAT IS IT AND HOW PREVALENT IS IT?

Dementia is not a natural part of ageing. It has been described and defined variously, reflecting increases in scientific and medical knowledge over time as well as changes to our understanding of human behaviour with a focus on concepts of personhood and citizenship. Dementia is currently used as an umbrella term or syndrome describing symptoms that occur because of the brain being affected by different diseases, conditions or illnesses. (Department of Health, 2009; Gov UK, 2015; Alzheimer's Society, 2016).

There are over 100 types of dementia, each typically associated with progressive decline in multiple areas of function, including memory, thinking speed,

understanding and reasoning, language and communication skills, and the ability or motivation to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as difficulty in controlling emotions, depression, psychosis, aggression and wandering¹³. These symptoms can occur at any stage of the illness causing problems in themselves and causing complexity for care givers.

Models are available to help understand the progression of the illnesses comprising dementia. These have come from different disciplinary backgrounds including medical, cognitive and neuropathological, and tend to refer to different stages of dementia. Much of the literature is not explicit on how the stages have been defined but some do attempt to relate the symptoms and behaviours of dementia to the different stages (Feil & Klerk-Rubin, 2002; Jones, 2009; Serrano-Pozo et al., 2011; Ellis, 2013; Giebel et al., 2015; Alzheimer's Society, 2016).

Serrano-Pozo (2011) sets out a neuropathological approach for diagnosis. Jones (2009) uses a behavioural staging framework based on Feil's work on validation theory (Feil, 1982) to provide reference points for care givers. Giebel et al (2015) have concluded that knowledge about performance in activities of daily living at different stages of dementia has implications for designing interventions which could subsequently impact on the quality of life experienced. Differentiating between the different stages of dementia might be considered less helpful if the view is taken that everyone is unique, and each person experiences the progression of dementia differently, influenced by many factors such as their physical traits and emotional wellbeing, the environment they are living in, and the support available to them. However, whilst every person experiences living with dementia differently, there is a trajectory common to all. The exact number of stages described can vary according to the level of detail ascribed to them, but there is general acceptance in the literature and information that dementia

¹³ Wandering is used as a term for the activity of walking with or without purpose. The wandering may be a result of determined action by the individual to find something or to communicate something to other people. If not understood it can be viewed by other people as lacking in purpose or restlessness.

progresses through three broad stages; early, mid and late (World Health Organisation, 2016), otherwise described as mild, moderate and advanced.

A lesser known classification of the stages has been provided by Jones (2009) in her behavioural staging model for dementia care. It attempts to provide a best possible understanding of the person's needs and abilities to help with appropriate care provision. The model has four stages named after the key behaviours observed; mal-orientation, time confusion, repetitive motion, and end stage withdrawal (Jones, 2009 p 73). Although its use is limited to the progression of Alzheimer's disease and progressive multi-infarct dementia, it is helpful in providing understandable hooks to which carers can relate.

These different classifications are based on either the time a person has been living with dementia, or on how far the symptoms of dementia appear to have developed. A strong adherence to different stages of dementia, however they are defined, could militate against bespoke or person-centred care. Most current classifications or stages are subjective in their application, and that subjectivity itself brings some limitation in developing a shared understanding. Even with these limitations, the definition of stages is helpful for many in achieving a shared understanding of the complexities of dementia. For that reason, this research project used the most commonly described three stages of dementia (early stage, middle stage and late stage) to promote discussion and to help develop a nuanced view of whether individuals with dementia can be supported to live well within extra care.

Dementia occurs in a very wide range of individuals. People with dementia comprise a diverse group differing in race, ethnicity, gender, age, disability, sexual orientation, socio-economic group, culture and place of habitat. Within the UK the Alzheimer's Society has estimated there would be 850,000 people with dementia by 2015; of whom 40,000 would be younger people, 25,000 would be from black and minority groups, and two thirds women (Prince, et al., 2014, p 5). It was estimated that the overall figure would rise to 1 million people with dementia in the UK by 2025 (Prince, et al., 2014, p. 5). Using the report

commissioned from Prince et al, the Alzheimer's Society also estimate that only 44% of people with dementia in England, Wales and Northern Ireland receive a diagnosis, and that the total population of dementia among individuals aged over 65 is 7.1%. On that basis it is realistic to anticipate that many people living in extra care housing are likely to experience the symptoms of dementia even though they do not have a diagnosis.

In the second UK report on dementia Prince et al (2014) noted a reduction of older people and people with dementia living in care homes since the first report in 2007. Consideration was given to whether the reduction was 'due to the effects of government policy (direct grants to local government) to promote the development of the additional category of 'extra care housing'' (Prince, et al., 2014 p 53). They went on to estimate the prevalence of dementia among those aged 60 and over residing in extra care housing as well as those living in residential care homes, nursing homes and Elderly Mentally Infirm (EMI) homes. They noted a caution about the estimate of 8.1% of the extra care residents with dementia compared with 57.9% in residential homes. Although the estimate for extra care is above the level of 3.1% estimated by Darton et al (2012), it is well under what might be expected from an average population. Further research on the prevalence of dementia in extra care populations is required.

THE POLICY OF DEMENTIA CARE

Cantley (2001) and Innes (2002) have argued that historically dementia and dementia care have not been seen as a high priority within the political agenda. Dementia and dementia care started to emerge as a policy issue for developed countries in the 1980s as concerns grew about the impact of a rapid growth in populations ageing with dementia and cognitive decline (Hofman, et al., 1991; Brayne, et al., 2011; World Health Organisation, 2012). Dementia and cognitive decline started to be recognised as important causes of disability in later life. Innes and Manthorpe (2013) recognised that not only in Britain, but in Europe

and beyond there was a shift in policy attention towards dementia when they said:

Dementia is set to become one of the key health and social care challenges of the 21st century and is attracting global policy attention (Alzheimer’s Disease International, 2011; Wimo, Winblad, Aguero-Torres, & von Strauss, 2003), mainly arising from concern about increases in the number of people with dementia, particularly in developed countries.

Public understanding of dementia still has some way to go. The World Health Organization (2012) set out a six-stage model of public acceptance of dementia, from ignoring the problem through to normalisation and acceptance of dementia as a disability (see Figure 2-4)



Figure 2-4: World Health Organization "Six Stages of Acceptance of Dementia" model from Dementia: A Public Health Priority
(from World Health Organisation, 2012, p. 88)

Two main perspectives have developed as dementia has become more accepted. The first is a materialistic perspective that dementia is a social, economic and health burden on society. Policy makers with this perspective are likely to look for changes that are concerned with minimising the economic impact of dementia with the view that cost-effective research, care and support systems should improve outcomes for people with dementia. The second perspective focuses on a phenomenological or idealistic view concerned with maintaining the person’s independence, dignity, identity and personhood¹⁴. It highlights the quality of the care and support elements of dementia to ensure that each individual lives as well as possible. These two perspectives are not mutually

¹⁴ Personhood is the state or condition of being an individual person

exclusive, with a key challenge being how best people with dementia can be supported within current and continuing fiscal constraints.

Dementia undoubtedly became more centre stage in the UK with policy documents such as 'Living Well with Dementia – A National Dementia Strategy' (Department of Health, 2009) and the 'dementia challenges' of the then Prime Minister David Cameron (Department of Health, 2012, 2015). Even with the new focus, there was often little attention on the contribution which housing can make to the experience of people with dementia.

The Living Well with Dementia National Strategy included a specific objective (objective 10) considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.

However, in 2012 the Prime Minister's 2015 challenge only referred to housing within one case study and one research description; there was no reference to housing within the main body of the text. By 2015 the Prime Minister's dementia challenge for 2020 included an explicit albeit small section on housing, going some way to no longer treating housing and wellbeing as separate entities for people with dementia. Opportunities to include housing colleagues in the descriptions of partners working together were still missed in other parts of the Prime Minister's 2020 challenge document. See, for example:

Councils and the NHS are now working with one another, and are encouraged to work with other partners including the independent and voluntary sectors, to provide better and more joined up care to local people through the £5.3 billion Better Care Fund. (Department of Health, 2015 p17)

and

There are real opportunities to improve our understanding of the way dementia affects local communities, including identifying and supporting more people with dementia in a timely way, for example by harnessing the knowledge and experience of those regularly working with older people in the community. This spans wider than the pivotal role of GPs, for example to practice nurses, district nurses, health visitors, paramedics, pharmacists, audiologists, optometrists, podiatrists, home care workers, physiotherapists, occupational therapists, social care staff and voluntary organisations. (Department of Health, 2015 p26).

With a wide range of professions involved in supporting people with dementia, there is likely to be an equally wide range of perspectives from those involved. Brown et al (2000) reported on the blurring and preservation of professional roles and areas of responsibility within interdisciplinary mental health teams, concluding interestingly that boundaries between professionals can be actively encouraged by the experience of interdisciplinary working. Consideration is required as to whether permeable or distinct boundaries between professionals help or hinder the support for an individual with dementia.

Innes and Manthorpe (2013 p 684) write about the challenge of being able to 'understand one's own perspective and to be aware of the multiple theories that shape dementia discourse and are likely to be underpinning others' world views of the subject.' They describe understanding dementia from three different perspectives; biomedical, social-psychological, and gerontological (Innes & Manthorpe, 2013, pp. 690-691). Their gerontological web of understanding is helpful in contextualising this extra care research which looks at the interplay between policy frameworks, the immediate interactional environment, and the broader culture within the extra care scheme. An adaptation of Innes and Manthorpe's (2013) web of understanding is set out in Figure 2-5. It illustrates the inter-relationship of the foci of this extra care research; how dementia is understood (theory), the influence of policy frameworks (policy), and the type of care and support systems that are in place (practice).

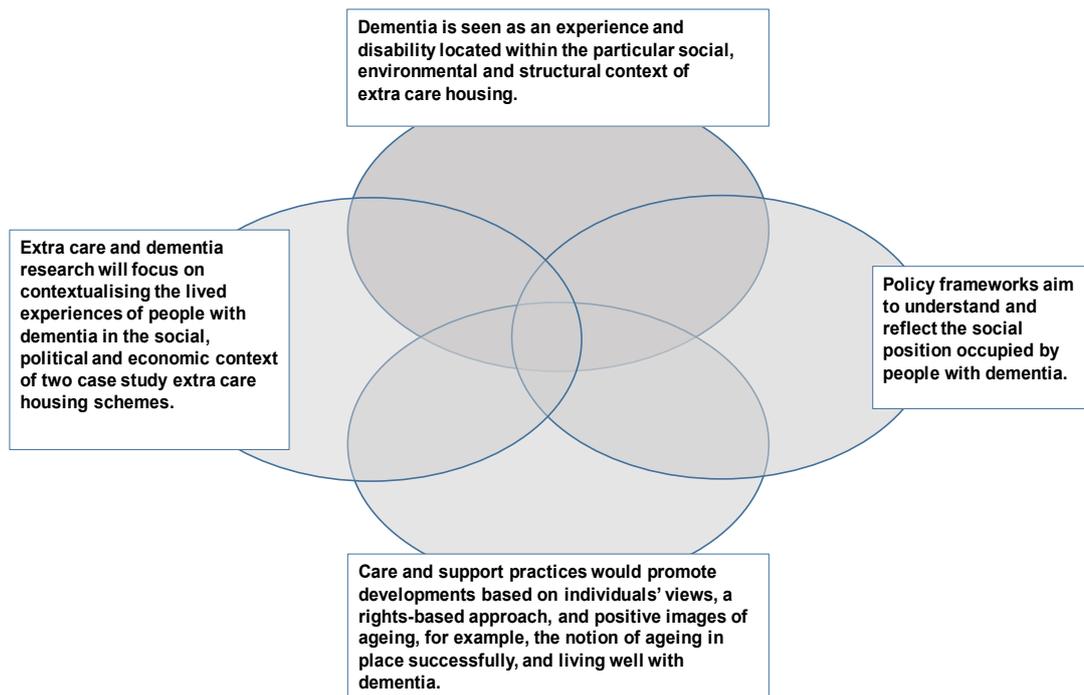


Figure 2-5: A web of understanding of dementia in extra care from a gerontological perspective
 (Adapted from Innes & Manthorpe, 2013 p 691)

What is not yet apparent is the extent to which the statements being made in national policy documents will be translated into local action to realise their strategic intentions. In part this will be affected by the perspectives and theoretical stance of influential policy makers. For example, those from a biomedical discipline may put a greater focus on researching causes and potential cures for dementia within a model where dementia is seen as a disease with symptoms that need to be prevented or treated. In contrast, those from a social psychological discipline may argue that the wider context of dementia care is best seen from within a social model of disability, with a focus on removing barriers and enhancing individualised approaches to care and treatment. Both may be required given there is no current cure for dementia.

The Mental Health Foundation (UK) published a paper on dementia rights and the social model of disability (McGettrick, 2015). The paper asserted that dementia is still too often seen through the lens of a conventional medical model, as an illness that needs a cure or treatment. The report argues that

developing a social model of disability for dementia needs greater and ongoing articulation of the lived experience of dementia. It sets out how the social model of disability could be used to reframe and reconstruct a world for people with dementia by breaking down a range of social, attitudinal, physical and environmental barriers to inclusion. Environmental gerontology has a contribution to make in describing, explaining and optimising the relation between older people with dementia and their socio-spatial surroundings.

Others have offered the view that 'a social model of disability goes some way towards improving our understanding of our responsibilities as non-disabled or non-demented people' (Gilliard, et al., 2005, p. 582) but would need to be adapted rather than just adopted for people with dementia (Owens, 2015). Notwithstanding some of the limitations of the application of the social model of disability there is growing consensus on the importance of continuing efforts to use a social care model, rather than a biomedical model, to situate our understanding of dementia care issues.

The legislative framework within which local policy and practice is developed is governed by the Care Act guidance (Department of Health, 2014). The Act and associated guidance sets out a person-centred framework for meeting someone's care and support needs, promoting a care and support system built around the individual, putting them in control as far as possible. Setting dementia within a social model of disability also raises the profile of other civil and human rights legislation including the Human Rights Act 1998 (Equality and Human Rights Commission, 2016), the Mental Capacity Act 2005 (Office of the Public Guardian, 2016), the Equality Act 2010 (Office for Disability Issues, 2010), and the United Nations Convention on the Rights of Persons with Disabilities (United Nations CRPD, 2016), all aimed at ensuring the person with dementia can maintain human rights and be active citizens.

It is useful to review Shakespeare and Watson's (2001, p. 10) account of the social model of disability in which they note that in Britain it 'distinguishes between the impairments that people have, and the oppression which they

experience. And most importantly, it defines 'disability' as the social oppression, not the form of impairment'. In trying to resolve some of their perceived difficulties with the British social model of disability, Shakespeare and Watson (2001 p25) point out that 'everyone has limitations, and that everyone is vulnerable to more limitations and will, through the ageing process, inevitably experience functional loss and morbidity' and that 'part of the psychological origins of hostility to disabled people may lie in the tendency of non-disabled people to deny their vulnerability and frailty and mortality, and to project these uncomfortable issues onto disabled people'. With that in mind, the next section of the literature review explores issues of belonging, identity, attachment and personhood.

BELONGING, IDENTITY, ATTACHMENT AND PERSONHOOD

Research is growing on the relationship between older people's physical and social environments and their health, life satisfaction and well-being (Oswald, et al., 2011; Buffel, et al., 2013). There is also mounting evidence that community, social networks and social support play a positive role in helping individuals feel socially and emotionally connected, with a subsequent impact on feeling they are 'ageing successfully' (Nelson & Prilleltensky, 2005; Bowling, 2006; Dykstra, 2009; Warburton, et al., 2013).

Provencher et al (2014) consider three conceptualisations of community; 'as a physically bounded place, as a set of shared interests and as a sense of belonging'. Savage, Bagnall and Longhurst (2005) found that people expressed a greater sense of connectedness with the area they lived in when it reflected who they thought they were as a person. May and Muir (2015) in a study of everyday belonging and ageing found that 'feeling comfortable in an area did not require strong social capital or close ties. A general feeling of 'friendliness', even from strangers, was often held to be an essential part of making participants feel that an area was a good place to live and the right place for them to be'. (May & Muir, 2015, Paragraph 4.1). They drew parallels with the work of Blokland

(2003) and Savage et al (2005) who noted that a sense of belonging does not require that the relationships between people in that community are close; a degree of anonymity can be experienced as offering space for privacy. May and Muir (2015, paragraph 8.5) concluded that 'it is important not to try to pre-determine what belonging consists of, but rather explore the ways in which the different dimensions of belonging – relational, cultural, temporal and sensory – interact with each other to contribute to a person's overall sense of (not) belonging, thus influencing that person's capacity to act in their surroundings'. From their study of older Chinese migrants to New Zealand Li and colleagues (2014) argue that sense of community is not predicated on active participation, but that a sense of community is 'based on the perception of similarity among members, where reciprocal relations facilitate the satisfaction of individual needs' (Li et al., 2014 p. 28). This is of importance to those in extra care housing trying to generate a sense of community with residents who move from a range of different locations, many with reduced ability to actively participate.

An individual's decreasing capacity to act, or loss of individual agency and a shift away from autonomy towards dependency on those who provide care and support, is characterised by the fourth age. This shift is exacerbated for people with dementia, many of whom find it harder to maintain their identity as their dementia progresses and social engagement becomes more difficult.

Interpersonal relationships play an important part in the formulation of the sense of self (McMillan, 2006), and yet those interpersonal relationships become more difficult as memories fade and as other people see the person with dementia changing.

As a person with dementia loses memories and is less able to sustain a current awareness of their own and other's identity, they are likely to become confused and anxious. For example, relationships may be thought to exist in a time frame that is no longer real, such as with parents who are now dead, or children who have grown up.

Although Bowlby's (1969&1979) work on attachment originated with infant and parent relationships, Bowlby's emphasis on behaviour in times of ill-health or loss is particularly relevant to people with dementia and their ability to engage socially. Bowlby explained attachment theory as 'a way of conceptualizing the propensity of human beings to make strong affectional bonds to particular others and of explaining the many forms of emotional distress and personality disturbance, including anxiety, anger, depression, and emotional detachment, to which unwilling separation and loss give rise' (Bowlby, 1979 p 127).

Bere Miesen has been a leading proponent of attachment theory as a means of understanding the emotional world of people with dementia. Miesen (1992; 1993) set out a theoretical assumption that dementia is a loss process that prompts feelings of being unsafe which can then activate an emotional need for security through an attachment figure. He particularly focused on 'parent fixation' in which the person erroneously believes that one or both parents are alive, finding that people with dementia displayed differentiated forms of attachment behaviour depending on the stage of their dementia (Miesen, 1993).

As cognitive impairment increases with the progression of dementia, orientation to the outside world diminishes and those once familiar may begin to appear strange or unknown. Wright and colleagues (1995) reflected that in an increasingly unfamiliar environment, overt attachment behaviours become a less useful way of finding safety and well-being. In addition, the ability to self-initiate attachment behaviours may be reduced (Wright et al., 1995). Replication and extension of Miesen's work (Browne & Shlosberg, 2005; Osborne, et al., 2010) has been less clear that attachment behaviours differed between stages of dementia but have confirmed the importance of viewing parent fixation and associated behaviours as psychosocial phenomena that arise from a relationship between pre-morbid¹⁵ individual characteristics, the environment and cognitive impairment.

¹⁵ Premorbid characteristics as used here refer to the characteristics that an individual had before the onset of an illness or disease, in this case before the onset of dementia.

The approach of the phenomenological school of psychology, where the 'subjective experience of the individual is seen as reality' (Brooker, 2003, p. 217), is helpful in exploring and understanding the impact of pre-morbid characteristics, the environment and the person's cognitive impairment on the lived experience of residents with dementia in extra care research.

The concept of personhood moves beyond the experience of individual people and encapsulates the way that people understand and relate to each other, drawing on both ethical and psychosocial understandings. The lived experience will be affected by the status bestowed on the person by those around them. Kitwood and Bredin (1992 p270) proposed that if the personhood of an individual with dementia is maintained that they can achieve 'a state of at least relative well-being'. In their work on personhood Kitwood and Bredin (1992) drew on Buber's (1994) contrast of two ways of being in the world and forming relationships with those around you, treating someone either as 'Thou' or 'It' in relation to yourself¹⁶. Relating to someone with or without dementia from an 'I:It' position signals some level of emotional detachment and objectification and will detract from their identity and personhood. Treating someone as 'thou' or 'you' is more likely to promote inter-subjectivity and preserve the personhood of people with dementia (Kitwood & Bredin, 1992).

Writers such as Sabat and Harre (1992), Kitwood (1993; 1994), Downs (1997), Sweeting and Gilhooly (1997) and Cohen and Eisdorfer (2001) have questioned the idea and extent of 'self' and 'loss of self' in dementia. Sabat and Harre (1992) talked about three types of self, the third of which is the publicly presented personae that requires the co-operation of others to exist, through for

¹⁶ Buber (1994) describes the two ways of engaging with the world; the first is called 'experience' in which man uses information about an object of experience (It), viewing it as a thing to be used, known or put to some purpose. There is a distance between the experiencing I and the experienced It, with the 'I' being an objective observer rather than an active participant. The second way of engaging with the world (and the one Buber says makes us truly human) is through 'encounter' in which man enters into a relationship with the object encountered, transforming the I-You by the relationship.

example, the roles and relationships an individual has with others. The way in which a person is perceived by others is central to the concept of personhood.

Kitwood and Bredin (1992) led the work on personhood, linking Buber's address of a person as 'Thou' to being able to recognise a person's individuality; which is key to understanding the uniqueness of each person with dementia, understanding the subjective experiences of the person with dementia, and enabling a relationship to be formed and maintained. Dewing (2008) offers a useful perspective in saying 'that others around the person with dementia consequently see them as a lesser or non-person, does not mean, in an absolute more sense, they are lesser.' (Dewing, 2008 p 7).

In writing about the denial of personhood in care settings for people with dementia, Kitwood (1997) argued that the approach to people with dementia needed to be reconsidered. Although Kitwood (1997) asserted that personhood had been reduced to two criteria of whether a person experienced autonomy and rationality, he also countered that personhood should be conceptualised more broadly to include relationships as one of the underlying principles. Kitwood's work on personhood and dementia has not been without critics (Adams, 1996; Dewing, 2008; Higgs & Gilleard, 2016). Dewing concludes that 'popularisation of Kitwood's work is resulting in an oversimplification and sidelining of his core ideas on moral concern for others as the basis of personhood' (2008 p 11). Higgs and Gilleard (2016 p 774), in their paper addressing the use of personhood argue that there is 'a danger... that in placing such a confused and confusing concept as personhood at the centre of any set of organisational practices of care it risks undermining the basic moral imperative of care that is central to society's responses to disabling old age.'

Notwithstanding some of the limitations of the concept of personhood, Kitwood demonstrates through his approach and methods how personhood can be embedded through the capacity to feel, perceive and experience subjectively and in social relationships with others. He identifies psychological needs as comfort, attachment, occupation, identity and inclusion (Kitwood, 1997), similar

to those of social engagement and belonging, affirmation of self, autonomy and independence set out later by Neibuhr (in Kaufman & Engel, 2016). Neibuhr's work itself has limitations because it provided no information on the cognitive functioning of the participants (Kaufman & Engel, 2016). Kaufman and Engel (2016 p 784) believed there were sufficient parallels in the work by Kitwood (1997), Neiburh (2004) Schulz-Hausgenoss (2005) and Stechl (2006) to conclude that despite some limitations, Kitwood's model of psychological needs had empirical evidence. The use of a consistent set of indicators has relevance for the extra care research in exploring how far people with dementia are helped to feel emotionally safe and secure, and is consistent with the four principles of person-centred care recommended as good practice in dementia care by NICE (2016).

The importance of personhood, relationships and dementia has been developed from Kitwood's (1993) seminal work, by Kitwood himself (1997) and others such as Brooker (2007), Buron (2008), Wilson et al (2009), Hughes (2013), Smebye and Kirkevold (2013), and Zeiler (2014). Some of the research has also focussed on how the person's subjective experiences of dementia are shaped within the context of their personal relationships (Forbat, 2003; Clare & Shakespeare, 2004; Hellstrom, et al., 2005).

While there is a comprehensive body of literature around managing dementia, and maintaining personhood and agency, insights into the role of housing in supporting people to live with dementia are relatively recent (Gabriel, et al., 2015). The experience of supporting people to live with dementia in extra care warrants further examination. A framework for conceptualising research focused on personhood in dementia provided by O'Connor et al. (2007) is set out in Figure 2-6 below, and will provide a useful reference point for this extra care research.

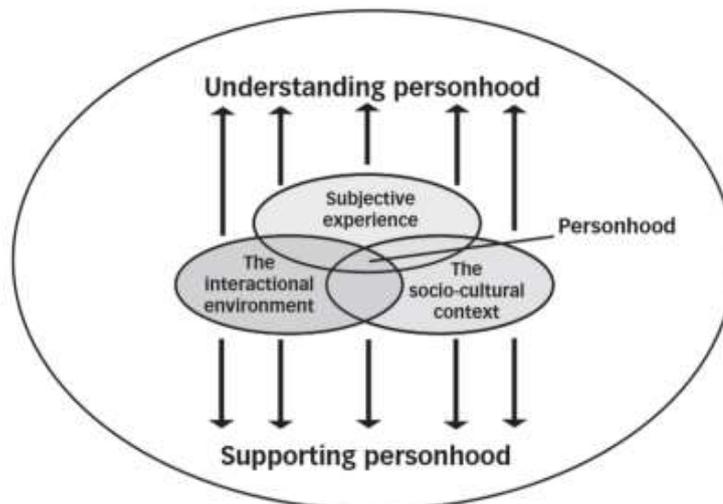


Figure 2-6: A framework for conceptualizing research focused on personhood in dementia
 (Source: O'Connor, et al., 2007 p 24)

The interactional environment will be explored in the next section of the literature review in relation to ageing in place and the use of age and dementia friendly design to make extra care schemes more accessible to individuals with dementia.

AGEING IN PLACE AND DEMENTIA FRIENDLY DESIGN

Environmental gerontology focuses on the relationship between older persons and their socio-spatial surroundings, and has been applied in housing design, institutional living and age-friendly communities (Wahl & Weisman, 2003). Three inter-related functions of the environment (Lawton, 1998) lay the foundation for an environment that is predictable, stimulates behaviour, and compensates for the reduced or lost competencies of an older person. 'Place' has come to be viewed as a key construct in conceptualising both the environments occupied by older persons and the older persons' interactions with these environments (Wahl & Weisman, 2003, p. 625). Together with active ageing (see Section 0), environmental gerontology provides a lens through which to consider ageing in place, relocation to a new place, and the role of the environment in supporting individuals to be as independent as possible (Mollenkopf & Walker, 2007; Oswald, et al., 2007; Van Hoof, et al., 2010;

Baumker, et al., 2012; Kneale & Smith, 2013; Ewen, et al., 2014; Cairncross, 2016).

The economic benefits of supporting individuals to remain in their own home are often combined in policy and media commentaries with the health and social benefits for individuals. There is a policy connection between the human aspiration to improve social outcomes for older people and the ability to provide a cost-effective model of care and support. For example, in their work on 'ageing in place' Sixsmith and Sixsmith (2008, p. 219) conclude that:

...the notion of 'Ageing in Place' has become an important issue in redefining health and social care policy for older people in recent years, with some proponents suggesting that "staying put" at home fundamentally and positively contributes to an increase in well-being, independence, social participation and healthy ageing amongst older people.

There is some recognition of an individual's strong attachment to home, the home's location in relation to family and friends, and the home's importance in maintaining emotional bonds and social networks (Gilleard & Hyde, 2007; Ball & Nanda, 2013). Increasingly though, the assumption that independence, and staying at home is best, is being challenged. The increased geographical dispersal of families together with changes to female roles in the 20th Century has impacted upon the social connectedness and informal support available to some older people. Sixsmith and Sixsmith (2008 p 233) offer an alternative view of home as a place of importance for emotional bonds and social networks when they say:

Home in old age can be a place of intense emotional experiences, frustrations and negative experiences, such as loneliness. There may also be significant weaknesses in terms of informal support, physical environment of the home and neighbourhood and social network, which undermine the person's ability to live independently.

Those two viewpoints are not mutually exclusive, one can have a strong attachment to home and its location and yet still experience loneliness. In his research with older people, Rowles (1978) explores the importance of geographical space and how that changes as one gets older. Some of the

participants in Rowles' research switched to forms of social network that were not dependent on geographical proximity, including television and radio, as their ability to connect physically with their previous networks diminished. Croucher (2008) confirms the importance of the physical environment in identifying that those who do move, often do so because they are experiencing health and other problems, commonly associated with reduced mobility.

Further emerging influences on the importance of home and location are the severe health and social care issues among British migrants who retired to countries such as Spain in the latter part of the 20th Century. The motivation for the moves were primarily to improve quality of life, particularly during the winter, with the climate being the principal attraction. Purchase of foreign housing for retired people as part of a financial plan to maximise material wellbeing has also been a factor in the decision to emigrate. In comparative research on northern European retired residents in southern European countries it was reported that:

The new transport and telecommunications technologies have not only enabled international 'amenity seeking' residential circulation and migrations, but also made them consistent with close emotional and instrumental bonds between consanguineous and other households separated by long distances. (Casado-Diaz, et al., 2004, p. 374).

Policy-makers and practitioners have an increasing awareness of the needs of older migrants and the challenges they pose for public policy in both the UK and in the country to which they migrated, particularly for health and social care requirements. The challenges are likely to become more uncertain until the implications of Britain's decision in 2016 to leave the European Union become clearer. There is some indication that happy and fulfilling lives are being abruptly changed as the person's resources (bodily, economic, social and practical) for independent living diminishes, and that institutions and friendship networks play a key role in supporting life (Hardill et al., 2005). What is less clear is the extent to which the strength of familial and social ties within their new country of residence will determine where emigrants choose to age as they become less independent. For some the choice may be to return to the UK,

which will challenge notions of local connection and entitlement to public funded housing and support.

Ageing in place is synonymous for some people with being in your 'own home', but according to Kneale (2013), purpose-built housing for older people has rarely been interpreted as being one's 'own home'. The British interpretation of 'ageing in place' was generally directed towards the adaptation of existing housing, and the development of theoretical 'age neutral' housing; that is housing that is designed to enable people of all ages including older people to function effectively.

In a Swedish study, with relevance to the UK, Abramsson and Andersson (2016) conclude that challenges such as those identified by Sixsmith and Sixsmith, and Croucher imply that large groups of older people will become increasingly dependent on having appropriately designed and situated living accommodation to function well. In the UK the Government spending plans included £194m capital allocation for 2016/17 in England for Disabled Facilities Grants (Department of Health, 2016). That allowed only limited public expenditure on adapting large numbers of general stock houses to meet the needs of the increasingly frail older population. At the time of this literature review the potential lack of investment in general housing adaptations cast a shadow over the prevailing policy of advocating for ageing in place.

To understand the role that extra care might play in realising the new aspirations and help in developing ways of being old it is important to recognise that society shapes the way old age is represented and given meaning. Notions of self, home, and community are central to the way in which older people make sense of the physical and biological changes brought about because of old age. As discussed earlier in the literature review, the culture of old age in western societies relates to science through bio-gerontology, and to the stages of a life course through social gerontology. Vincent (2006, p. 681) argues that 'definitions of ageing and death that focus on biological failure lead to a cultural construction of old age whereby diversity across the life course is devalued'. The

notion that creating age-friendly environments is especially important to frail older people is explored by Cramm et al. (2016) who assert that there is a dynamic fit between the person and the environment. The more frail and old a person, the greater their dependence on neighbourhood to support their well-being. Yet at the same time, their expectations of being able to benefit from neighbourhood characteristics such as access to outdoor spaces and buildings, adequate housing, and social and civic participation seems to reduce along with the level of respect and social approval accorded to them.

Extra care housing has positioned itself to provide an alternative housing option where aspects of the physical environment can enhance social neighbourhood characteristics enabling older people to function better, and to age in place. Extra care aims to deliver on the aspiration to have a place that is home which can increase well-being, social participation and healthy ageing amongst older people. To succeed in enabling older people to age in place, extra care schemes need to go beyond the physical and biological changes that older people experience, to recreate life memories and connect individuals to their past lives. The 2015 study 'Later Life' by Ipsos Mori and published by the Centre for Ageing Better found "social connections are as important as money and health to a good later life". Their research revealed that older people found it hard to prioritise between three strongly interrelated factors; namely health, financial security and social connections.

A policy approach which combines housing and social care strategies with a wider interpretation of ageing in place to include more bespoke accommodation options could give greater emphasis on extra care within the constrained fiscal arena. Whilst there is emerging evidence of extra care being a cost-efficient way to address the housing needs of older people (Netten et al., 2011; Weis & Tuck, 2013; Moriarty, 2015), an integrated policy approach would need continued debate about the impact of central planning and the welfare benefits strategies on the ability of the market to realise affordable models of specialised housing such as extra care.

Beach (2016) reported that close to a third of people who had downsized or were considering downsizing expected to release equity and save on household bills, and that specialist housing could have a major impact on freeing up the market in larger houses. He also commented that a policy shift in emphasis was needed, away from portraying downsizing as an obligation to the young (to release larger houses), towards one where downsizing represented better opportunities for older people in later life to make positive choices to enhance their own lives and wellbeing and those of their family.

There is a drive towards an acceptance that older people should be cared for at home within their community (Department of Health, 2014). There has and continues to be debate about where 'home' is. There has been equal debate about what constitutes 'community' and which community is best placed to support individual older people. The UN Madrid International Plan of Action on Ageing launched in 2002, encouraged policy-makers globally to promote ageing in place in the community. They advocated for due regard to be given to individual preferences and affordable housing options for the older person, and for housing provided for older people to appropriately account for their care and cultural needs (Hillcoat-Natelltamby, et al., 2010). In drawing attention to the need for more autonomy, choice and control in the way older people manage their homes and lead their lives, the HAPPI3 report (Best & Porteus, 2016 p. 10) sets out the pre-requisite of a 'planning environment that proactively encourages and assists the delivery of a greater range of well-located, well-designed and well-managed retirement housing models...'

The environmental impact of well-designed housing is two-fold. First, the design of the building can help or hinder an individual's daily activities within the environment (Jones & Van der Eerden, 2008; Fleming & Purandare, 2010; Waller, et al., 2013) as illustrated by the varying levels of inclusivity set out in Figure 2-7 below. Second, the social environment and culture within a scheme can impact on opportunities for interaction with others (Jones, 2009; Robertson, 2013; Elias & Cook, 2016). Research on the quality of life and building design in residential

and nursing homes for older people at the turn of the 21st century found significant positive associations between aspects of the built environment and the residents' quality of life (Parker, et al., 2004). Subsequent design research has focused either on generic models of extra care or on specialist buildings specifically for people with dementia, such as residential care.

Research on generic models of extra care housing has resulted in recommendations for best practice in providing a good quality of life for residents (Robson, et al., 1997; Barnes, et al., 2012; Orrell, et al., 2013; Dwell, 2015) with the production of detailed design specifications or guidelines for older people's housing and or extra care. These design guides range from general guidance (Lewis, et al., 2010; Park & Ziegler, 2016) to specialist areas such as lighting and design (Lewis & Torrington, 2013), thermal comfort (Lewis, 2015), sense sensitivity (Mazuch, 2014) and the outdoor environment (Burton, 2007).

Ageing in place - using design to increase potential success

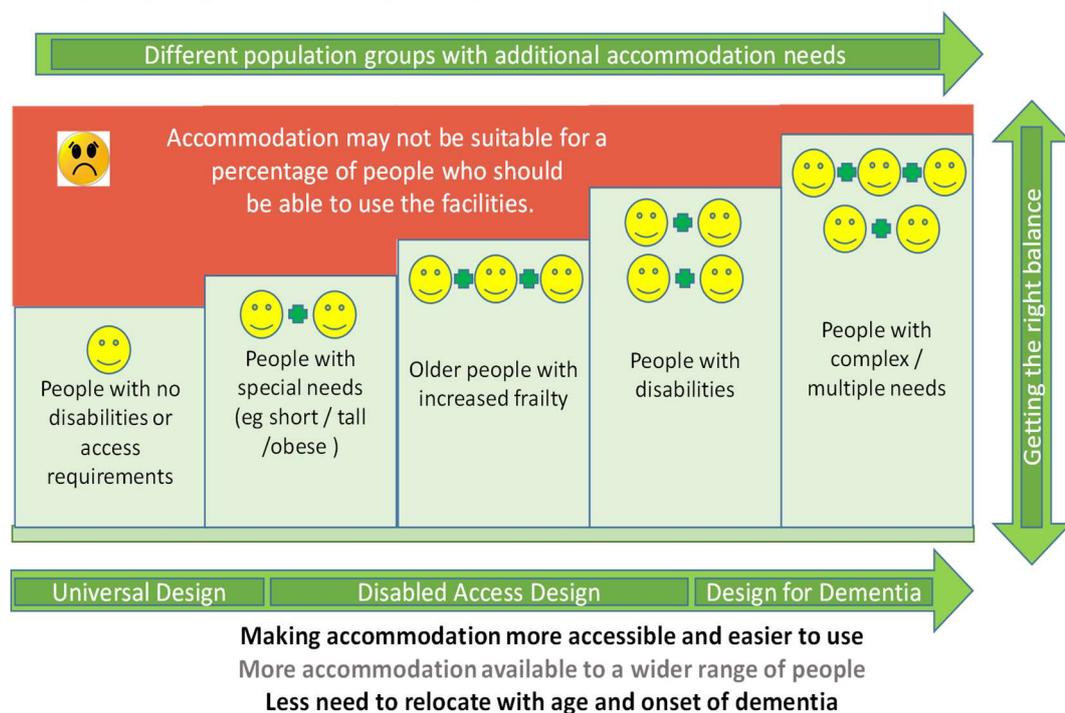


Figure 2-7: Ageing in place with well-designed housing
(Figure has been adapted from original diagram of unknown source)

Research on design for dementia includes work on architecture and interior design (Brawley, 2001; Fleming & Purandare, 2010; Van Hoof, et al., 2013) and specialist research on matters such as designing environments to optimise visual perceptual considerations for people with Alzheimer's (Jones & Van der Eerden, 2008). Specialist design guidelines include those in interior design (Fuggle, 2013), as well as specialist areas such as lighting (McNair, et al., 2010) and the outdoor environment (Mitchell & Burton, 2006; Pollock, 2007) amongst others. More recently, Faith et al's research (2015) reported that people living with dementia in long-term care settings can find their way around the environment better if the spatial experience appeals to the senses and creates memorable interactions as well as providing visual clues. Faith et al (2015, p. p216) also noted design alone is not enough, and that good design for dementia should be coupled with good quality care.

The King's Fund delivered a programme, Enhancing the Healing Environment, designed to assess and improve the dementia friendliness of hospital settings (Francis, et al., 2003). The programme was later refined to assess and improve the dementia friendliness of residential homes. Forty-two NHS and 74 Social Care pilot projects were funded to use and evaluate the assessment tool through the Department of Health's Dementia Capital Investment Fund (Department of Health, 2015). The pilots used the tool to identify areas for improvement in dementia design, with three main areas emerging; indoor built environment; technological environment; and outdoor built environment. The pilots reported benefits to both people with dementia and to staff resulted from the programme of improvements, as set out in Table 2-1 below.

Benefits	To people with dementia	To staff
From internal built environment interventions	Reduced tension, stress, anxiety; aggression and disturbed behaviour; reduced length of stay and the increased number of discharges to usual residence; reduced slips, trips and falls; reduced incontinence episodes; improved patient experience; improved sensory stimulation; and improved access to sunlight.	Improved working environments which have increased staff retention and reduced staff sickness and absence levels.
From supportive technology interventions	Improved dignity; improved interaction between staff and patients/residents; improved medical outcomes; reduced agitation; and improved mood.	Improved communication and better understanding of residents' and patients' needs.
From external environment interventions	Improved independence and encouraging involvement in activities; reduced falls; reduced incidents and violence; and improved quality of life.	Improved service delivery through provision of additional resources. Improved staff morale.

Table 2-1: Enhancing the Healing Environment benefits to people with dementia and carers

(Source: Department of Health, 2015 p 6)

The evaluation report made recommendations for the Department of Health and Delivery Boards that:

...dementia friendly core design principles need to be developed to guide future planning, design and operational processes, and that future design guidance should be dementia specific; account for different types and stages of dementia; and take into account new evidence, long-term studies and contextual changes.... (Department of Health, 2015 p7).

More recently the King's Fund has further developed the tool to assess the dementia friendliness of extra care housing (The King's Fund, 2014) which is being adopted by some housing associations. There has been little evaluation to date of the impact on the spatial experience of people living with dementia in generic extra care models.

CONCLUSION

This initial literature review began with a description of extra care housing, what it is and how it has developed in the UK. It then considered issues relevant to ageing and living well, dementia, its prevalence and the policy of dementia care. The review reflected on the importance of identity, attachment and personhood

to individuals living with dementia. Drawing on active ageing and environmental gerontology, the current discourse on ageing in place was considered together with the potential impact that dementia friendly design can have on the home environment.

This research also used the literature review to reflect on the issues highlighted by the pilot questionnaire (described in Section 1.4 and Chapter 2). Rather than being looked at separately, these ran through each aspect of the review. The analysis of literature showed there was little conclusive evidence in the existing research about how best to identify which individuals with dementia would benefit from a move into extra care, how individuals who develop dementia once they have moved into extra care can be supported, and how triggers that cause an individual with dementia to move out of extra care can be avoided. Although there was research published on extra care for people with dementia (Malley & Croucher, 2005; Dutton, 2010; Barrett, 2012), there was little which explored whether or how the combination of policy frameworks, the interactional environment, and the broader culture within extra care constrains or enhances the experience of an individual living with dementia.

Informed by the initial literature review, this research set out to understand these issues from the experience of those living and working in extra care, with a view to informing the current operation and future development of extra care housing schemes for older people, including those living with dementia.

3. CHAPTER THREE: METHODOLOGY AND ETHICAL CONSIDERATIONS

3.1 INTRODUCTION AND BACKGROUND TO THE RESEARCH

Building on the introduction to the research topic provided in Chapter 1, this chapter outlines the conceptual framework and methodological approach used. It describes the research approach, which used qualitative methods including questionnaires, focus groups and individual interviews within a grounded research framework. Participant involvement is discussed together with the planned research activities and development of data. The chapter details the case study sites and how participant involvement was sought, together with the ethical issues and governance matters that were addressed. It includes reflections on the impact of the relationship between the researcher and the participants. The methodology and methods are reviewed, and consideration given to how far the findings from the research can be generalised. The researcher was explicit with participants that it was not within the remit of the research to directly change the current service, but that the findings of the research were intended to provide insights and potential new knowledge to influence the way that extra care may be designed, commissioned, developed and operated in the future.

3.2 CONCEPTUAL FRAMEWORK AND METHODS

This study into extra care and its appropriateness for people with dementia was grounded in real world experiences, involving participation of individuals with diverse backgrounds. The breadth of experiences was integral to the critical realist approach adopted, and influenced the research approach, methodology and methods.

3.2.1 The research framework and methods

The research involved working with members of the extra care community to develop an understanding of what extra care is, what it means to individuals, and whether or to what extent it is appropriate for people with dementia. Members of an extra care community include tenants or residents and their family, professional care and support providers, scheme managers, commissioning and housing developers, architects and designers, construction companies and regulators, as set out in Figure 3-1.

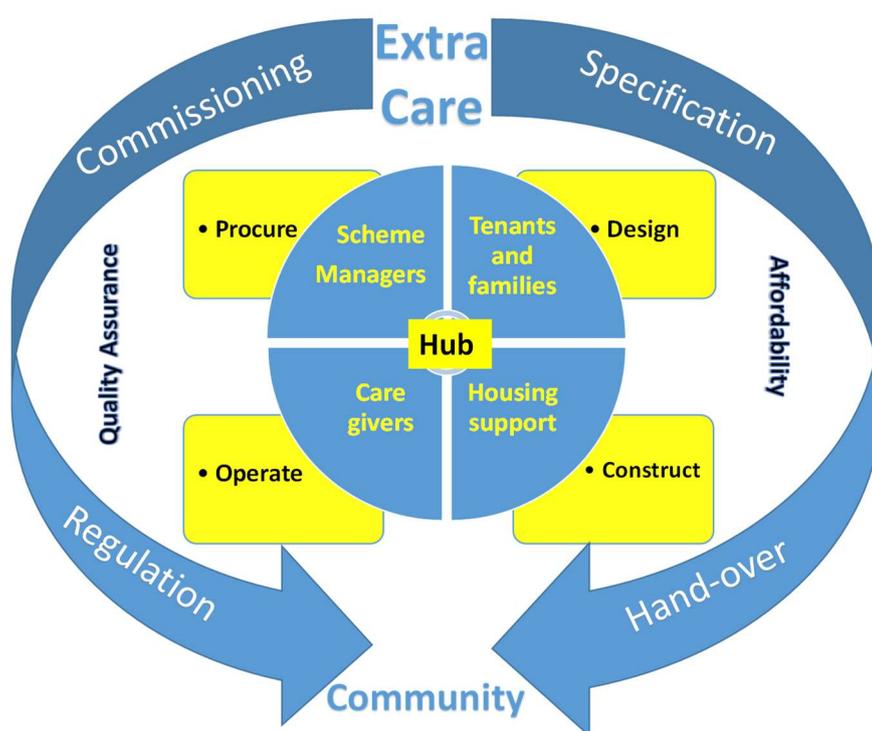


Figure 3-1: Members of an extra care community

From the point at which a scheme is commissioned through to handover for day-to-day operation it goes through stages of procurement, design and construction. It is important that those who are going to manage, live and work in the schemes can influence the way the scheme is developed and operated. Individual members of the extra care community are more, or less influential at different stages of extra care development and delivery. This research set out to include a full range of views of what worked well or not so well, and why.

Critical realism provided a framework for the researcher and participants to develop or 'ground' a theory about extra care. Theorising helped critique and suggest changes for the extra care community. The approach aimed to get beneath the surface of extra care and uncover assumptions that were not explicit or obvious to others, but which could help in understanding how extra care works.

A grounded theory approach was used with different research methods to investigate how individuals with dementia experience extra care and whether it is a suitable form of accommodation and care to support people to live well with dementia. With no pre-conceived hypothesis about a best model of extra care to support people with dementia, the approach was used with different groups of participants to highlight the similarities and differences in experiences, with frequent checks and comparisons of the emerging data (Glaser & Strauss, 1999; Creswell, 2009).

An overview of the grounded theory methodology used is set out in Figure 3-2 below. It was used to explore individuals' experiences, understanding, and interpretation of social practices and the processes involved in extra care delivery. The research first explored with a range of individuals involved in the extra care community, whether or how the current extra care model was appropriate for people with dementia, including what helped or hindered them living in an extra care environment. This inductive part of the grounded theory research included a pilot questionnaire (described in Section 3.2.2) as well as individual interviews, observations, environmental assessments and focus groups at two extra care sites to discover and test ideas and concepts about supporting people with dementia. The intention was to develop a model to share with those involved in the research and the wider extra care community.

In developing a model, further insights were sought about two key themes that had emerged; one of social worlds and the other of organisational excellence. A second literature search was undertaken around these two themes as part of the

grounded theory approach to better help explain the experiences of extra care being described by participants.

The nascent theoretical model was shared through interviews with a wider range of participants to help gain more insight into if and how extra care could benefit people with dementia, and whether best practice guidelines could be developed. Insights from the further literature review are set out in Chapters 7 and 8, leading to a new theoretical framework in Chapter 9.

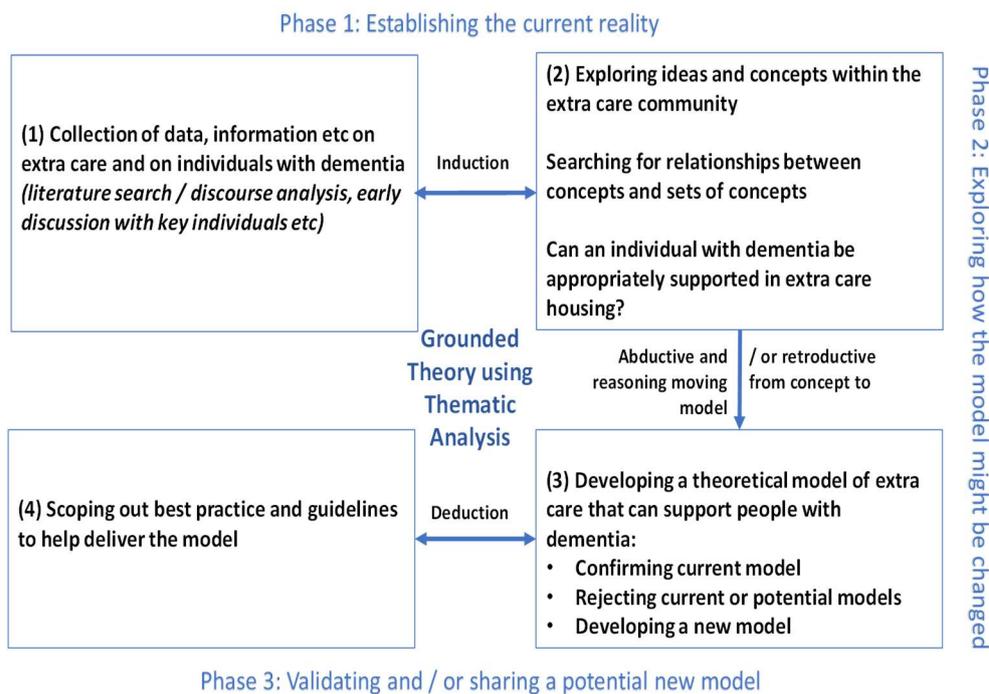


Figure 3-2: Overview of the extra care research methodology

The nature of the grounded theory approach used in this research is consistent with views expressed by Suddaby (2006) and Vincze (2010) about what grounded theory is and is not. Suddaby suggests that grounded theory involves interaction and organisation of data in a way that allows interpretation whilst not being too bound by long held assumptions. Vincze provides a more technical analysis when she discusses how:

Grounded theory emphasizes induction, deduction, and verification as integral parts of inquiry, and it accepts the duality between deductive (i.e., generalization from a priori conceptualizations) and inductive (i.e., inference of particular facts or observational evidence to general principles) reasoning logic. (Vincze, 2010, p. 431)

The framework for this study allowed a priori interpretations and assumptions to be challenged as part of the inquiry process to formulate, test, and reformulate emerging concepts with a view to establishing a theoretical base for the existing or a revised extra care model. It was essential to recognise that the research findings would not provide a definitive blueprint for extra care policy and practice, but findings could make resulting policies or guidelines more informed.

3.2.2 Developing the research process

The study sought to gain an understanding of extra care models before seeking rich and deep understanding of the experience of living and working in extra care through detailed case study work.

A questionnaire (see Appendix 4) and secondary data were used to develop a broad understanding of the current range of UK extra care provision. Findings from the questionnaire were used to confirm that two proposed case study extra care schemes were typical of the broader population of extra care housing schemes. For practical reasons, the case study schemes were based in the East Midlands, working with two different housing providers. The findings of the questionnaire also helped form a view that analytical generalisations relevant to the wider population could possibly be made from the two case studies. The decision on whether the findings could provide insights or generalisations was recognised as a possible limitation of the research, discussed further in Chapter 10.

The research then went on to develop a detailed understanding of models of extra care from a case study of two extra care schemes, which were compared and contrasted with other non-case study schemes. The research was structured around three phases, reflecting different parts of grounded theory:

PHASE 1: Establishing the current 'reality' (induction)

PHASE 2: Exploring whether generalisations from the case studies could lead to a revised model (abductive reasoning to deduction)

PHASE 3: Validating and sharing an agreed model or best practice (deduction).

3.2.3 Research questions and use of case studies to find out people's experience of extra care

The primary research focus was to consider how far it is possible to enable people with dementia to live in extra care. Mason's (2002) approach to designing qualitative research was used to establish three secondary lines of enquiry which were used during the induction phase of the research (the initial fieldwork with participants within the extra care community). They were developed to determine how extra care is perceived by individuals, what would be necessary to enable a person with dementia to live in extra care, and whether it is achievable:

- What is extra care, and what does it mean to those who live and work there?
- Is this model of extra care appropriate for a person with dementia?
- What modifications to the extra care model might make it more appropriate for individuals with dementia?

Each of the secondary lines of enquiry had a subset of more detailed questions to drill down into the research problem. It was anticipated that these could provide prompts for the interviewer, being used selectively as required. In the event, the detailed questions were not used as they were not in keeping with the grounded theory approach; the questions had potential to introduce preconceived ideas that could stifle the co-production of knowledge with participants.

A limited desk top / internet review of literature on case studies was undertaken to consider how best to elicit the views of those living and working in extra care. Yin (2009, p. 18) describes a case study as

...an empirical inquiry about a contemporary phenomenon (e.g., a "case"), set within its real-world context—especially when the boundaries between phenomenon and context are not clearly evident.

It is not easy to establish clear boundaries in extra care schemes. Each has an identified community or set of individuals and organisations who interact together. The way that professionals connect to the different schemes varies, as does the extent to which the extra care community moves beyond the immediate physical location of the scheme. Variable features of natural real-life situations such as this can make them suitable for case study approach (Aaltio & Heilmann, 2010).

Case studies, either single or multiple, should help understand a phenomenon. Concentrating on units of analysis (i.e. the case) can be more effective than characterising methods for collection and analysis of data (Willig, 2008, p. 74). This study focused on two extra care schemes as primary units of analysis to understand the lived experience which led to two theoretical propositions around the importance of social worlds and organisational excellence in extra care. It was a challenge to differentiate factors located within the case study from external factors that influence participants of the extra care community.

Interviews and focus groups were used to help participants to share their knowledge, experiences and views of extra care and its appropriateness for people with dementia. This was felt more appropriate and less intrusive than the researcher observing people's experiences direct. Helping residents with dementia to participate in discussions and share experiences was anticipated to be a challenge, described further in Section 3.3.5 on participant involvement, and Section 3.4 on ethical considerations. The researcher's own observations of non-verbal communication during discussions were used as an 'indirect' method for assessing rich data that might be available from people living with dementia (Aaltio & Heilmann, 2010). For example, one participant living with dementia used arm movements when he was speaking with other participants. The researcher inferred that the more active the arm movements were, the more strongly the participant felt about what was being said.

The experiences of individuals with dementia in extra care are affected by the behaviour of other individuals, and the interpretation and implementation of

organisational policies and procedures. The complex inter-relating issues affecting individuals and organisations influenced the choice of a case study methodology. Indeed, Aaltio & Heilmann (2010, p. 67) said that authors such as Clegg, Kemp and Legge have said that sometimes complexities of

...organizational behavior, including individual and group behavior in an organization, as well as understanding and explaining it in some work communities, is so complex a task that sometimes only case study can offer an adequate foundation.

Having made the decision to use a case study approach, the typical extra care characteristics identified through the pilot questionnaire were drawn into case study selection criterion. Six criterion were used:

Criterion 1: the schemes should ideally be public-sector commissioned or supported extra care housing schemes.

Criterion 2: preference would be given to schemes that had been built for purpose and were typically between 50 and 100 units in size.

Criterion 3: extra care was sought that had been developed and or delivered through a partnership with housing association landlord, local housing authority and local social services authority were sought.

Criterion 4: there should be on-site 24 hour, 7 days a week care and support.

Criterion 5: residents were sought who were over the age of 55, with and without dementia.

Criterion 6: the case study sites could provide an opportunity to involve associated stakeholders such as commissioners and architects.

The characteristics in criterion 1-5 are not untypical of other extra care schemes (Twyford, 2016). The similarity was important as it could make the findings or insights relevant or generalisable to other parts of the extra care industry. A case study was sought which met the criterion and which would minimise the travel burden for the researcher.

A cross-sectional case study using two extra care schemes was used to enable comparisons to be made on a limited number of pre-conceived dimensions and variables thought to be relevant. The dimensions included; a range of individuals with differing levels of dementia; use of person-centred approach and culture within the scheme; the designed environment; and use of organisational policies and procedures. Two variables were identified; an on-site residential care unit specialising in support for those with dementia (in only one of the two schemes); and regional (small) and national (large) registered housing providers.

3.2.4 Understanding the experiences and what they revealed

Writers such as Kitchen (2000), Fawcett (2004), Mackenzie and Knipe (2006), Burrell (2009), Gray (2014) and Leary (2014) have been helpful in contributing to the body of knowledge of paradigms, philosophical perspectives and approaches, and how these reflect on practice. In looking for an anchor for this research the work of Burrell and Morgan (2009) and Howick and Ackermann (2011) provided some clarity around paradigms and paradigmatic frameworks. Howick and Ackermann (2011, p. 504) assert that the philosophical dimensions of a paradigm provide the grounds (what Mingers and Brocklesby (1997) term as the 'why') for the types of activities that are undertaken. Burrell and Morgan provide a comprehensive history and analysis of social theories, using a framework to describe four paradigms each based on a genre of social theorists with similar assumptions about the nature of social science and the nature of society.

The four paradigms have two main variants; their degree of objectivity or subjectivity; and their sociological dependence on radical change or regulation. A relativistic or subjective ontological approach is concerned with the nature of phenomena and how they are seen to exist in the social world. This is consistent with the critical realist approach of this study, which explored whether factors prevailing in the immediate environment or the broader social culture of extra care constrained or limited a person with dementia living there. The study sought to establish whether any constraints imposed by organisational

structures can be removed, and as a result whether a person with dementia can be better supported to maintain their personhood and independence within an appropriate environment. Important here was the standing or status 'bestowed upon one human being by others in the context of particular social relationships and institutional arrangements'. (Kitwood, 1997, p. 7). This implied recognition, respect and trust across the different members of the extra care community.

Everyone's social reality is relative, affected by their knowledge and experiences, their social relationships and their interactions with others. The varied experiences of individuals shaping the reality of extra care practice can lead to multiple models of extra care being described. The behaviours and actions of individuals and organisations, which are affected by their view and reaction to social structures within extra care, are assumed to be meaningful, providing an understandable rationale for best practice.

The research sought to gain an agreed view of extra care by jointly exploring with a range of stakeholders the emerging model or models of practice and issues highlighted in the initial literature review. The literature was used to stimulate discussion rather than stifle participant contributions through the presentation of preconceived ideas. Participants' backgrounds (described further in Section 3.3) affected their power or agency to influence their lifestyle within the structure of the extra care schemes. In an examination of agency and structure Fleetwood (2005) concludes that critical realism's ontological approach provides a powerful analytical device. One of the intentions of this extra care research was to discover whether the ontological stances of those involved might help or hinder the development of a shared model of extra care and the development of best practice in supporting people with dementia.

Different types of reasoning were used within a grounded theory approach (see Figure 3-2) to understand the research problem at different phases of the study. The initial phase of the research (pilot questionnaire, focus groups and interviews) included a review of data, using abduction to make sense of the early findings and explore themes or generalisations from the research data gathered

thus far. Themes developed around whether or how extra care could support people with dementia, which were checked back with each set of participants to ensure that they were an accurate reflection of their experiences.

The next phase of the research involved focus groups and interviews to further work with the extra care community to develop an initial theoretical model from the themes discovered. It was during this process that two emerging theories of social worlds and organisational excellence were brought together, described in Chapters 4 and 5. They were explored further in interviews with senior managers in national extra care housing organisations not involved in the case studies. Only after the initial model was revised with participants and compared with the real-world experiences of others outside the case study was consideration given to whether the themes or model could be generalised to a wider extra care population.

The research took an organised approach to investigate extra care in a real world setting (Gray, 2014). It set out to identify the specific problem that needed clarifying, validate or build a theory, and provide results that would be of significance to the specific extra care organisations involved in the case study, and beyond. A systematic framework was used to consider and justify which methods and sources of data could provide the best material within the research, and what practical or ethical considerations would arise (Mason, 2002). Within the constraints of this research the intention was to use mixed qualitative methods. General advantages and disadvantages of mixed method research have been established (Mingers & Brocklesby, 1997; Jackson, 1999; Bryman, 2006; Tashakkori & Creswell, 2007; Howick & Ackermann, 2011; Gray, 2014) as well as specific advantages of using mixed method research for maximising the inclusion of people with dementia in the research (Nygard, 2006; Murphy, et al, 2015). It was anticipated the use of mixed methods in this research would increase the meaningfulness and validity of the concepts and theories being developed.

Ways to gather the views of people with dementia and their family carers, and to support them to participate in research have been described including; focus groups (Bamford & Bruce, 2000), interviews (Acton, et al., 1999), observation (Briggs, et al., 2003) and diaries (Välimäki, et al., 2007). As part of the planning process the South Yorkshire Dementia Research Advisory Group were consulted on appropriate methods for maximising the inclusion of people with dementia (2 June 2016; 9 March 2017), and as a result a mix of 1:1 interviews, focus groups and observation were used with secondary data analysis as appropriate (McKeown, 2016). Specific methods were discussed with research participants at the beginning phase of the case study field work through open meetings with residents, staff and managers at each extra care scheme. It was agreed that the first and second phases of research would be undertaken using: focus groups, individual interviews, observation at allocation panel meetings; and environmental assessments. The mix of methods were chosen to deal with the complexity of understanding the extra care experience from different perspectives. The focus groups and individual interviews were complemented by allocation panel observations and the environmental assessments. Literature was used iteratively throughout the data analysis and theory development stages of the research to support and extend the emerging theoretical model of extra care housing for people with dementia.

As the last phase of the research evolved it was important to include extra care organisations from outside the immediate case study to see how generalisable the findings might be. Interviews with senior manager members of the extra care community were considered the most appropriate method, affording an opportunity to maximise the limited time available from individual managers.

An assessment of practical issues that could arise during the research was undertaken using CoRTE principles (Murphy et al, 2015). CoRTE principles aim to maximise the inclusion of participants by gaining **C**onsent, maximizing **R**esponses, **T**elling the story, and **E**nding on a high (CoRTE). Required changes were managed and contingencies put in place as part of the ongoing research

management process. Appendix 6 sets out a comparison of anticipated issues and those that arose. The main issues were around building trust and rapport and having meetings at times that suited participants. Time arose as an issue for the on-site managers resulting in a change to the format of the focus groups. One participant objected to the focus group being recorded, discussed in more detail in Section 3.8.3. Issues or risks were discussed within the supervisory process as part of the governance arrangements for the research project. Ethics and practical issues were key elements in justifying the research methods chosen and the methodological approach used and are considered in Section 3.4.

3.2.5 Summary of influences on the research approach

This section has considered philosophical assumptions about the constitution of knowledge and human and organisation behaviour. It has described how a critical realist stance recognises the different experiences and realities of all the players involved in delivering and living in extra care, whilst also considering varying issues of power and relationships between organisations, groups and individuals. A grounded theory approach was adopted to reflect with extra care community members on their experiences, and to develop theories that help understand and explain those experiences. The grounded theory approach was used to help the group consider limitations of the extra care model, and whether any changes could improve the experiences of people with dementia. The choice of focus groups, interview and other qualitative methods was described as part of the mixed methods used. Constraints of the research were recognised and practical issues arising from them were described. The conceptual framework and choice of methods for the research, set out in this chapter are summarised in Figure 3-3 below.

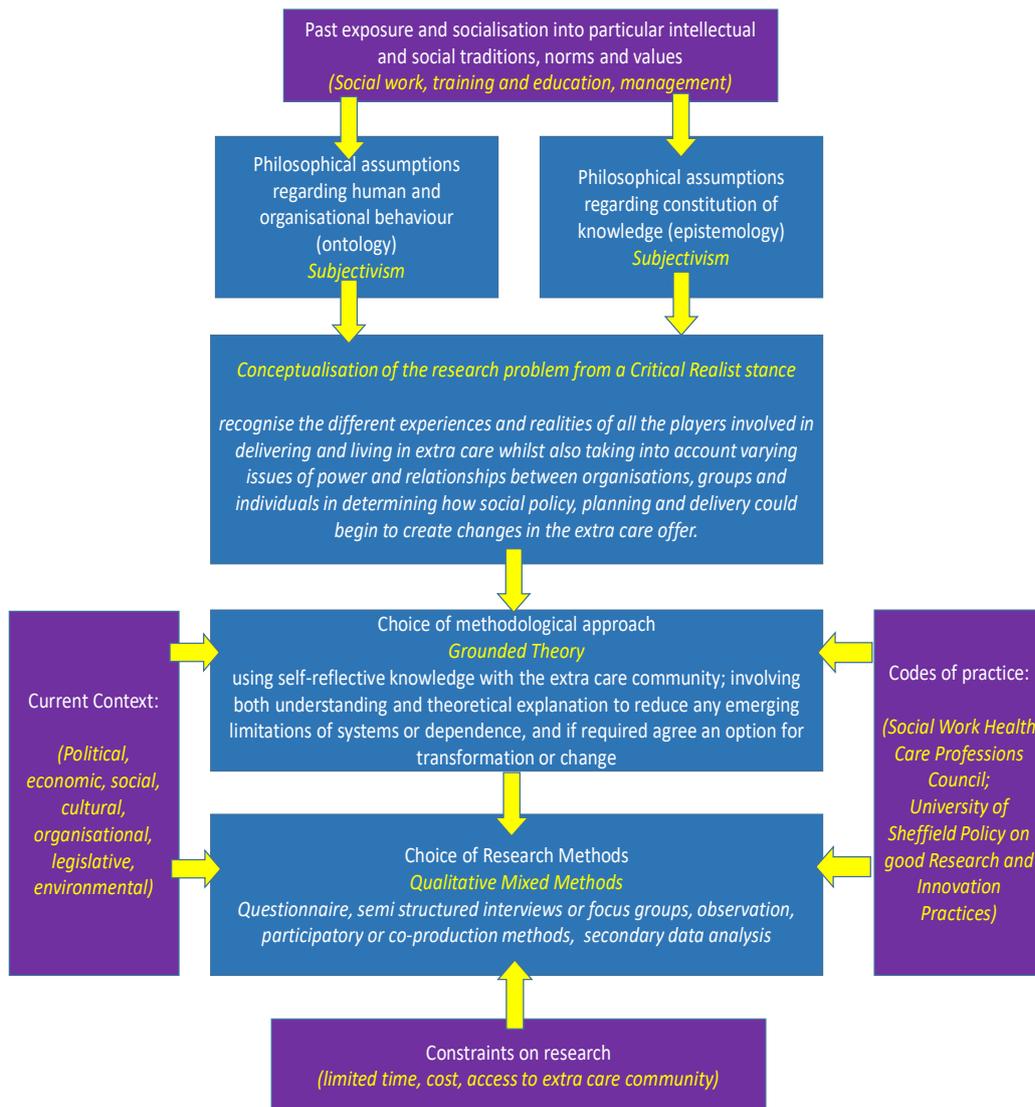


Figure 3-3: Influences on the research approach

3.3 RESEARCH SITES AND PARTICIPANT INVOLVEMENT

Two organisations with extra care housing schemes in the East Midlands gave approval for the research to be undertaken in one of their schemes, subject to voluntary participation of those living and working at the scheme. Appendix 7 describes the characteristics of both case study schemes. Both case study sites were situated in district / boroughs with a population of over 100,000 and between 5-6% of the population aged 65 and over and living alone. The number of people living with dementia in each locality was not atypical of the national profile (1,350 people in one town and 1,500 in the other).

The case study schemes were not reliant on public subsidy for their ongoing operational viability. They were developed to be 'affordable', with local authority support to manage the allocation panel for the apartments. Both had separate housing and domiciliary care providers. The schemes had rented and lease ownership apartments and were similar in size to many extra care schemes with between 55 and 65 apartments. The pilot questionnaire (see Section 3.8.1) confirmed that the proposed extra care housing schemes for the case study were not atypical of the national picture.

Four participant groups were invited to take part; residents and family carers; allocation panel and scheme managers; housing support and care staff; and commissioners and developers of the schemes. Potential participants were invited to take part in focus groups, additional activities, or interviews as appropriate to their role. Separate focus groups were run with residents, managers and staff to explore the reality of living and working in extra care schemes.

Additional research activities to enable residents to best share the lived experience were agreed jointly at the beginning of the case study. It was intended that these could include a range of activities as discussed with the South Yorkshire Research Advisory Group (McKeown, 2016). When residents at the two participating schemes were asked to suggest activities, none were forthcoming. One resident took part in an environmental assessment of their apartment.

Interviews took place with senior managers, commissioners, and other specialist professionals were used to explore the emerging findings from the first phase of focus groups and other activities at the case study schemes. Interviews were also undertaken with key professionals working outside the case studies to establish whether the findings and model were generalisable to other extra care schemes.

There was some limited change to the membership of the focus groups because participants had either changed staff role or joined the case study schemes since the start of the research. This proved useful in validating and adding to the findings from the first phase of focus groups.

3.3.1 Resident participants

All people living within the extra care were eligible to volunteer to take part in the study. Family members and friends were also eligible as they may have had different perspectives to bring. Consideration was given to achieving a representative balance of the extra care population in terms of age, gender, ethnicity, disability, level of need, and type of tenancy agreement. The resident participant group was intended to include residents without dementia as well as residents with early stages of dementia who retained mental capacity to take part in the research

It was agreed that participants would be excluded from the research if they did not have mental capacity to consent to take part (see Section 3.4). No-one was excluded on this criterion. Participants who were deemed to be emotionally vulnerable, physically frail, experiencing significant distress or experiencing difficult family circumstances that would make participation inadvisable would also have been excluded. Two people identified themselves as having recently cared for someone with dementia who had died. They were supportive of the research, but said they were not emotionally strong enough to take part at that time, thereby self-deselecting.

Eleven residents were recruited to take part in the research, including seven single people and two couples. Of the two couples, one included a partner living with dementia, and the other included a partner who had previously supported someone living with dementia. Two people with dementia volunteered to take part. One did not have a specified dementia, and the other was living with vascular dementia. Of the 11 participants, seven lived at case study 1 and four lived at case study 2 extra care schemes. The participants varied in age from 59 to 93 years, with an average age of 78 – see Table 3-1.

Age	Number of residents
55-64	2
65-74	2
75-84	2
85+	5

Table 3-1: Age of participating residents

Five male and six female residents took part in the research study. All classed themselves as British White. All resident participants said that English was their main language, and none reported communication difficulties that would prevent them taking part in the research group and individual interviews. The resident participants had varied experience of living with dementia, see Table 3-2. The researcher did not ask to see a medical diagnosis of the dementia; of the two participants, one had self-diagnosed and other was reported by their carer to be living with dementia. Four people were carers or supporting someone living with dementia. Three people had previously supported an individual living with dementia. Two people reported no immediate involvement with individuals living with dementia.

Experience of living with dementia	Number of residents
No direct involvement	2
Resident was living with dementia	2
Resident was caring for someone with dementia	4
Resident had previously cared for someone with dementia	3
Total	11

Table 3-2: Resident participant experience of living with dementia

Resident participants all had mental capacity and were able to consent to take part in the research. One resident had moderate, and consent to take part was initially judged by the family / staff on site, but then confirmed by the researcher with the individual themselves. The researcher is trained to do mental capacity assessments in line with the ethics approval given by the National Research Ethics Committee.

3.3.2 Allocation and management participants

The allocation and management participant group included 15 people; nine people in case study site 1 and six at case study site 2. Their individual roles are set out in Table 3-3 below.

	Case study 1	Case study 2
Housing manager	1	1
Domiciliary Service Manager	2	1
Direct Care Service Manager	1	1
Adult Care Fieldwork Service Manager	2	1
Social Worker	2	2
Housing authority manager	1	0
Total number of allocation manager participants	9	6

Table 3-3: Number of allocation panel and scheme manager participants by job role

The individuals were employed in five primary organisations or departments. The housing managers were employed by the two housing associations, one at each extra care scheme. The housing authority manager is employed by the local borough council, the domiciliary and direct care service managers are employed by the local authority domiciliary agency, and the field work service managers and social workers are employed by the local authority social services. Of the 15 participants four were male and 11 were female. This lack of male participants reflects that for some roles there were no males in those positions within the schemes rather than any bias in recruitment to the research programme.

3.3.3 Staff group participants

Fourteen staff members participated in the study, six at case study scheme 1 and eight at case study scheme 2. Two of the 14 staff members were male as shown in Table 3-4.

Case Study Site	Number of male participants	Number of female participants
Scheme 1	1	5
Scheme 2	1	7

Table 3-4: Number and gender of staff group participants by scheme

3.3.4 Individual interviewees

Ten individuals were interviewed in the first and second phases of the research study to obtain perspectives that were from those connected to the extra care schemes, but not directly working or living in them. They included a senior manager from each housing association; a safeguarding service manager within the County; four senior managers within the Local Authority covering domiciliary, commissioning and contracting divisions; and three managers from a comparative extra care scheme in the County including an independent sector care provider.

It had been anticipated that architects and construction company representatives would be interviewed during phase 1 of the study. Issues raised by focus group participants in phase 1 of the grounded theory were not pertinent to architects and construction company representatives. It was decided not to interview architects and construction company representatives unless new and relevant data emerged during the phase 2 focus groups, which did not happen.

Senior managers from regional and national housing associations were interviewed in the second phase. A manageable target population for these individual interviews was based on specific inclusion and exclusion criterion (Luborsky & Rubinstein, 1995; Gill, et al., 2010) set out in Appendix 8. The use of inclusion and exclusion criterion had potential to cause some homogeneity across the group of interviewees. Five types of homogeneity were considered, including demographic, physical, geographic, psychological, and life history (Robinson, 2014). The small size of the target population for individual specialist interviews, together with the voluntary nature of participation, meant that there

was limited action that could be taken to avoid homogeneity. An attempt to avoid demographic or physical homogeneity was made through the last inclusion criteria that potential interviewees would not be excluded because of their race, ethnicity, gender, age, religion or disability, and that if possible there would be positive selection to ensure that both males and females were represented. The researcher sought to avoid geographical homogeneity so that if appropriate the findings could be generalisable outside the case study county. Psychological or life history homogeneity was not sought because it would not be in keeping with the diversity of perspectives valued in the approach of this extra care research. The research proposal set out that there would be up to six individual interviews. Four interviews were secured from the potential population by targeting specific organisations who met the first inclusion criteria (national, regional and not for profit), and by addressing the research request to senior managers / directors.

The researcher outlined the purpose of the research and the lines of enquiry for the interviews in the request. The intention was to enable the senior manager or director to consider who was the most appropriate person in the organisation to take part.

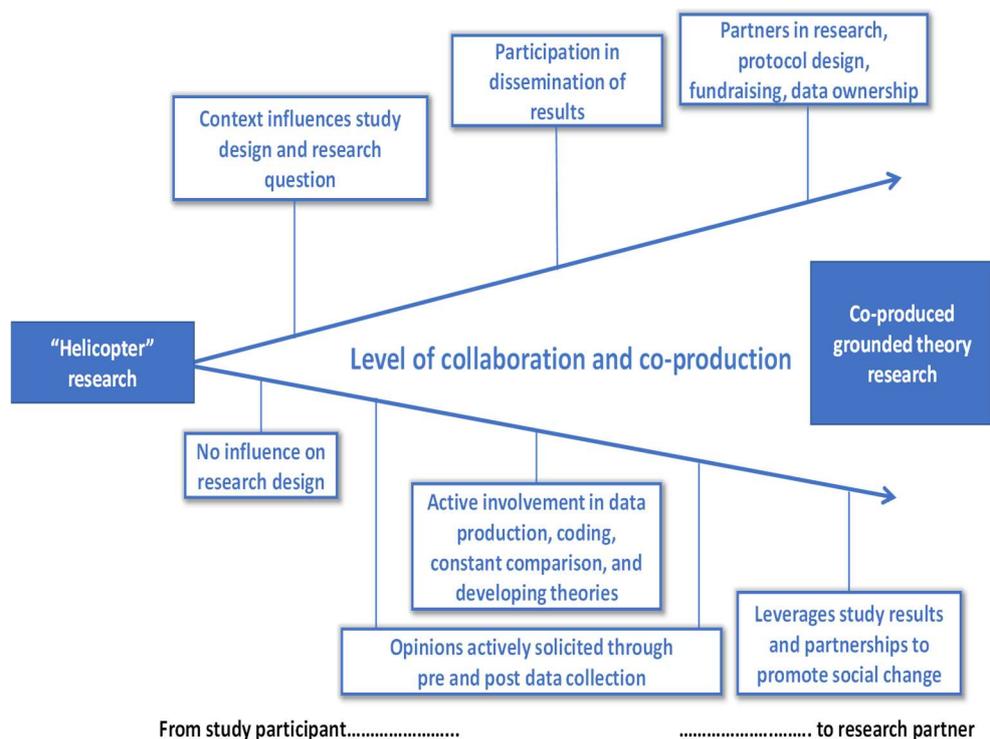
An opportunity was sought to share the findings with the Local Authority's health and social care joint commissioning group. It included seven local authority commissioners and commissioners from half of the Clinical Commissioning Groups. The purpose was to share the findings and theories emerging from the research, and to promote discussion of them to consider how valuable the insights were and how generalisable they might be.

3.3.5 Participant involvement and collaboration

Involvement and collaboration can mean different things to different people. A premise of the grounded theory used in this extra care research was that shared production of knowledge between the researcher and the 'subject' or participants was essential. Members of the extra care community not only have the right to engage in the research, but also have much to contribute to its rigor,

relevance, and reach (Balazs & Morello-Frosch, 2013). The community based participatory research model presented by Balazs and Morello-Frosch was useful in exploring how far this extra care grounded theory research involved members of the extra care community. The potential degree of involvement in the research is depicted in Figure 3-4, where levels of engagement increase as extra care community members are transformed from study participants to research partners.

More traditional housing and social care research typically collects community information or data from housing community members with researchers taking a 'helicopter' view of the situation. This more passive participation is illustrated on the left side of Figure 3-4. Involvement and collaboration increases towards the right of the figure. Community members become more active research partners, and a more detailed experiential view of the situation is sought. As the relationship between researcher and participants moves towards the right co-learning between community members and researchers increases, with more opportunities to inform community developments and to link research to policy action (Balazs & Morello-Frosch, 2013, p. 10).



Adapted from Balazs and Morrello-Frosch (2013) p 10

Figure 3-4: Grounded theory research as a continuum of efforts with varying degrees of involvement and collaboration in the extra care research

It was outside the scope of this research for participants to be full research partners, which would have required involvement in the research protocol design, fundraising and data ownership. These matters were set and agreed by University and National Social Care Research Ethics Committees before participant recruitment started. The researcher sought active participant involvement in designing research activities, data production, and theory development. A high degree of participant involvement in the extra care research was sought by using a plan, act, check, review (PACR) model originating from Kolb’s work on experiential learning (Kolb, 1984), itself developed from others such as Rogers, Jung and Piaget. Participant involvement in this extra care research is illustrated in Figure 3-5.

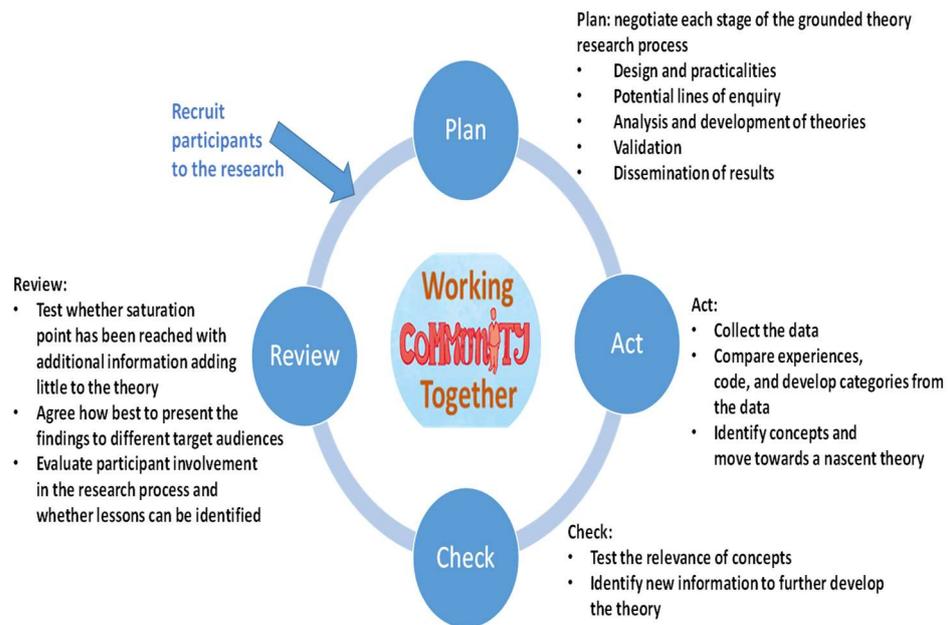


Figure 3-5: Plan Act Check Review model of participant involvement in extra care grounded theory research.
(Adapted from Kolb, 1984)

Using those four headings, the extent of participant involvement in this extra care research was reviewed by the researcher using a measurement scale drawn from the schematic of grounded theory research set out Figure 3-4. The scale depicts the degree of participant involvement and collaboration from 1 – 4:

Level 1: No influence

Level 2: Opinions actively sought by the researcher

Level 3: Active involvement and participation

Level 4: Full partners and use research finding for own purposes

The researcher’s review of co-production within the research process is set out in Appendix 9. The research started with good intentions to fully involve and collaborate with participants during the research, but the practical realities of the research programme limited their realisation. Most of the involvement was achieved by the researcher pro-actively seeking participants’ opinions on each stage of the research programme (level 2 involvement and collaboration) rather than enabling participants to be actively involved in all stages (level 3).

Levels of engagement varied at key stages of the grounded theory research process. The researcher worked closely with resident, staff and scheme managers to shape the research activities, generate data, identify the extra care model and provide initial validation of the application of social worlds and organisational excellence theories. The researcher then used secondary data from ongoing literature searches to develop the concept of social worlds and identify managerial tools that support quality and operational excellence. Commissioners and senior managers were involved in confirming and validating the extra care model, and especially the application of social worlds and organisational excellence theories to the extra care setting. It was a challenge to ensure the approach balanced the views and needs of resident and front-line staff with those in managerial positions. Maintaining a balance was essential to ensure the voice of the resident was at the forefront when writing about findings with managerial implications set across the two disciplines of sociology and management.

There is little available in the body of literature on how full participation and collaboration can effectively be achieved within grounded theory research. Future research could usefully contribute to this area of knowledge.

3.4 ETHICAL ISSUES AND THEIR GOVERNANCE

Birch and Miller (2002) found that the experiences of encouraging participation in their own research did not live up to the ideal of 'participation' presented in ethical codes of behaviour and their own hopes of encouraging the research respondent to feel part of the process, and that subsequently ethics was something that needed to be negotiated throughout the research process.

Ethical issues relevant to three main participant groups were identified during the planning stage for the extra care study. For the group of individuals with dementia and or their carer the issues included ensuring there was diverse representation and that any fluctuating mental capacity and involvement could be managed through appropriate communications and actions by the

researcher. In determining who should take part the possible vulnerability and sensitivity of people who may be grieving should be considered, as should the potential to make payments for informal or formal carers to attend to support individual participants. It would be important to ensure that residents and family could feel comfortable discussing personal support matters with carers present.

There were different ethical issues to consider for organisational representatives, including whether individuals were expressing their own or their organisation's view, and how any power dynamics of the different agencies would be managed. Ethical and confidential access to organisational information and commercial sensitivities would be important, and there could be potential for a biased outcome if payment is made for architects or developers to contribute to the research.

There were also ethical issues pertinent to the researcher, including their ability to reflect on their own role and the impact of themselves on the research process. The potential for the researcher to influence or constrain the outcome based on previous knowledge and experience should be recognised and countered if possible.

The issues outlined above, together with the practical issues arising from the research methods outlined in Section 3.2.1, are illustrative of matters that had to be addressed to ensure the research was of a high quality, safe and ethical. Ethical and practical issues in research design and fieldwork are governed by membership of the social work profession through the Health Care Professions Council, by the British Society of Gerontology, the British Sociological Association, and by Sheffield University's policy on good research and innovation practices.

Ethical issues surrounding personhood, dementia and maximising the inclusion of people with dementia in research underpinned this study (see Appendix 11). In her recommendations for future extra care research, Dutton (2009)

emphasised the need to make paramount the input and active involvement of people with dementia at all stages of the research. This extra care research was committed to involving people with dementia, appropriately, throughout the different phases of the research. The study sought to negotiate participation of individuals with dementia as part of the planning process and needed to be sensitive to the possibility that the level or type of participation may shift during the research period.

Full ethical approval was given by the National Social Care Research Ethics Committee (NRES, 2016). The main issues considered by the NRES were the design of the project and the extent of participant involvement; eligibility to take part in the research; recruitment of participants; consent of participants to be involved in the research; potential risks, burdens and benefits to participants (see Appendix 110); and confidentiality and privacy.

Ethics considerations were kept under review throughout the research programme, with an annual report to the National Social Care Research Ethics Committee. The final element of the project was to feedback the findings to participants. Two feedback meetings were held, one to each scheme with all participants and other people who lived at the schemes invited. It was important for the lead researcher to acknowledge the power differential between herself and the resident participants. As stated earlier, from the outset it had been made explicit that the research did not have the remit to directly change practice in the two schemes, yet before the feedback meeting there was still obvious concern from some participants who were living with dementia that the outcome of the research might influence their being able to remain at the scheme. The relational power dynamics between participants and researcher and the responsibility of the researcher to ensure the wellbeing of participants throughout the research process was not underestimated.

The meetings provided an opportunity for participants from different groups to share their views with each other. The opportunity appeared to be a very liberating experience for some of the residents who, in a safe environment, were

able to discuss some of their on-going concerns directly with those in a position to respond to them.

3.5 DEVELOPING THE DATA

The mixed qualitative methods used in the research provided a rich source of data. This section sets out the aim, approach and processes that were adopted to develop the data, to identify results significant to members of the extra care community who participated in the research, and to assess their potential significance for those working elsewhere in the field of extra care.

The aim of analysing qualitative data is to identify patterns, concepts and themes to help understand the findings (Patton, 2015). It usually involves a range of processes and procedures to make sense of the data collected (Mayring, 2000). Data analysis helped explain and understand the appropriateness of extra care for people living with dementia, moving beyond the literal, to interpret the symbolism and meaning of the data. It also considered the effect the researcher had on the interviews, focus groups and observation (Mason, 2002; Johnson & Duberley, 2003; Gray, 2014).

Data analysis was not a one-off event within grounded theory, but a cyclical activity across different phases within the extra care research process. The general approach taken was to begin with preliminary analysis of the data, moving towards detailed analysis as more information emerged. Variable/codes and themes were identified in working through the data, including the field work summaries, research notes and highlight reports which were used as aides to capture issues for later review. Attempts were made to reconcile different participant experiences and understandings of the data and to consider the insights provided by exceptions as well as emerging themes. Literature that may offer further insights on issues raised by participants was explored to provide further data for analysis. Steps were taken to address any identified researcher bias by using an interactive or cyclical approach to understand and review the

emerging data and early findings within the extra care community and research context.

Data were collected and analysed over the three phases of the research. The high-level data collection and analysis process used is illustrated in Figure 3-6, which shows how data are described, organised, classified and sorted, and then connections made to identify relevant issues, themes and patterns.

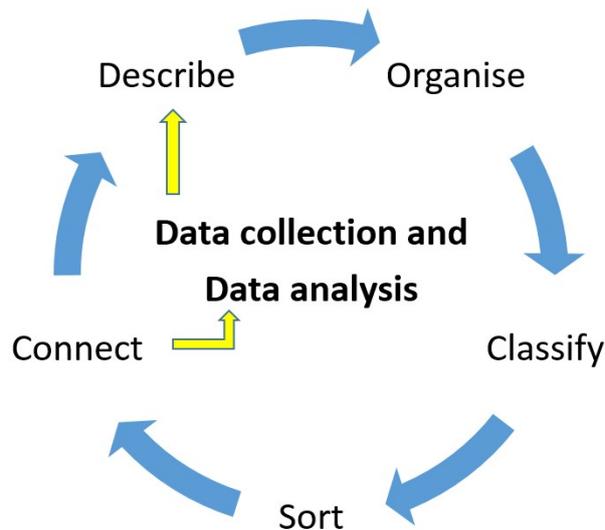


Figure 3-6: High level data collection and data analysis process

The phased nature of the research required sufficient time for data analysis at each stage so that the analysis could inform the direction of subsequent research questioning. It was anticipated that practical issues would arise when collecting the data. In gaining ethics approval (NRES, 2016) assurance was given that data collection and storage would be secure, would protect both the data and the data contributors, and would adhere to legislative requirements. The ethics submission set out that data analysis would be written in plain language, accessible to the range of contributing stakeholders, and that issues of anonymity and confidentiality would be agreed with contributors. The ethics submission also confirmed that the extent to which data was shared would be agreed in advance with participants involved, and contributors would be advised of plans for data retention and disposal.

Whilst attempting to anticipate methods of data collection and processing it was essential to avoid pre-judging what the findings might be. Data analysis was quality assured both during data collection and handling, and before finalising the doctoral thesis. Quality assurance during data collection and handling involved triangulating data from the researcher with data from the Local Authority Stakeholder Engagement and Consultation team, and with data from additional comparisons of the emerging themes with relevant literature as part of the development of the grounded theory. A spreadsheet was used to capture, manage and compare data from the different data sources. Quality assurance before finalising the thesis involved checking the findings were credible and reliable, being aware of any limitations to transferability of findings, and being clear about the level of generalisation possible from the findings within the case studies to the wider extra care communities. Further discussion on understanding the data and findings is set out in Section 3.8.5.

3.6 REFLEXIVITY BETWEEN THE RESEARCHER AND PARTICIPANTS

The relationship between researcher and participant is a fluid one; it changes and is negotiated. The nature of the relationship is especially important where the researcher is seeking to co-produce the research with participants. Cunliffe and Karunayaka (2013, p. 365) say they:

build on feminist psychologist Michelle Fine's (1994b) conceptualization of "working the hyphen" and the fieldwork experience of Geetha to offer the notion of hyphen-spaces as a way of emphasizing not the boundaries, but the spaces of possibility, between researchers and respondents.

They provide a useful schematic Figure 3-7 of four hyphen-spaces (insiderness – outsiderness; sameness – difference; engagement – distance; and political activism – active neutrality). The schema is used to illustrate the fluidity of the researcher's position, the potential multiple researcher-participant identities that can arise, and the implications they may have for research. In earlier work Coffrey (1999) suggested that hyphen-spaces can be "personal and emotional, constraining, and yet an opportunity for reproducing and implicating ourselves, our relationships, and our personal identities" (Coffey, 1999, p. 1). Cunliffe and

Karunanayake go further, to suggest that how we work in these hyphen-spaces impacts both on research design and methodology, and on the multiple identities researchers may find themselves experiencing and developing with research participants.

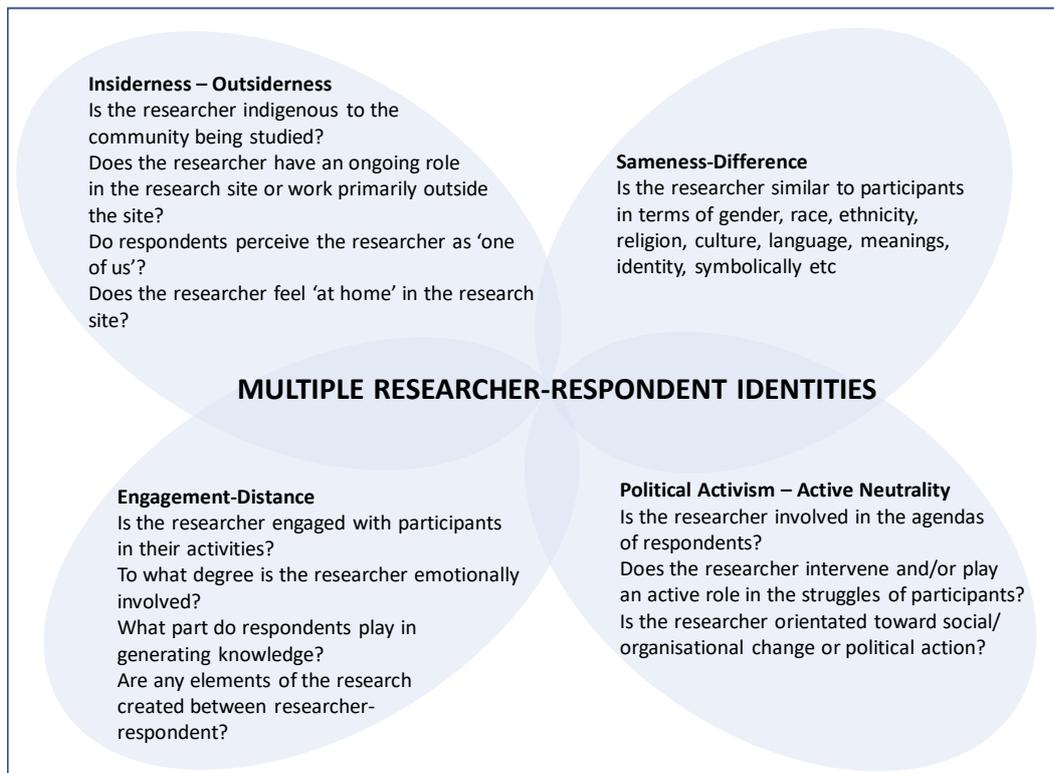


Figure 3-7: Mapping four hyphen Spaces
 (Source: adapted from Cunliffe & Karunanayake, 2013, p. 372)

The researcher’s position within the four hyphen-spaces was reviewed in readiness for the field work phase of this extra care research, set out in Figure 3-8 below. The researcher was not an impartial outsider; but seen variously by different participants. For example, the researcher believed those people she had previously worked with closely when employed by the Local Authority saw the research as non-threatening. Those who had been aware of the researcher in a previous work role (without knowing her individually) were perceived by the researcher to have a healthy scepticism for her impartiality from the Local Authority. Those participants who had not previously known the researcher were thought to have open views depending on their own standpoint and view of the research. This latter group were mainly front-line staff and residents.

<p>Insider – outsidersness</p> <p>An external outsider to most participants, being both outside the organisations involved in the scheme and outside their normal realm of activity. Previously an indigenous insider to some commissioners and managers with whom the researcher had previously worked.</p>	<p>Sameness – difference</p> <p>Similar to participants re race, ethnicity, culture, language; gender is not an issue; religion has not been considered; the symbolism of meanings or identity have not been considered; different in age to some (residents) but similar to staff, managers, commissioners and developers (mainly late-working age).</p>
<p>Engagement – distance</p> <p>Partially engaged - through previous involvement in procurement of the extra care; disengaged as now removed from direct employment and in an independent researcher role; engaged because of emotional psychological attachment through father with dementia.</p>	<p>Political activism – active neutrality</p> <p>Neutral in terms of not playing an active role in the agendas and struggles of participants but aspiring to make a difference through development of a social agenda for change within the design, commissioning, development and operation of extra care schemes.</p>

Figure 3-8: Extra care researcher positioning using Cunliffe and Karunanayake's four hyphen-spaces

The researcher's positioning brought some privilege, or advantage, in terms of relationships with participants. It also brought some challenges. For example, in a resident focus group (8 March 2017) one of the resident participants was sceptical about how the results of the initial work would be portrayed and asked who was funding the research. Without bias the researcher was able to reassure him that it was independently funded and that the research would be impartial and not influenced by any funding conditions.

3.7 DISCUSSION OF THE METHODOLOGY

Background

The researcher's stated intention was to use a critical realist approach for the research. Oliver (2012, p. 2) describes how critical realism:

...marries the positivist's search for evidence of a reality external to human consciousness with the insistence that all meaning to be made of that reality is socially constructed. It accepts that the social constructions themselves can constitute what we know as the reality of our social worlds.

The research assumption was that there was an objective reality existing independently of participant's thoughts, but that the description of that reality is mediated through filters such as meaning-making and social context (Oliver, 2012). Because participants each had their own filters there would be differently perceived realities of extra care to be explored. How individuals experienced the 'reality' of this extra care research project reflected their own backgrounds, the context within which they lived and worked, and what sense they made of it. Research assumptions were drawn from knowledge of participant's experiences and the narratives they told. Figure 3-9 sets out a relationship map indicating how the researcher assumed she and the research were positioned by participant groups with different lived experiences.

The researcher's motivation for undertaking the research was important. The initial drive to start the research was because individuals with dementia were living in extra care more or less successfully. Using a critical realist lens gave an impetus to answer ontological questions such as 'who lives and works in extra care, why do they live there, and how is extra care experienced by people living with and without dementia?'. Concepts were identified from the initial literature search to help understand research data collected, and to help focus on the social practices and processes in extra care. Although these concepts could help research understanding, there was concern that the researcher should not impose her own notions of what those social practices and processes should be. The research did not seek to judge the experiences of those living and working in extra care against preconceived notions or ideas. Instead the ideas were used to stimulate discussion with those living and working in extra care, and to follow those discussions wherever they led.

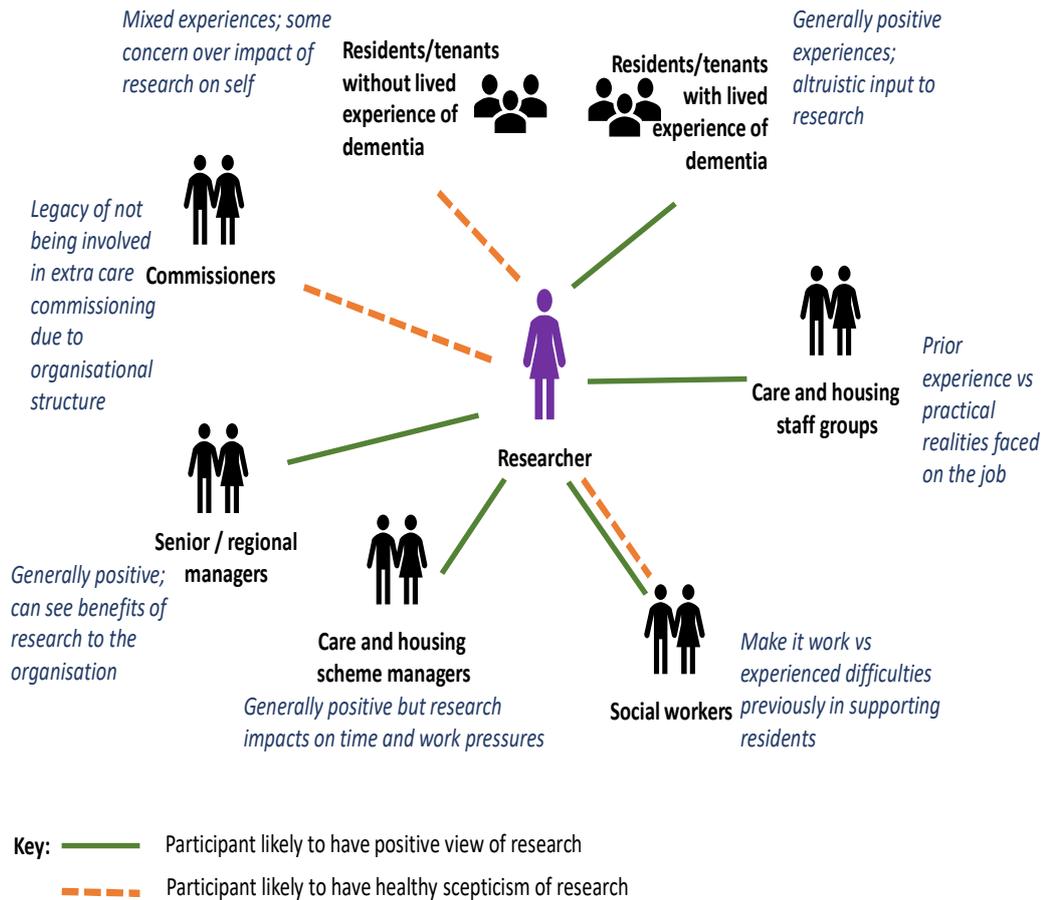


Figure 3-9: Researcher assumptions of positioning by participant groups

Moving from preconceptions and developing a grounded theory approach

Concepts that originally appeared important included supporting individuals through person-centred care, the design of the environment, and policies for operating the schemes. These were used as prompts when asking those living and working in extra care what important issues needed to be understood and explored further to better comprehend the social practices and processes in place. Where the concepts were helpful they were used as a starting point to connect the world being experienced by those living and working in extra care to a world that could be understood by others.

As the researcher embraced the study and gained distance from previous work roles, it was easier to become a more critical researcher. The focus shifted to explore the experiences of those living and working in extra care by using three lines of enquiry:

- What is extra care, what were the first expectations of those who live and work in extra care when they first arrived?
- Is the extra care in this scheme appropriate for a person with dementia, and why?
- What changes might make it easier to support individuals with dementia to live well?

Whilst hoping for a research outcome that would improve the experience of individuals living with dementia in extra care, it was also important to explore whether individuals could avoid being 'set up to fail'. That included investigating whether individuals were being inappropriately placed in extra care schemes which could not meet their needs.

The research focus had shifted from exploring how to improve the experience of extra care for individuals with dementia to asking whether extra care was appropriate for individuals living with dementia. And if so, what were the practicalities and possibilities. This nuanced shift in the research question led to a review of the research proposal, including the proposed methodology using critical realism and grounded theory. The proposal set out that:

A critical theoretical approach provides a framework for the researcher and participants to develop or 'ground' a theory about extra care. Theorising will help critique and, if required, propose change for extra care society. The approach will aim to delve beneath the surface of extra care and uncover any assumptions that may not be explicit or obvious to others, but which may help in understanding how extra care works. (Methods Chapter Assignment and Confirmation Proposal section 5).

The extra care research put ontological questions such as 'how do people who are living with and without dementia experience extra care, what are the practices that are at play in the extra care organisation, how do managers and staff support them, how do residents respond to them?' before epistemological questions about whether the researcher's knowledge of extra care and people living in them represented the reality. Without bringing in any a priori theories the aim was to discover which concepts, when translated into processes and practice, affect people living with dementia in extra care, and whether there are

any inter-relationships between those concepts that make the experience more, or less positive for individuals. Ultimately the aim was to identify how the experience could be made as positive as possible, or to identify when the experience might be sufficiently negative to suggest extra care is not an appropriate setting for an individual living with dementia.

Adapting the grounded theory approach to make sure participant voices were heard

When reviewing the use of critical realist grounded theory, it was helpful to reconsider what was meant by theory. Within sociology, Glaser and Strauss (1999) say that theory is a strategy for handling data that allows researchers to describe, understand or explain the social world. Although the researcher had some preconceived notions about living with dementia in extra care it was not clear at the outset of this extra care research what practices or processes might be causing different experiences of living and working in the extra care schemes. This suggested that an adaptable approach to the research be adopted in line with Creswell's (2013) review of qualitative inquiry and research design. Oliver (2012) suggests that critical realism and grounded theory are highly compatible because they both move from observation to theory, both recognise that the interpretations could be wrong and may need to be adjusted, and both recognise that practice and theory are interconnected.

The requirements or core aspects of critical realism were assessed to see whether they could be met by a grounded theory approach. Appendix 12 matches grounded theory to the core aspects of critical realism with reference to works by Glaser & Strauss (1967), Oliver (2012), Fleetwood (2013), and Gibson & Hartman (2014). The assessment took account that the methodology should be capable of operating across epistemological paradigms, it lends a voice to the relatively powerless, it helps uncover causal mechanisms, it recognises knowledge as tentative and fallible, that it has emergent relations and processes, and that explanations are sought to explain or link events and experiences to their underlying generative mechanisms.

This assessment supports the claims of others such as Oliver (2012) and Edwards et al (2014), that critical realism and grounded theory approaches are compatible. In this extra care research, a critical realist grounded theory approach was adopted to explore the lived experience of residents, staff and managers to help understand and explain how individuals with dementia are supported to live in extra care. The critical realist grounded theory was important in identifying any causal powers shaping how well (or not) individuals with dementia live, and helping explain how the nature of any causal powers impacted on social processes and practices in extra care, which in turn shaped the experience of individuals with dementia living in extra care.

Using grounded theory in the research, as set out in Figure 3-2 allowed initial progress to be made in understanding people's experiences before focussing on specific types of information that might illuminate the concepts further. As stated earlier, although preconceived notions were used to stimulate discussion, it was essential that those preconceived notions were not forced or imposed into the process of data collection and analysis.

Two extra care schemes were included in the research to explore whether the findings might be attributable to mechanisms at play in extra care schemes generally, or whether they were attributable to the individual extra care schemes being studied. Direct comparisons were made with one other extra care scheme through individual interviews, and indirectly with more schemes. Glaser (1978) introduced both formal and anecdotal comparisons of data as a means of yielding more information on the area being explored. Data slicing (Gibson & Hartman, 2014) is another process used to identify where to go for new information as part of the formal comparison process. Given the limitations of a detailed study of just two extra care schemes a combined process was used to constantly compare new slices of data from outside the case study with existing data. The constant comparison of new and existing data helped validate or generate new ideas about data which had been revealed by the different participant groups.

Developing theory from participant experiences

An intensive examination of the social practices and processes and experiences in extra care was undertaken, consistent with Meyer & Lunnay's (2013) description of abductive and retroductive reasoning. Participants were introduced, but not limited to, initial ideas set out in broad lines of enquiry. The researcher used abduction to analyse new data and information that grew from discussion about those ideas. For example, the importance of the role of cliques emerged from discussions about how people supported each other, and where people congregated. It was not anticipated that cliques would feature so strongly across all participant groups. Danerark et al (1997) suggested that when abductive and retroductive inference are used together they can lead to the development of new conceptual frameworks or theories, whilst Meyer and Lunnay (2013) suggest retroductive inference is used to identify circumstances without which emerging concepts can't exist. The rest of this section will discuss the range of activities that provided the data and the process used to make sense of the data.

3.8 DISCUSSION OF THE METHODS

This section will first set out how and when the different research methods were used within each phase of the research before then going on to review how the data were analysed.

3.8.1 Phase 1: Pilot questionnaire

A pilot questionnaire was used to establish a national picture of the variety and types of extra care schemes and how they support individuals with dementia. The process for developing and distributing the questionnaire is described in (Appendix 4), together with a copy of the questionnaire itself.

The findings of the pilot were used to confirm the appropriateness of two possible case studies for the main research project. The findings revealed a picture of practice across the country as a backdrop from which to explore issues important to those living in, working in or commissioning and developing the case study extra care schemes. This pilot findings endorsed the notion that individuals with dementia were being supported in extra care schemes, and that careful consideration and design could create a helpful environment to support individuals to live as well as possible. However, the findings were limited by the voluntary nature of the responses. Whilst rich information was gained from those who did respond, caution should be exercised in interpreting the data yielded, which cannot be considered as statistically significant. Nonetheless the findings did offer a deeper and more current narrative on previous research findings (Dutton, 2010), and did provide both confirmatory and contradictory views on anecdotal information gained from the extra care housing market (Dence, 2015).

The qualitative nature of the questionnaire led to variations and subjective interpretations in scoring. This was evidenced by the responses of two different managers who responded on behalf of the same scheme. A further example includes the same illustrations being used to justify different scores made by different people. One respondent made a corporate reply on behalf of 30 schemes which inevitably resulted in non-tailored responses which could distort the results. For that reason, the scoring was adjusted to avoid skewing the results. Notwithstanding the subjective nature of the responses, the summary profile of scores did show a close 'grouping' of scores from providers across the different areas, giving a broad view across the board.

Use of terminology within the questionnaire did not always lead to clear answers, and in retrospect could have been better phrased. For example, the reasons for leaving a scheme included 'inappropriate behaviour' which could have reinforced a negative view of dementia behaviour. It may have been better to use 'disinhibited' behaviour and seek comments. Another example was the

word ‘confused’, which may have been better described as ‘disorientation’. The use of terminology is evolving to promote best practice in dementia support (DEEP, 2014), and future research materials could usefully be shared with a dementia research group such as the South Yorkshire Dementia Research Advisory Group to ensure that latest best practice is included.

3.8.2 Phase 1: Focus groups, interviews and other activities

Two allocation panel meetings were attended at the start of Phase 1 to gain an overview of how individuals were prioritised and allocated an apartment in the case study extra care schemes. Environmental assessments of the communal areas were also undertaken, using an independent evaluation tool, to help the researcher become familiar with the building, and to have an initial assessment of how dementia friendly the extra care schemes were.

The environmental assessment of the community area in each extra care scheme was undertaken using the Enhancing the Healing Environment assessment tool (The King’s Fund, 2014). Duplicate assessments were undertaken separately by the researcher and by a County Council research officer with responsibility for supporting accommodation and care services. Some variation in scoring was noticed across the four assessments (see Table 3-5), reflecting the different experience and background of the assessors.

	Number of domains within the assessment scored	
Scores Profiles:	Case Study scheme 1	Case Study scheme 2
Assessor 1 and 2 gave the same score	13	16
Assessor 1 scored higher	19	15
Assessor 2 scored higher	13	13
Number of valid domains scored	45	44

Table 3-5: Consistency and variation in environmental assessments of extra care communal areas

Not all areas or domains of the extra care schemes were scored by the assessors, who only had access to communal areas. A separate environmental assessment

of an apartment was undertaken with a resident at Scheme 2. The information from the assessment of the apartment was used to provide background information for the researcher. As no comparison assessments were undertaken the results of the apartment assessment have not been used as part of the formal data evaluation. The limited application of the assessment tool within this research did not in itself provide a robust and independent evaluation of the physical environment, but was valuable in providing prompts for, and contributions to, discussions at the focus groups.

Eight focus groups and one interview were undertaken within the two extra care schemes, involving two different housing providers, the local authority, and one district / borough council. The semi-structured focus groups and interviews followed three lines of enquiry rather than specific pre-defined questions. Questions were “asked when appropriate and when there was something to ask about” as suggested in Hughes (1992, p. 444) in her approach to ethnography. Although certain consistent themes were discussed in all groups, each focus group and interview were unique since questions were asked based on individual situations being described by participants.

All eight meetings were recorded (with full consent), but the individual resident interview recording failed. A researcher note was made immediately after the interview and this was used instead of a full transcript. Six interviews were undertaken with commissioners, contracting managers, and senior housing and social care managers who each had links to the case study extra care schemes. One visit was made to an extra care scheme in the north of the England that had been purpose designed and built as a dementia friendly scheme. A further interview was undertaken with a senior manager of a national housing association with extra care villages for comparison.

Most interviews were tape-recorded and transcribed. As far as possible data were triangulated to ensure the quality of the data gathered. Informal calls or emails to interviewees were also made whenever researchers needed

clarification. Notes taken during and after the interviews were also used in this process.

In total, 24 research events took place in phase 1 of the programme (see Table 1 in Appendix 5).

3.8.3 Phase 2: Focus groups, interviews and other activities

The researcher met with participants again in the second phase of the research. The meetings had four aims; first, to share the themes that emerged across all focus groups and interviews during phase 1; second, to confirm that those themes were an accurate reflection of the discussions and experiences; third, to gain new insights or data resulting from the second phase of discussions; and last, to share and get feedback on theories emerging from the data. Nine focus groups were held. One informal meeting was held with a small group of residents at Case Study 1 scheme. One resident, at Case Study 1, requested a follow-up interview or discussion after the focus group, which was undertaken by telephone.

It had been the intention that focus group membership would remain constant between phases 1 and 2. The time gap between the two phases resulting in some attrition due to managers and staff members leaving or changing roles. New participants were recruited for the second phase which affected the second and third aims of the meeting. More insights were generated by the new group members with less emphasis on confirming what had been discussed at the previous focus group.

The planned focus groups for managers and allocation panel group members were poorly attended by Local Authority officers, with one focus group aborted entirely. The researcher had to make a difficult decision about how best to address the gap in participation from the manager and allocation panel group. Attendance was not compulsory, but individuals had not opted out of the research. The issue appeared to be the tension between commitment of time to the research (1 hour) balanced against operational demands. After discussion

with the Assistant Director of the Local Authority it was agreed he would convene a one-off focus group with the social services staff across the two schemes. It was suggested it would be a helpful comparison to include a fieldwork service manager from a third scheme that had a different arrangement for care provision.

The original intention had been to have multi-agency manager and allocation panel focus groups at each scheme. Because of the poor attendance, single agency focus groups were held instead. The single agency format proved helpful in enabling participants to articulate experiences that they might not have shared in a multi-agency forum with partners.

By this stage the two theories of social worlds and quality management had emerged from the findings as relevant to how people experience living and working in extra care. Individual interviews with senior managers of housing associations with responsibility for quality assurance or quality management were sought for the final part of the second phase.

As with Phase 1, the focus groups and interviews were recorded and transcribed. Researcher notes were made after each event to capture key issues. It is of note that one focus group was not recorded because one of the new recruits did not consent to the recording. The advantages and disadvantages of proceeding with the focus group were considered by the researcher. There were two options; to proceed with the participant but without recording the meeting, or to proceed without the participant but with the meeting recorded. Neither option provided a satisfactory solution, but it was decided to proceed with the participant rather than potentially alienate the whole group. The decision not to record the focus group discussion impacted on data collection. The focus group had some very rich discussions, illustrated with reference to real life situations that showed how the themes that had been drawn out of phase 1 interrelated with each other and were very applicable to the setting. The data were captured through the researcher's notes after the focus group but the notes did not reflect the depth of discussion or the detailed illustrations. The range of focus groups, interviews

and other activity undertaken in Phase 2 is summarised in Table 2 of Appendix 5.

3.8.4 Phase 3 Validating and sharing the model

The last phase of the grounded theory involved meeting back with participants who had shared their experiences of living and working in the extra care schemes. The purpose was to reflect to them the model of extra care that had emerged, the theories that underpinned it, and to see how far they would validate the model as acceptable. It was only at that stage that there would be confidence that the insights and findings could be developed into more formal reports, the thesis, and potential best practice guidelines. Three meetings were arranged; one for the local authority joint commissioners, one for all those involved at each of the Case Study schemes. They took place between August and October 2017.

3.8.5 Thematic analysis within the extra care research

Research data were subjected to thematic analysis using both abductive and retroductive reasoning. In seeking to understand the data the researcher tried to identify the 'empirical' experience of participants before exploring the structural and social contexts within which those experiences were set. In his review of Max Weber and critical realism's contribution to a generative view of causal explanation in social science, Eckstrom (1992, p. 115) asserts that "the essence of causal analysis is the elucidation of the processes that generate the objects, events and actions we seek to explain". In this research, the data were reviewed to see which object, events or actions were important to the lived experience of individuals in extra care. Thematic analysis was used to understand how or why processes led to those events, in what were often complex interactions.

Thematic analysis was used as a tool within the grounded theory approach adopted for this research as shown in Figure 3-2. Thematic analysis is described as a foundational method for qualitative analysis (Holland & Todres, 2003; Ryan

& Bernard, 2003; Braun & Clarke, 2006), and is consistent with the high-level data collection and analysis process outlined in Section 3.5. Braun and Clarke say it has a theoretical freedom that enables it to provide ‘a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data.’ (Braun & Clarke, 2006 p 78). Whilst valuing the flexibility of thematic analysis it is helpful to have a structure to follow. Braun and Clarke’s (2006) six phase guide to performing thematic analysis and Ryan and Bernard’s (2003) four task approach are not dissimilar.

Thematic analysis in this extra care research was not linear as described by others such as Ely et al., (1997). Rather it was developed over a period between phases 1 and 2 of the research reflecting five stages, comparable to the stages of Braun and Clarke and Ryan and Bernard, as shown in Table 3-6.

Braun and Clarke Phase of thematic analysis	Ryan and Bernard Task within thematic analysis	Extra Care Research Stage of thematic analysis
Familiarise yourself with data	Discover themes and subthemes	(1) Capture the material as data, familiarise yourself with data, do initial search for common topics or codes
Generate initial codes		(2) Organise the data and confirm the codes. Search for themes by organising the data into concepts and categories
Search for themes		
Review themes	Winnow themes to a manageable few	(3) Develop relationships. Review the themes, define the categories and identify any that are core
Define and name themes	Build hierarchies of themes or code books	
Produce the report	Link themes into theoretical model	(4) Explore the narrative behind the themes
		(5) Review and link to theoretical model

Table 3-6: Comparison of three approaches to thematic analysis

The range of different terminology used within thematic analysis is not helpful in working with different participants who are not familiar with the terms. The researcher did not describe the process in detail but gave a ‘lay persons’ account of the process when discussing with the groups how the themes had been identified, linked to concepts, and then to categories.

Data were collected from focus groups and interviews and then analysed to find themes that reflected the experiences, meaning and realities expressed by participants (illustrated in the first and second task boxes of Figure 3-10 which sets out the process of generating core categories from initial data). In collecting and analysing data there was contemplation of the broader social context, and how it impacted on the reality of individuals’ experiences.

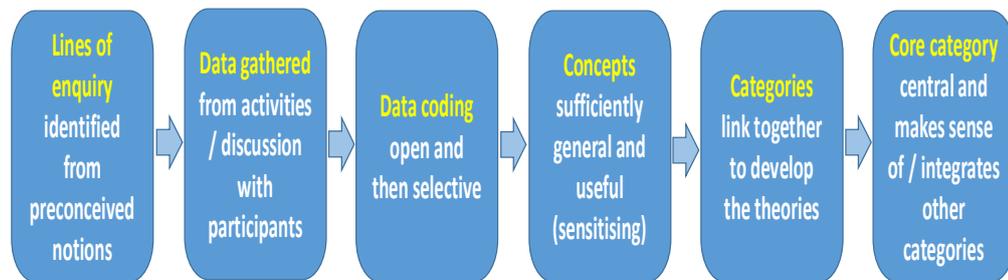


Figure 3-10: Thematic analysis - from data to core categories

Themes did not simply emerge from the analysis process but were actively generated by the researcher (Taylor & Ussher, 2001). The researcher attempted to ‘give voice’ to the participants in the research (Fine, 2002). In doing so the researcher undoubtedly played a role in identifying patterns and themes from the data which were of interest to the research study, driven by the scope of the lines of enquiry, the researcher’s own experience and knowledge of the topics being discussed, and the arguments being developed. Recognising that this could lead to researcher bias, a quality assurance process was in place. The quality assurance involved checking themes from the researcher’s transcripts with those themes identified by members of an independent Stakeholder Engagement and Consultation Team (SEC team) who attended the focus groups. Although the notes from the recorded transcripts were more detailed than the

notes taken by the SEC team there was not a substantial difference or gap between the two, and the same areas were covered.

Critical realists suggest that there should be a pragmatic checking of emerging theories back to the reality from which they were generated (Bhaskar, 1978; Elder-Vass, 2004; Edwards, et al., 2014). Such testing should reveal whether the central critical realist goal, that the theory fits the practice of experience, is achieved. How far a theory should be tested pragmatically was a matter for judgement by the researcher. Themes that were developing were checked back with the focus groups at the end of the meeting, and again later as the research progressed as it was important to make sure that themes emerging were relevant to individuals with dementia living well.

A description was sought for what living well with dementia would look like. The National Dementia Declaration for England (Dementia Action Alliance, 2010) was created for people with dementia and carers. The Declaration was developed with people living with dementia and set out seven outcomes people with dementia and their carers said they would like to see in their lives. A review of the statements by the Alzheimer's Society led to a launch of five revised statements in April 2017. The revised statements are rights enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law (Dementia Action Alliance, 2017). The five revised statements were used within this extra care research as a proxy for how an extra care scheme could support individuals and their carers to live well with dementia. The statements are applicable to people living with any type of dementia regardless of age, stage or severity, and include:

Dementia Declaration Statements:

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it
- We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness
- We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live
- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future
- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part

(Dementia Action Alliance, 2017)

The themes agreed with the focus groups were coded and clustered into concepts which, when translated into service processes and practice, could impact either positively or negatively on people with dementia living in extra care. For example, the concept 'having a helpfully designed environment for everyone' can make it possible for an individual with dementia to navigate their way around the extra care scheme more easily, to participate in activities more easily, to have more choice and control over what they do, and to have a better sense of belonging and being a valued part of the community. These are all things that are important to living well.

Each of the concepts from the thematic analysis was validated against the Declaration to see if it could contribute to at least one of the statements as shown in Appendix 13. If a concept didn't contribute to one of the statements it

was rejected as not relevant to the research question. There were a few concepts which contained relevant codes but did not provide a helpful description for other people, including concepts classed as key themes, potential barriers, and potential enablers to support people with dementia. If a concept was discounted, the codes contained within the concept were subjected to further comparative analysis to see if they better fitted into other existing concepts. If not, the codes were held on one side as an aide-memoire for the researcher when completing the further analysis.

The concepts were grouped into categories that could be linked to develop possible theories. At the end of the first phase four categories had been identified: an individual who flourishes, planning the right model, developing community processes, and developing people.

Those four categories were each made up of five concepts developed from the data coding. The relationship between categories, concepts and codes is set out in Figure 3-11, and the concepts within each of the categories are illustrated in Appendix 14.

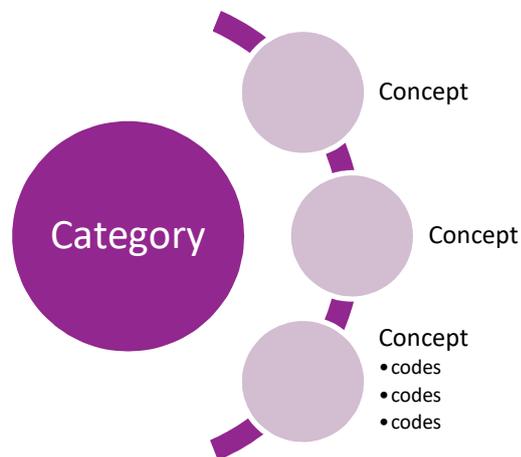


Figure 3-11: Relationship between categories, concepts and codes within thematic analysis

Explanations were contrasted to see if they were the same or different between the two extra care schemes and the different participant groups. The explanations were tested with participants in the second set of focus groups and

interviews before any theories were put forward for questioning and testing in alternative extra care settings outside the two schemes involved.

During the second phase of the research the categories and concepts were discussed and validated by participants, with new information added as appropriate by the focus groups. Through the process of discussing, contrasting, and comparing the concepts, the groups decided that one of the concepts within the 'developing people' category was a duplication, and was removed. The focus group discussions also challenged some of the categories. For example, in a category for 'developing people' much more emphasis was put on the support offered to individuals, not just from carers and family, but also from other residents. Taking into account the points raised at the focus group, the codes were re-analysed, and the concepts and categories were subsequently updated to individuals living well, a clear description of what extra care housing is, a well-developed community, and an effective team, shown in Figure 3-12

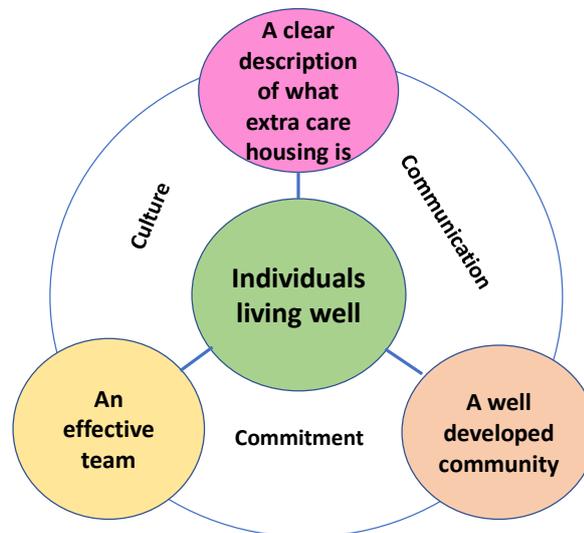


Figure 3-12: Four linked categories that emerged from extra care focus groups and interviews

The extent to which the theory should continue to be tested was a matter for judgement, which the researcher kept under review as the second set of focus groups and interviews proceeded. At the last planned focus group in April, members of the group suggested that new experiences could still be gained by

interviewing managers at a comparable extra care scheme within the county where the care was provided by an independent sector provider. A further focus group was arranged at the comparative scheme, which was one of the first to be established in the County. It had many similar characteristics to case study schemes 1 and 2, with some notable differences including that it was older (6 years), was slightly smaller (15 fewer apartments), was based in the heart of a town rather than in a suburb and had an independent sector rather than local authority care provider.

The comparative focus group provided an opportunity to look at a new slice of data to continue or expand on the theories that had developed from the phase 2 focus groups at the case study schemes. Reflecting on the purpose of the research helped make the judgement that testing was now sufficient. Seeking and analysing data in this extra care research was molded by wanting to find explanations that made sense and were valid in the light of the experiences of residents, staff and managers living and work there. The research sought to re-describe participants' experiences in a way that could help others to understand the practicalities and possibilities of individuals with dementia living in extra care. At the end of the second set of focus groups there was confidence that sufficient understanding of the experiences of living and working in extra care had been gained; few new experiences were revealed in the second set of focus groups, and participants of the focus groups accepted, or agreed to differ, with the explanations and theories being put forward.

Two embryonic theories were growing from the four categories of individuals living well, a clear description of extra care as a model of housing with care, a well-developed community, and an effective team. The first area of theory was around the use of way groups and individuals related to each other and to the space around them, the second area was around delivering the right service and having the right quality service.

The last task within the second phase of the grounded theory (Figure 3-2) involved further development of these nascent theories. Building on the initial literature review of ageing well, belonging and identity, active ageing and ageing in place, further literature on social worlds theory was explored. Social worlds theory appeared to bring together concepts of social interactions between individuals and groups with 'place' a key construct to conceptualise both the environment occupied by residents and resident's interactions with the environment. Managing the delivery and quality of service had not been reviewed as part of the initial literature review but emerged in focus groups and interviews as an area of importance to participants. Approaches to quality management and service delivery were explored in the literature (see Appendix 15). The concept of Total Quality Management, which is recognised internationally, appeared to provide a broad perspective linking quality to the direction, policies, and strategies of an organisation. Literature specific to quality management approaches within the housing with care sector (including extra care housing) were then reviewed. Ideas and theories of quality management and operational excellence were next tested out in specialist interviews held with senior managers from housing associations outside the immediate case study schemes. New insights were gathered, and the data reviewed again.

After collecting and analysing the data the researcher reflected on how effectively thematic analysis had been used within this extra care research. The five stages of the extra care thematic analysis set out Table 3-6 were expanded into a more detailed description in Figure 3-13. The process and stages undertaken in the thematic analysis enabled the researcher to develop the data with participants living and working in extra care, to analyse the data, and to share it back with those participants. The researcher was then able to make amendments, to further explore the emerging themes and to validate them before developing a theoretical model. Participants contributed variously at different stages of the process, leading to questions about the extent to which participant involvement or co-production were achieved.

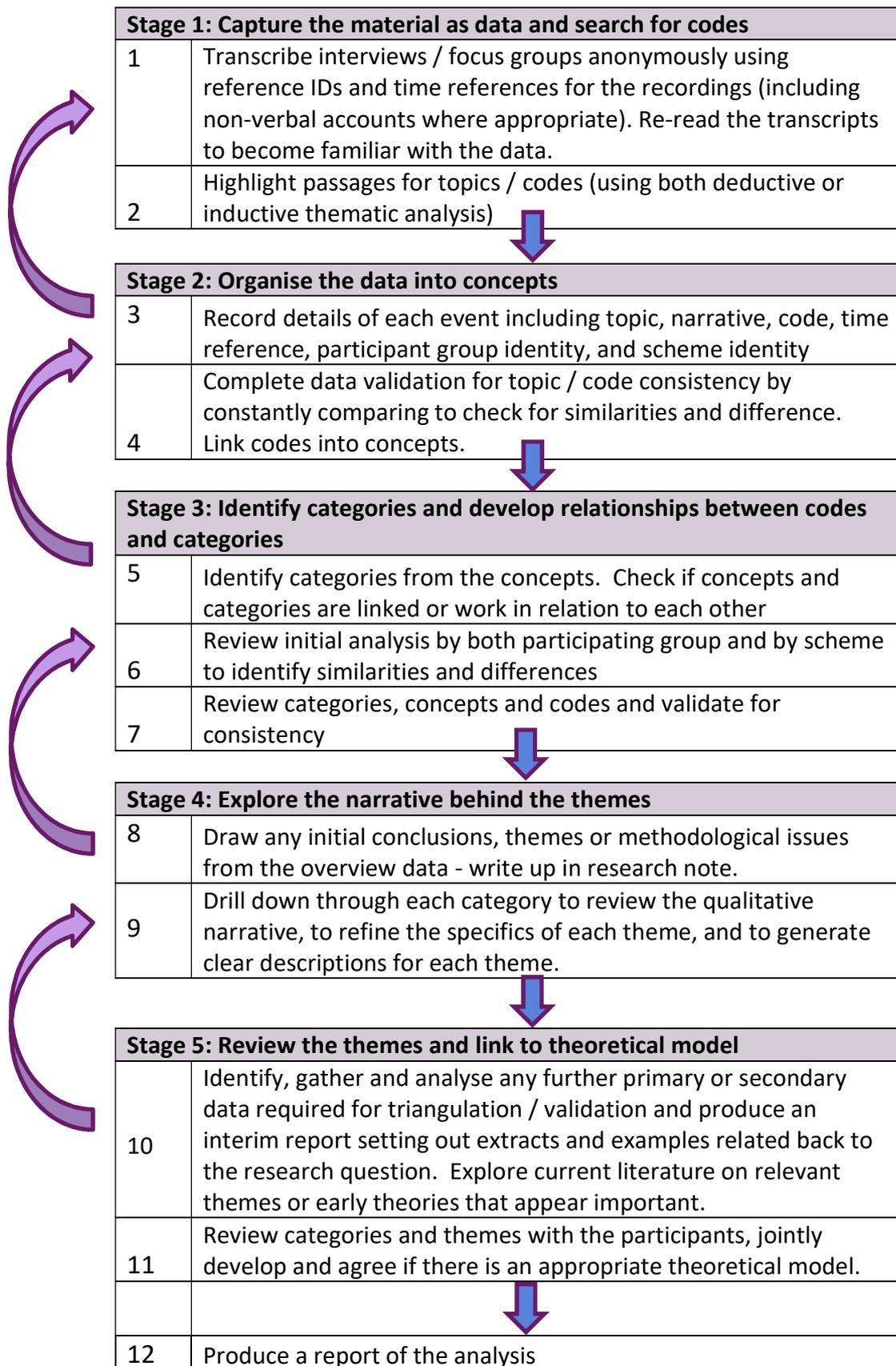


Figure 3-13: Stages in Extra Care Research Thematic Analysis

3.9 GENERALISING FROM THE FINDINGS

It was recognised that each extra care scheme was unique, and that the case study findings or recommendations may not be directly replicable in other settings. By contrasting the results across the two proposed schemes the research looked for reasons why similarities or differences could be anticipated, or whether themes would be capable of theoretical replication. The range of qualitative methods used within the proposed case study (pre-questionnaire, focus groups, participation of residents with dementia, interviews and physical environmental assessments) enabled some level of comparison and triangulation of data and findings to be undertaken (Glaser & Strauss, 1967; Silverman, 2002). Further slices of data (Glaser & Strauss, 1967) from other schemes were sought, giving different views from which to understand the categories developed from the original data and findings.

The extra care grounded theory case study enabled two theories to be developed to help understand how far extra care is appropriate for individuals with dementia, and what helps individuals with dementia to live well. That was done by identifying similarities and contradictions in data gathered, subjecting new observations to rigorous analysis, and exploring the impact of the varied relationships within each of the extra care environments with participants. Whilst the aim was not to provide a definitive blueprint for how extra care schemes should support individuals with dementia, it was intended that best practice might be developed based on the intensive and contextual case study. When the study first started it was uncertain whether a case study comprising two extra care schemes, within a limited time frame of just under one year, undertaken by one researcher, was manageable without compromising the quality of the research output. By using an iterative grounded theory approach, it has been possible to monitor and assure the quality of the study at each stage. That was important in seeking sufficient rich material from which to develop insights and generalisations. The use of data slicing and comparison of schemes and interviewees at each phase of the study has led the researcher to believe

that some level of generalisation is possible. This appeared to be confirmed through interviews with senior managers and extra care providers outside the immediate case study sites, but further work would be required to test out whether it is sufficiently robust to conclude that the findings are truly generalisable across all extra care settings. In considering generalisability it is helpful to consider the first of Day's two fundamental propositions about generalisability (Blumer & Bain, 1939, p. ix);

First, inquiry in any field should recognise the necessity of continuous appraisal of the nature of the knowledge being acquired. Does it consist of the record of observed uniques, the reappearance of which cannot be anticipated, or does it at least suggest generalizations which may be expected to illuminate and to some extent make more manageable later experience under similar circumstances?

It was outside the remit of the research to directly change practice in the extra care case study sites, but it was an aspiration that the study would provide insights to bring about change in policy and practice if required. In the spirit of Day's proposition, this research claims that the findings illuminate experience and provide valuable insights relevant to designers, commissioners, developers and operators of extra care schemes supporting people living with dementia under similar circumstances. The research process itself has generated some partnerships with participants that should help promote policy and practice changes within the organisations involved. This could be more powerful if research participants, particularly residents, take part in disseminating the results to a wider audience.

3.10 CONCLUSION

This chapter set out the methodological approach intended for the doctoral project researching extra care housing and its appropriateness for people with dementia. It explored how a critical realist approach was helpful in considering whether or how the interplay of themes emerging from the research affected the lived experience of people with dementia in extra care. The research used a mix of qualitative methods including questionnaires, focus groups and individual

interviews within a grounded research framework and took account of both practical and ethical governance issues. The chapter considered that a case study approach was appropriate to the research topic, and that the grounded theory approach enabled two separate theories of social worlds and organisational excellence to be integrated, providing new insights into the experiences of people living with dementia in extra care.

4. CHAPTER FOUR: LIVING WELL IN A CLEARLY DEFINED EXTRA CARE SCHEME

4.1 INTRODUCTION TO DATA ANALYSIS AND THE FINDINGS

Research participants' accounts of how well or not individuals with dementia live in extra care housing are portrayed in this chapter and Chapter 5. To help set their accounts into context, brief background information about the research participants is provided. Key issues identified from the participants' lived experiences were collected from focus group conversations, interviews and other activities between October 2016 and September 2017, and then analysed thematically. The focus groups allowed individual voices to be heard, issues were acknowledged, and contributions from all participants sought. The focus groups and other activities also allowed views to be shared and collective experiences told, adding a richness that would not have been afforded if individuals were interviewed alone.

These two chapters have been the most difficult to write, as some of what was discussed in focus groups was implied or unspoken. There were many leading sentences that petered out or were left hanging in mid-air. This was particularly apparent in the staff groups where one staff member would make a comment, pause, and another staff member would pick it up and continue the conversation based on unsaid assumptions that appeared to be understood by the rest of the group. The analysis has attempted to bring some balance to the issues raised, providing authenticity and a sense of proportion without distorting the findings. As described in Chapter 3, the analysis process involved categorising the key themes with the associated concepts that arose. To ensure a balanced set of views were represented in the findings, the detailed concepts were reviewed again to see if any had been missed or mis-categorised.

The themes or issues arising from the focus groups and interviews have been used to describe what would ideally underpin extra care housing. They have

been developed into a model that sets out the complex inter-relationships between an individual living well and having a clear vision, having a well-developed community and having an effective team to support individuals. This chapter covers the vision for the extra care scheme and individuals living well. Chapter 5 covers the development of community and having an effective team to support individuals. The model that emerged has been presented in the spirit of Box (1976, p. 792) who said that:

Since all models are wrong the scientist cannot obtain a “correct” one by excessive elaboration.

That is, there is not an assumption that the model is ‘right’. Rather, models are a simplification of reality, which are useful in seeking an economical description of natural phenomena. The extra care model set out in this chapter therefore provides a tentative representation of extra care, which was used to provoke further analysis when exploring, as part of the grounded theory approach (Gibson & Hartman, 2014), whether the themes had already been covered in existing literature. The findings described here and in Chapter 5 are discussed further in Chapter 6 providing insights from the body of relevant literature into the lines of enquiry that emerged from the participant discussions.

4.2 A PEN PICTURE OF EXTRA CARE RESIDENTS

The demographic makeup of participants was described in Chapter 3. This section provides additional vignettes of the residents involved in the research study to help contextualise their comments about their lived experiences in extra care. Pseudonyms have been given to preserve anonymity of residents but at the same time to enable the reader to trace an individual’s narrative across the thesis to build a picture of them and their views as individual actors in the life of extra care. Staff and managers working within the extra care schemes were not given pseudonyms as the recordings of the focus groups in which they were involved did not lend themselves to the identification of individuals, and one meeting was not recorded verbatim.

Alan and Zoe bought their extra care apartment six months before the start of the research. They had moved from the south of the country to be near family, who had children with health problems. Their son, who lived about 3 hours away by car, supported them with financial and practical issues for the apartment. Zoe was very proud of Alan, who had had a professional job in a University. She herself had returned to study later in life at the same time as their children were studying. Alan and Zoe were in their late eighties and early nineties, and Alan had been diagnosed with dementia. They liked to spend a lot of time in their apartment but did enjoy events such as the film club. They liked to keep themselves to themselves.

John and Josie had purchased their apartment. John had been a lecturer at a university in the north of the country. He was proud of his wife Josie, who had had many voluntary roles and had studied at post-graduate level, receiving an award for the best post-graduate of the year. Josie had been invited to take paid employment in one of the public services where she had been a volunteer, but she had declined as it would have meant a possible move away at a time when she had children. Josie had supported her father who lived with dementia in a residential home. He had had episodes of aggression, which the home couldn't manage, even with medication. Josie's sister had also lived with dementia and Josie described how they experienced intolerance from other people when they went out together. John and Josie took an active part in the extra care scheme both leading a group and supporting individuals with their interests. John and Josie commented on how kind residents were to each other. They lived with a cat.

Mary rented an apartment and lived on her own. She was one of the younger residents. Mary had medical problems that could cause her to forget things or to be muddled, but she didn't have dementia. She was aware how she was affected by the mental problems and was open with others about the difficulties this could cause. She classed herself as someone who was independent but needed support. Mary had no direct experience of caring for someone with

dementia, but she was very supportive of other people within the extra care scheme. Mary had been a member of the residents group when the extra care scheme first opened but wasn't any longer by the time the research started. Mary expressed strong views about how extra care had been promoted and said that her experience was quite different.

George moved into the extra care scheme with his wife Edna, who had been living with dementia. Edna remained at the extra care scheme until she died, supported by George and the extra care staff team. George had worked in the motor trade and was a keen gardener. He tended the gardens at the extra care scheme. George supported the Campaign for Real Ale and continued to go on their monthly trips. George had five children and ten grandchildren, some living in the UK and some abroad. He used an electronic tablet to keep in touch with family, and to store important photos of his wife. George said that he didn't like to socialise much but liked to attend groups and 'person watch'. George participated in another research project on public patient involvement.

Audrey rented an apartment with her husband Eric. Audrey and Eric had a son and daughter in law who lived in the town. Eric was living with dementia and went to a day service. Audrey described how as a couple they could be isolated within extra care. They didn't come down to the communal areas much because Audrey was worried about Eric causing a disturbance. Eric's dementia had progressed significantly in the weeks before the research started. Eric did not participate in the research.

Frank and his wife rented an apartment, which they shared with their young adult daughter. Frank's wife had physical disabilities and had been temporarily staying in a local nursing home. Frank hoped she would return to the extra care apartment, which was fully adapted for her needs. Frank was one of the younger participants, under the state retirement age. He had had a diagnosis of vascular dementia for about a year. He still drove and visited his wife in the nursing home. Frank smoked and had frequent visits to the front door to smoke outside. This kept him in contact with other residents and staff.

Nora was another of the younger residents, having moved into a rented apartment with her older husband Jimmy. Nora had worked as a carer. Jimmy had had physical health problems and lived with dementia. After an episode in hospital he had been transferred to a nursing home in a neighbouring town. Nora then lived alone in the extra care apartment and had found the separation very difficult. She drove and visited Jimmy daily in the nursing home. Sadly, Jimmy died during the period of the research. Nora continued to live at the extra care scheme and returned to work as a carer.

Walter and his wife Ann rented their apartment. Walter's wife had been diagnosed with dementia eight years ago. They had moved because their previous accommodation was unsuitable for their needs even with adaptations that had been made. At the time of the research Ann was having four calls a day from carers, with Walter providing round the clock support. Ann rarely left the apartment and spent her day in a reclining chair with views over the garden. Although Ann was living with the advanced stages of dementia, she did enjoy the events and shows at the extra care scheme to which Walter was able to take her. Walter went out twice a week to do the shopping when his wife had a carer to support her. Walter remained involved with what was happening in the extra care scheme through the carers and housing support staff that came to support them. Ann did not participate in the research.

Sarah lived in the extra care scheme alone. She had moved to the extra care scheme from a residential home. She had multiple health needs and was visited by the district nurse. Sarah used a motorised buggy to get around. She ate her lunches at the café within the scheme and was well-known by the restaurant staff and by other residents, who provided her with company. Sarah had a cat. Sarah had previously worked as a home help. Her husband had lived with dementia, and she had supported him at home. It was some years since he died.

4.3 WHAT PARTICIPANTS SAID ABOUT EXTRA CARE

As set out in Chapter 2, three main questions were explored with participants in

the focus groups and with interviewees at the extra care schemes. They were:

- What is extra care, and what does it mean to you?
- Is the extra care in this scheme appropriate for a person with dementia, and why?
- What modifications to the extra care scheme might make it easier to support individuals with dementia and their carers to live well?

Four inter-related themes were identified from the stories told by participants through focus groups and interviews. The themes identified described an extra care model that was recognisable to the different participant groups. The themes were not prioritised in any order but included: first, the importance of a well-planned vision that describes the extra care model of housing with care; second, factors that would help an individual to live well; third, the importance of a well-developed community; and fourth, the effectiveness of the formal and informal team of people supporting individuals. These themes became the four components of an extra care model, set out in Figure 4-1. It was assumed that an individual with dementia would be better able to live in extra care if the four main components were in place, and conversely might live less well if they were not in place.

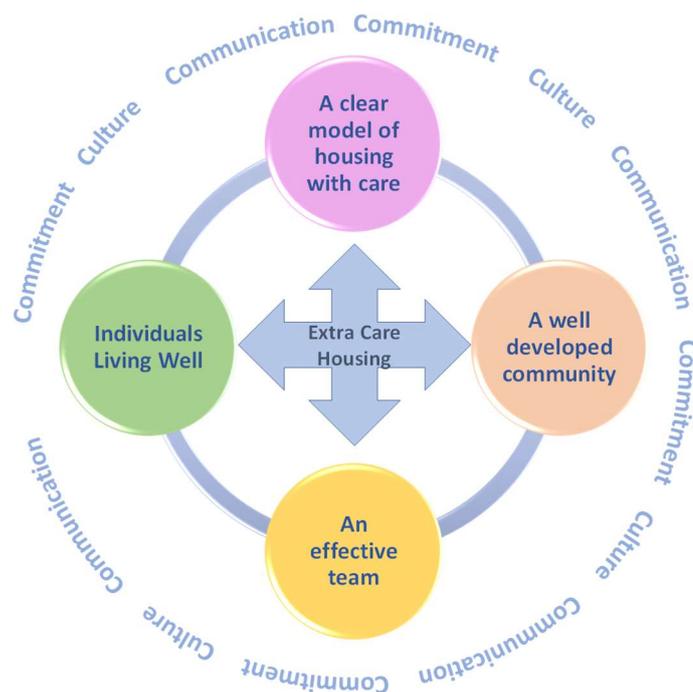
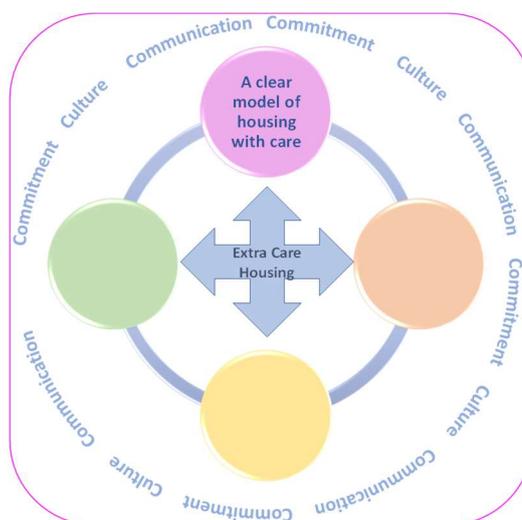


Figure 4-1: Four inter-related themes constructed from participant discussions

At the second set of focus groups, residents confirmed that the four-component model would ideally underpin extra care housing for older people with dementia. No one individual component was deemed more important than the others in enabling someone with dementia to live well, but a synergetic connection between the four should better support someone to live as well as possible. The participant discussions also highlighted the importance of having the right culture in the scheme, having a positive commitment from all those who live and work there, and having effective communication. These were described as the ‘glue’ that influenced how easily the four inter-related components might work together. The rest of this chapter describes the four components and the ‘glue’, setting out both collective and divergent participant views of the individual elements that comprise each component.

4.4 DEFINING EXTRA CARE

The most important issue to emerge from all the focus group discussions was having a clear understanding of what extra care service was. Senior managers said that having a clear vision of extra care started at the very beginning when the extra care scheme was first developed.



Partners working together to commission, operate and monitor the agreed service was thought to be essential. Having a helpfully designed environment was important to everyone, as was having policies, guidelines and processes that supported residents, family, staff and other professionals. Another important aspect discussed by participants was to have a process that enabled appropriate moves in and out of extra care so that residents and family were helped to make

the right moves as easily as possible. The elements that contributed to a vision for a well-planned model of extra care are shown in Figure 4-2.

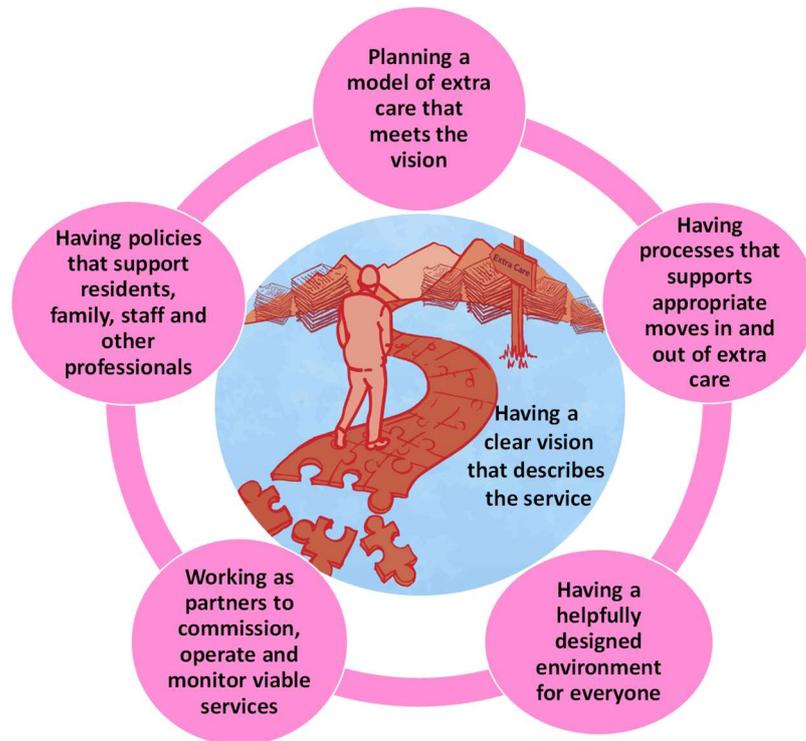


Figure 4-2: Elements that contribute to a clear vision of extra care housing

4.4.1 Extra care within the spectrum of housing with care

The divergent views of what extra care is were expressed by one manager who said:

Some [residents and family] have felt that it was 24-hour residential, that there would be someone popping in every hour and making sure they were ok kind of thing. Others have felt that it was just like a retirement village and it wasn't going to be for people with any kind of health problem, disability or anything. Yes, that's what they were thinking.

Although there may not have been a shared understanding of extra care, participants talked about it being an ideal 'bridge gap' for someone; making the gap smaller between independent and dependent living and filling the gap between either living in their own home or living in residential care. An aspiration articulated by the different participant groups was that extra care would provide a home for life, without requiring a further move into residential care. In commenting about residents, staff at one scheme said:

They're not coming in thinking they might have to move on. They think this is going to be their final place.

Recognising that there was sometimes a mismatch between the vision and the reality, Mary observed:

You see, I think a lot of families think it's the answer to prayers, this place. They're not quite ready for a care home, but they're not, you know, they're not living independently. But it's not like that in reality. Not for somebody with Alzheimer's. And we have seen quite a few people come in here and deteriorate rapidly.

Participants talked about the need to make sure that both the advantages and limitations of an extra care scheme were effectively communicated to people considering a move. In particular, the fine line between independent living and extra care was discussed.

The importance of being independent with appropriate support when first moving into extra care was raised as an issue by managers, staff and residents alike. The complexity of defining independence and different levels of need for support was acknowledged as a potential barrier to understanding what extra care could provide. One manager said:

I think the level of need here, you know, high, moderate and low level of needs are subjective to your levels of experience. If you come from a professional perspective you know, we see people with extremely high nursing level type needs. If you were Joe Bloggs from the community, you probably haven't experienced that, you are not knowledgeable, and so actually what a resident might feel is a high-level need is probably a low-level need to a social worker.

This, and other similar comments gave rise to discussion in the focus groups about the need for effective and honest communication about whether a move into extra care was appropriate for individuals. There were many conversations about the complex combination of an individual, their history, their personality and temperament, the disease of dementia, the built environment, and how they all affected the ability of someone to live well.

Both managers and staff participants thought that the stage of the dementia journey was critical to whether an individual could make a successful move into

extra care. When discussing whether extra care is suitable for people with dementia, one manager said:

I think your difficulty is by the time most families consider moving to such a place as this, they [*the person with dementia*] are already quite disorientated.

There was a consensus that a move was more likely to be successful if the individual could find their way around the building without getting lost, could manage to establish new routines, and could develop new relationships, with appropriate support from family or carers. There was no definition of what 'appropriate' support comprised; that was dependent upon each person.

In talking about people with dementia there appeared to be a contradiction between the aspiration to support individuals with varying levels and types of need, and the application of the allocation criteria to people with dementia. There was a very insightful discussion at one of the allocation panels where one of the managers said:

I think in terms of actually admitting people here with dementia, I think the timing would be crucial for when they entered into here. Preferably as soon as the diagnosis is made, I think... But... The problem is, going back to the diagnosis. They probably won't be eligible for social care input at that stage anyway. So, they are going to present at the allocation panel as someone with no needs [...] So all this would be losing time, we're losing precious time to orientate someone, to get them adjusted to it before their needs start to develop, and that's I think going to be the issue, a massive issue, to do that. Yes.

The panel then went on to discuss how the person with early stages of dementia was likely not to be allocated an apartment in preference to someone who was presenting with higher physical needs. It was thought that by the time they did appear eligible they may not be considered suitable because they may be unable to establish new routines and not be able to settle into unfamiliar surroundings. There was acceptance that over time individuals with dementia would increasingly need help to manage routines, to maintain relationships, and to find their way around the building; but it was important that they could manage their daily lives with appropriate support when they first moved in.

4.4.2 The importance of environment

Age-related changes and impairments can make it more difficult to understand and navigate the built environment. These can be sensory, physical or cognitive impairments. Individuals with dementia may have a combination of such impairments affecting their functioning, behaviour, mobility independence, and how well they live. A well-designed environment can support the needs of people with sensory, physical and cognitive impairments by incorporating accessible and dementia friendly features to help individuals orientate themselves and manage their daily lives. Environmental assessments were undertaken at both extra care schemes using the King's Fund (2014) 'Enhancing the Healing Environment' tool. The tool includes seven areas that measure how far the housing environment promotes meaningful interaction and purposeful activity; promotes wellbeing; encourages eating and drinking; promotes mobility; promotes continence and personal hygiene; promotes orientation; and promotes calm, safety and security.

The highest scores attained by both schemes were for promoting meaningful interaction and purposeful activity, and promoting calm, safety and security. Neither schemes scored as well on promoting wellbeing, promoting mobility, and promoting orientation. The assessments undertaken within this research were not set up to be rigorous or robust enough to provide statistically significant evidence, but the general findings were consistent with comments made by research participants in the focus groups. For example, Frank commented positively:

I expected an apartment that I could live in with my wife [with mobility problems]. Unfortunately, she's not here at the moment, but that's exactly what we got.

And Walter commented:

We basically needed wider doors. Here there's wheelchairs and doors... easier access from the bathroom. There are two doors, and we can get in the bathroom from any direction.

In contrast there were less positive comments such as:

For dementia people this place looks like a rabbit warren because it all looks the same. There is nothing for a dementia person to look on to say, 'oh I go that way' or this... it needs something there. I don't care whether it's blumming roses or something like that, but they need to find their way back to where they live.

Similarly, a staff member commented:

The design hinders me as a staff member. There is no consistency, so anyone with dementia would not cope. There are issues with different designs of door for instance, and how they open with a fob or code.

Whilst recognising that the design could be improved to support individuals with dementia, there were mixed views about how far dementia design features should be incorporated further into the schemes. Both residents and managers said that they didn't think introducing dementia design would be accepted now, but if the features had been incorporated before the scheme opened they would have been. Tensions between what was dementia friendly and what would be acceptable to those without dementia were apparent in several discussions.

Comments were made by staff and managers such as:

We aren't a care home, and people have invested their money to come and live here so [...] and ... probably signage or pictures or something... I think that's where we do have to draw the line and think, well actually ... we are independent living... cos I wouldn't want to see it [dementia design].

Commissioners and developers shared those views, which was encapsulated by one interviewee who said:

Our schemes are [meant] to be dementia friendly, but they are not dementia schemes, and if you make everything pictorial signs, then some people would say 'that's not actually quite the feel that I want'. They don't want to be reminded of that. It's about 'ordinary'. What we are trying to create is 'ordinary housing at great quality that is compatible with the whole range of people's needs that live there... So, I think there's a continuous need to keep looking at what's working and what doesn't work, to try and balance that with a whole range of needs and abilities, including those with dementia.

Getting the right model and right environment is an on-going process. It is especially important that there is an open culture where residents and staff are encouraged to communicate their ideas about what works and doesn't work,

and so that residents can be involved in shaping continuous improvements to the scheme.

Participants in the focus groups discussed the aesthetics of the scheme and how the interior design can help or hinder someone's ability to find their way around and manage routines when they move into an extra care scheme. Audrey told how her husband struggles with doors, with knowing which floor he is on, and getting confused in the lift when on his own. The role of staff in providing prompts and informal support was described as important to helping someone find their way around the environment. Carers commented on the use of 'unscheduled' care time¹⁷ to support new residents to develop routines and relationships:

It is for things like, if you get a new resident, to help them come down and integrate into the group. To take them into the café, to introduce them to people, to sit with people. Which is not perhaps going to be in their support plan because once they get going it will be alright. They just need that bit of help with their routine – don't they?

The limited time available to carers that was not directly scheduled to provide planned care was the subject of many discussions and will be returned to later in Section 5.2.5.

Staff also described how they had to be assertive with other professionals when considering people with dementia and the impact of the environment on their ability to cope in extra care. One said:

We had a strategy meeting with everybody, and the professionals were saying, 'this is not the right place for Florence'. And we said, 'hang on a minute', it was four weeks, because I knew she had already built her routine in here. She knew where the front door was. She knew where the corridor was. She knows where the office is. That's a quality life for the people with dementia, if they don't do that much... So, if that was taken away to put her in a 24-hour care because she is coming out of the room, it would dement her. She will be gone. The first is the environment change, and the second she doesn't know the people, third she has got a high level

¹⁷ 'Unscheduled' and 'unplanned' care are terms that are used interchangeably by participants. It is the care and support that is provided to residents that is not part of a time-tabled care plan or staff rota. It is also sometimes referred to as 'downtime'.

of dementia as well. So, we asked for 4 more weeks didn't we, to work with Florence....

Having policies and guidance with sufficient flexibility to support residents, staff and other professionals to make considered decisions based on a person-centred approach for each person was thought crucial in making sure that moves in and out of extra care were appropriate.

4.4.3 Working flexibly together within a policy framework

Mutual honesty between professionals, individuals and their families about meeting the levels of need of individuals with dementia was described by managers and staff as essential in not setting people up to fail. That was tempered with concern that members of allocation panels were not able to visit all potential residents before an apartment was allocated. The nomination protocol and allocation guidance stipulate that the housing provider will liaise with the council to arrange for a community care assessment to be carried out for each applicant, but it was felt that this may fall short where a social worker was not previously allocated to an individual.

Commissioning, operating and monitoring the viability of extra care services was mentioned many times by different participant groups, and the café facilities were of great significance, both to provide a hub for community activity, and to enable more vulnerable residents to get a nutritious meal each day. In both schemes the viability of the café or restaurant was of concern. All participants groups suggested a range of improvements, which included using the café as a base for activities, helping individuals to get to and from the cafe, having more staff to deliver meals, and providing a subsidy. Improvements would need a multi-faceted approach and would be difficult for any one partner to implement alone. There was an acknowledgement from participants that budgets would impact on the improvements being suggested.

The issue of limited funding was raised by all participant groups. One of the staff members commented about a resident:

She went to 'abc' home, it's residential...yes... she'd been there before, so she was happy there before she came here. She was happy helping them wash pots and everything, but then again, it's cheaper here isn't it?

Whilst one of the social work team members said

I think the reality is ... particularly in terms of support... it's funding. Particularly in terms of services now, what its being driven by, it's funding. Certainly, the notion is we'll keep people at home as long as possible. You know, we'll try everything in our power to keep people at home, we exhaust all options around telecare. You know, we'll put in equipment, we'll put checking systems into people's homes, and only on that basis... until you've got that evidence we'll not admit to residential care. So, community is the only option until one's needs tip over. That is the reality, you know.

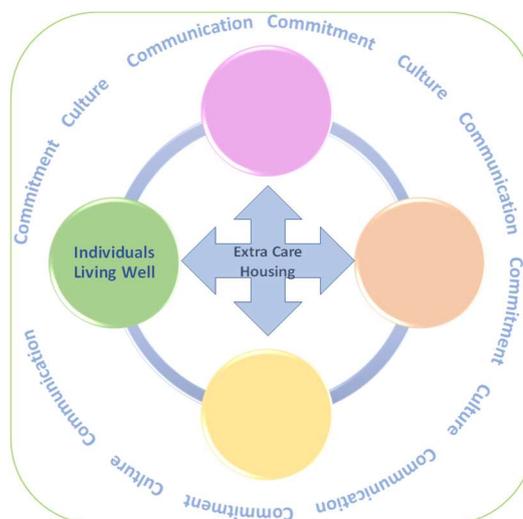
It was not clear from some of the comments whether the different participants saw being in extra care as living in the community, living in a residential setting, or something else. For example, one manager made a few references to 'people living on the street' as opposed to living in extra care. It was unclear whether this meant that those people living on 'the street' were classed as living in the community, or what the manager thought extra care was in relation to the community. Commissioners, designers, providers, staff, and residents brought a nuanced understanding of extra care, which influenced how effectively they worked together to deliver an extra care housing scheme to meet the needs of all stakeholders, including residents living with dementia.

This section has set out five elements that affected how a model of extra care housing was provided in the two case studies. The five elements are; having a clear vision that describes the service and can be understood by everyone; working as partners to commission, operate and monitor viable services; having a helpfully designed environment for everyone; having policies that support residents, family, staff and other professionals; and having a process that supports appropriate resident moves in and out of extra care. This section has described why those elements were important to participants. Examples were used from interviews and focus groups to bring their understanding or experiences to life, including examples that demonstrated how the five elements impact on people with dementia. The next section further explores what

participants thought could help individuals live well in extra care.

4.5 LIVING WELL

This section covers elements of living well; being independent in a supportive environment with person-centred services which maintain the rights of people and enable them to take appropriate risks.



4.5.1 Independent living in extra care

In the last section the notion of independence or 'independent living' was considered in relation to the model of 'extra care'. In some discussions 'independent living' appeared to be a short-hand for 'we have limited resources, so residents need to be as independent as possible and not ask for help'. In others it appeared to be short-hand for 'the scheme is designed to be 'extra-care' and that is why there are so many people with higher levels of need'. At the very first resident focus group Mary was keen to start the meeting by saying:

Can I just begin by telling you something... you know that extra care [name of extra care scheme], when I signed up to come here it was independent living with support [...] what we get from the scheme managers is that it's 'extra care', but it was independent living with support when I signed up to coming.

It was a theme that Mary returned to again and again at the focus groups and the feedback sessions; that she had moved into the scheme with the understanding that it was to support independent living, but that her expectations had not been met. As another comment demonstrated:

This is when it was independent living with support. But then that was channeled at us, for if we put queries in one direction. But then if we'd got

something else to say, it was extra care. There was never any clarification to which actually this scheme was.

It appeared that the two approaches of 'independent living' and 'extra care' were not mutually exclusive, but interchangeable dependent on the circumstances prevailing at any one time. One staff member appeared frustrated with the juxtaposition of these two descriptions when they said:

One minute you're saying it's independent living to somebody, you know you can live on your own, and then in the next it's... 'oh but you've got to have a care need, and we can support you'. So, it feels like to me that we are contradicting ourselves at times, and I think that then adds to problems with professionals and with families....

For Mary, the consequence of the misunderstanding was that she was living with people who needed a substantial amount of care and who were not as active in the community as she had anticipated, which affected her ability to live as well as she had hoped.

4.5.2 Living well in a supportive environment

Concepts of ageing, being independent and living well were considered in detail in Chapter 1. Although it is hard to define or measure the key components of living well, both resident and staff participants gave some positive examples of people with dementia living well in extra care. Examples were also given where individuals living with dementia could have been better supported either within the extra care scheme itself, or in a different setting.

Features that help an individual live well were drawn from the discussions with participants and are set out in Figure 4-3. They include maintaining and reflecting personal identity, having a positive approach to managing risk and safeguarding issues, having person-centred teams and providing person-centred support, understanding dementia, and having the right culture.

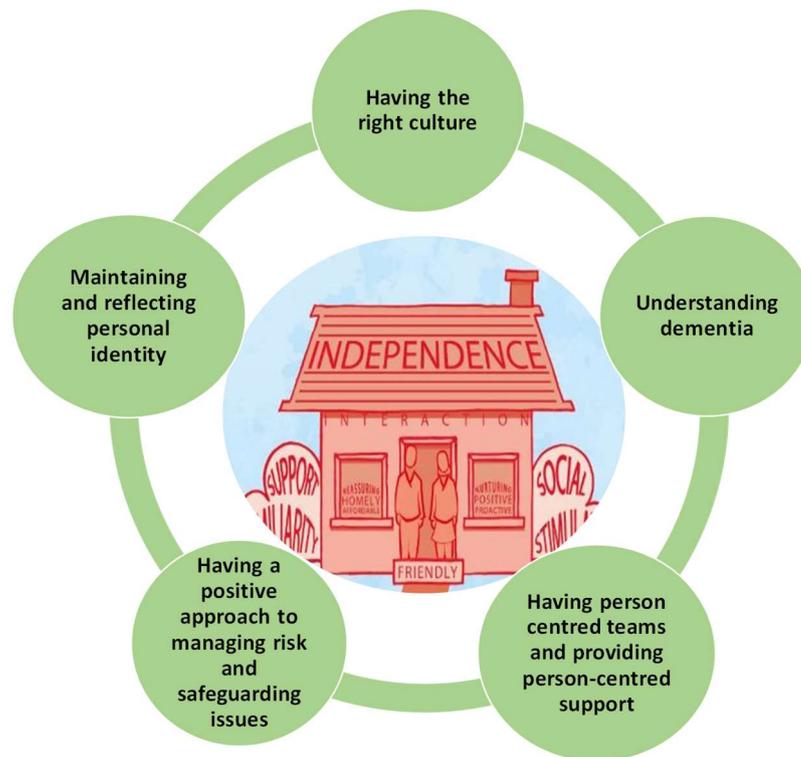


Figure 4-3: Features that help individuals to live well

The word ‘culture’ was used by many different participants. It developed as a label for something that was intangible, but about which there was a shared understanding. Culture is a key sociological concept with a theoretical base and a set of beliefs, customs and practices that are present in each situation with a particular group of people at a point in time (Sewell, 2005). Culture is an important concept within this extra care research because it plays a crucial role in shaping social relationships, maintaining a sense of order at the scheme, and influences how people interpret their role in the extra care scheme. Culture affects how people behave.

Research has shown that the social environment and culture within a scheme can impact on opportunities for interaction with others (Jones, 2009; Robertson, 2013; Elias & Cook, 2016). The people who contribute to the culture in extra care include residents, staff, and managers who live and work together. Having the right culture was sometimes expressed in terms of having a good ambiance.

The ambiance appeared to be affected by relationships, by the presence of dominant residents, and by how staff and managers addressed any conflicts that arose. Conflict was said to arise sometimes when individuals demonstrated challenging behaviour. For example, staff described a situation that occurred with a person with learning disabilities:

There was an incident... Yes, an incident... and it's scared quite a few of them off [other residents]. The gentleman we were talking about with learning disabilities, who's moved out now, but he... [change of person speaking] he was aggressive... he was... and he was very aggressive towards one of the tenants, and after that they stopped coming down.

Although this example was of a person with learning disabilities, similar conflicts typically occur when individuals with dementia are unable to express their needs in a way that can be understood and responded to by other people.

Consequently, the reaction of the person with dementia to the situation can be disturbing to those around them (Cohen-Mansfield, 2001; Gauthier, et al., 2010; James, 2011). Participants described how the behaviours or actions could be minimised by mutual resident support, by the flexibility and responsiveness of staff, and by having the right balance of residents with different care needs. Understanding dementia was said to be important to developing the right culture. Having a supportive environment where dementia is understood was described as helpful to individuals living well, but there appeared to be variable levels of understanding of dementia amongst residents. When trying to understand why that might be one carer said:

You know the people who are here, in their 60s 70s and 80s, dementia wasn't a big thing, so they don't understand it. So once somebody starts going down that way they are just... like... not closed off to them, but they don't want to incorporate them in stuff that they are doing.

On the other hand, there were also residents who understood dementia but were described as not being empathetic towards those people living with dementia. One carer said:

There's a number of people who well understand dementia, and I think some people are quite self-absorbed... and I don't think there's any other word for it... if it's affecting their bubble then they don't like it. And just as importantly they are not very compassionate.

A sense of what is normal was also cited as a reason for not accepting people with dementia. When talking about situations that become difficult to manage one manager said:

It becomes very apparent, if you are quite well presented and you keep yourself to yourself, don't cause an issue, you'll get on fine.

Similar views expressed in other discussions indicated a lack of willingness to embrace anybody who was different, or who challenged the residents' sense of self. One manager thought it was easy to be ignorant and stigmatise someone with dementia because:

It's frightening, because they are seeing it [dementia]. Whereas someone who lives in the community may take it on board a little bit better because they don't see it day in day out.... If they think that's going to happen to them, they want to block it away don't they?

When individuals with dementia didn't appear to act rationally, for example when not accepting support, staff were concerned that other residents might think the individual was being neglected. A staff member said of a man who refused support with personal care:

He sat in the foyer a lot, where there were a lot of people... that caused friction as well because people would say 'he smells, he shouldn't be sat there, the staff aren't looking after him.' They didn't know what we were doing in the background, and we couldn't say, 'well we're doing this, this and this'. And then they would say 'well you don't do nothing for him, he smells'.

Residents who participated in the research had mixed views of people with dementia. One seemed intolerant of people with dementia, calling them '*those dementia people*', whilst another resident commented that there was more acceptance than there had been in years gone by:

Well in the old days they wouldn't know what it [dementia] was. No, no... lost his mind, as old people do, you know. They were put in mad houses a lot, weren't they? It was awful... Yes, even from when I worked, there seems to be more acceptance.

Being accepted and having positive relationships with other people seemed to suggest those living with dementia could better retain their sense of self, or personal identity. Audrey described being reticent to come down to the

communal areas because other residents didn't know what Eric was like before he developed dementia:

As I say, one of the reasons I don't come down with him is because he's... he talks to anybody... he's got to stop and talk to everybody. It doesn't matter who they are, whether they know him or not, and sometimes it's... it's a bit embarrassing you know, some of the things he does, and I think that's why....

For the individual to develop relationships with other residents and with staff, participants believed it was important to understand the person with dementia and to see beyond the dementia to the person they were. Although access to care and support to meet an individual's needs is one of the core ingredients of extra care housing (Riseborough, et al., 2015, p. 2), delivering that support in a person-centred way could be challenging. It was said to be easier if you knew the person's background or history. At one of the schemes it was reported that, across staff members, there was marked difference in understanding and approach to one resident, depending on how long individual members had known or been involved with him as his dementia progressed.

4.5.3 Living well with person-centred care services

Caring for an individual with dementia typically relies on both anticipated and impromptu support. Care services in extra care often give unplanned as well as planned care, provide an emergency response when required, and are responsive to residents' changing needs. As one staff member said:

I personally think this is what extra care is for [people with dementia]. I don't think it's about the scheme, it's about the individual, because everybody is completely different. So, I think it's...we've got people who are diagnosed with dementia who are managing completely independently, and they don't have any care calls, and they've got that diagnosis of dementia. But then we've also got people who have got the diagnosis who are having 4 care calls a day, and you question then 'is it the right place?', but I don't think it's about extra care, it's about the individual. Because everybody is so different with dementia....

Tailoring services to the individual is not always so easy to achieve in practice. Participants referred to resource constraints, and sometimes either a lack of

clear role boundaries between the housing and care staff or too rigid a boundary, which resulted in some support not being the responsibility of anyone to provide. Examples given to illustrate the difficulties often included non-physical care tasks. Those that were especially important to people with dementia included helping someone to take part in group activities, reminding someone to come down to the café, providing support to manage anxiety, offering support to remember to take medication, and offering individualised and purposeful activity, which could prevent behaviours that challenge from arising.

4.5.4 Living well involves taking risks

Being person-centred was linked to having a positive approach to managing risk. The acceptability and nature of risk-taking was hotly debated and reflected many viewpoints. The balance between positive risk-taking and being protective was an issue for some staff and managers. One person compared what happened in extra care with what would happen in somebody's previous home before moving:

We've got that gentleman, haven't we? You know, that they've got a risk assessment for what do we do if he is not in [his apartment]. Well what do we do about somebody that lives on a street who is having a service from us 3 times a day? We don't know that they are going to the pub with somebody and getting pickled and coming home. They manage it themselves... you've got to come back to that. What would we do if they lived on a street?

The housing and care team tried to help him to be independent, whilst also feeling an obligation or responsibility for him because he was resident in the extra care scheme and in receipt of personal care services. There was a link here back to the first theme; being clear what extra care is and having policies that support residents, family, staff and other professionals.

One of the biggest risks identified was the difficulties that arise when individuals walk out of the scheme and are unable to find their way back. In discussing

policy limitations, a staff member raised the issue of how they should respond when they think residents may be at risk of not being able to find their way back:

I think a prime concern as well is that we are told it's their own homes. We have had a couple with dementia that have gone out. We have gone and fetched them back, but we were told we should have let them go.

A manager commented that:

There's the wander alerts that are programmed into the carer's handset... But the responsibility wouldn't lie with the staff to track them, it would have to lie with the family.

The family response was not always seen as proactive by managers and staff. One staff member's comment illustrated that there can be a misconception by family members of what extra care housing provides:

Was it her daughter who thought the doors were locked, the front doors, so she couldn't get out? They didn't actually... They are locked from the outside, but we don't lock people in, they aren't locked from the inside.

All participant groups spent some time discussing whether it is possible to prevent individuals with dementia from walking out of the scheme when they wouldn't be able to find their way back. On a practical level one manager commented:

You know, yes there might be 6 or 7 staff working at that moment. But they may all be engaged with another person, and not in the communal area watching what that lady was doing. So as her illness progressed that became a problem.

There was concern that staff, if they tried to prevent someone from leaving, could be accused of depriving the individual of their liberty. As one resident pointed out:

People have walked off, and they've been picked up on the road because the carers can't follow them or stop them going, because it's impeaching their civil rights....

All participants discussed the constraints of depriving someone of their liberty. Not unsurprisingly managers and staff had a greater awareness than residents of the Deprivation of Liberty Safeguards (DoLS), which were introduced into the Mental Capacity Act 2005 by the Mental Health Act 2007:

It [putting a lock on doors/ sensor on doors] interferes with a person's liberty doesn't it? They are independent living. You can't just take those choices away from someone. If they haven't got a DoLS in place, there's nothing we can do....

Staff that had previously worked in residential care were very attuned to the requirements of DoLS, which provide a framework for approving the deprivation of liberty for people who lack the mental capacity to consent to necessary treatment in a hospital or care home. Staff within this research were not always clear whether DoLS applied to extra care housing. At the time of the research the Deprivation of Liberty Safeguards only applied to hospitals and care homes, not to extra care housing. Instead, the Court of Protection must authorise any deprivation of liberty designed to ensure that a person gets the care or treatment they need in a setting that is not a hospital or care home. The Law Commission (2017) report on the revision of DoLS suggested that changes are required¹⁸. They recommended that DoLS are repealed as a matter of urgency and are replaced by a new scheme called the Liberty Protection Safeguards. The new safeguards would streamline the process for assessing whether a deprivation of liberty is necessary and obtaining the required authorisation (Parkin, 2017). The proposed scheme will apply to any health and social care setting, not just care homes and hospitals, which will include extra care schemes.

Retrieving people who had walked out of unlocked public areas in the schemes was a significant issue when considering whether people living with dementia could stay in extra care. Being disorientated and getting lost outside was one of the key issues for participants. The issue is one reflected in other extra care schemes outside this research (Healthwatch Wokingham Borough, 2017, p. 9), and will be discussed further in Chapter 6.

¹⁸ At the time of writing the final draft of this thesis (February 2018) the Government had made an interim response to the Law Commission's proposals (The Law Commission, 2018). The response welcomed the Law Commission's report and confirmed that they will be engaging with a range of stakeholders to understand in greater detail how the Commission's recommended changes can be implemented. The Government confirmed that it will provide its final response to the report in Spring 2018.

Being unable to manage purposeful walking may trigger a move from extra care, but there are strategies that can be explored first to minimise the negative impact of 'wandering'.

Two examples were given. The first was to help someone orientate themselves inside the scheme, which involved making the door to an individual's apartment more recognisable. Although personalising a front door was generally viewed as a helpful strategy for people with dementia, there were some barriers to doing so. One carer said:

It's a fire hazard, we're not really allowed to personalise the door. I suppose if it were signage, that was fire proofed, it would be fine.

The carer then went on to indicate that apart from the potential fire risk, personalisation of doors may be seen negatively by saying:

I've seen that [personalising doors] ... We'd start becoming residential then wouldn't we... You don't put a picture of yourself on your front door, do you?

The second example illustrates how staff supported a resident who needed to go outside:

Bob moved into extra care, has had a settling in period where he was all over the place... He's got a very good personality, and if you get to know Bob, and you get to know his history and background, and you talk to his family [...] And it's the approach with Bob that is important. If you were to be telling him what to do, he won't want to do that. But if you make Bob think he is making that decision, that that's what we should be doing, he's happy. He's happy with that. Sometimes you know, he will want to wander outside without his coat on, and it's absolutely pitting it down with rain. Now if we were to say to Bob 'you need to go and put your coat on' he would say 'No I don't, and I'm not'. But if you were to say 'Oh, flipping heck Bob, you know, it's cold out there, it's nippy out there, well I've got my coat on, where's your coat?' and we encourage him to get his coat and he's fine. Some of the other people who live there think Bob shouldn't be in extra care. They say 'Bob shouldn't be here. Why have you brought Bob here?'

A national extra care provider described how their staff use a framework to explore what might cause the walking; the biological reasons for someone walking with or without purpose; the psychological reasons, or social

environmental reasons (James, 2011, pp. 27-32). Possible solutions would then be considered and might for example, include the use of telecare and targeted deployment of staff. The possible solutions attempted to address both safety and dignity issues for the individual in a supportive environment.

4.5.5 When risks compromise the individual

Even when extra care offers a supportive social environment, the barriers of the built environment may be too difficult for that person to manage safely and with dignity. It was suggested by participants that if safety and dignity were compromised it may be appropriate for the person to move to a less disabling environment like a care home. A senior manager of a national extra care organisation said:

Living in a care home can be great [...] There are social environments that we can control [in extra care] but built environments cannot be substantially changed.

He went on to say about residential care homes:

The design of the building can provide a really good environment and there can be constant company... but relatives hear the term 'locked in' and 'care home' and it seems like a lesser option because of stereotypes....

Unacceptable risk taking, which was frequently cited as a reason to consider whether extra care continues to be suitable for individuals with dementia, is discussed further in Chapter 6. Unacceptable risk taking was linked to keeping someone safe.

Safeguarding issues were explored by both staff and manager participants. One issue was a complex case involving possible financial abuse by a family member; six were around issues either of likely deprivation of liberty within the extra care scheme or having an individual who might abscond or go missing; and three were potential instances of intimidation or bullying from other residents.

Intimidation or bullying is a difficult situation to address but it was not considered appropriate for management through safeguarding procedures. The safeguarding lead for the authority thought that managers and staff at the

scheme should manage the interpersonal dynamics of residents, but it was not clear locally who should be responsible or whose role it would be. There were examples of tenancy agreements being used in resident meetings to remind residents to be respectful of others; but tackling intimidation and bullying at an individual level was deemed problematic by residents, staff and managers alike.

Tackling difficult issues of behaviour and potential abuse became more complex when individuals with dementia were the abusers rather than the one being abused. Understanding, and preventing or effectively managing behaviours that may lead to potential safeguarding situations, are likely to be more effective if an individual's premorbid characteristics¹⁹ are known. Examples were given by the safeguarding lead, which reflected the difficulty of safeguarding individuals both in private domains such as their own apartment, and in public environments. A private situation was described where there was a history of domestic violence between son and mother; the son had mental health difficulties and the mother then developed dementia. In this instance safe contact between the two was arranged in the public areas of the extra care scheme. A second example involved an individual from the community with a history of sexual offences who was regularly making visits to female residents at a scheme. Safeguards were put in place to make sure that he never went to their apartments with them on their own.

Whilst recognising some of the potential barriers to someone living well in extra care staff, managers and residents in this research also demonstrated a strong commitment to helping individuals settle in to live a normal life. One carer said:

And people that we have got here living with dementia, some of them are quite rightly placed, and they do live a normal life with help from care staff. We have had hiccoughs, we have had to go down routes of how can we solve this problem? Ummm... but it's worked out for certain people. But we've still got issues ongoing with other people, but a lot of our problems come from the people without dementia; they're the ones that stir it, yes... [they ask] 'what are they doing here?'

¹⁹ Premorbid characteristics as used here refers to the characteristics that an individual had before the onset of an illness or disease, in this case before the onset of dementia.

Another carer commented that extra care was appropriate for people with dementia when they said:

God yes, I think some... people... it's life [*it being dementia*]. It's happening, so yes, and it's a lovely place for people to be, a lovely place, yes. And it's safe, so why ... it's happening! [people with dementia living in extra care].

4.5.6 Living well reviewed

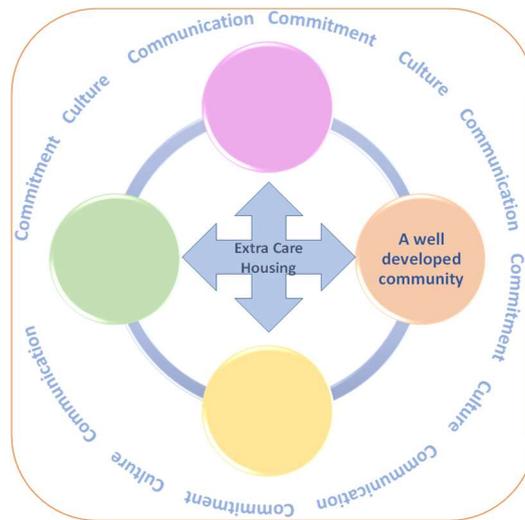
At the start of this section it was noted that it was difficult to describe what living well looked like. Some of the less tangible factors that help individuals to live well in extra care, including those living with dementia, have been explored above. Understanding dementia and providing person-centred support are key to having a positive approach to managing risk and safeguarding individuals appropriately. Being able to understand the person behind the dementia was an important factor in how other people, including staff and other residents, responded to the person. Staff and managers described how they grappled with getting the right balance between promoting individual freedom, managing behaviours that can challenge, managing risks and helping someone to live as normal a life as possible. Residents who participated in the research also showed insights into the dilemmas posed by this balancing act.

The link between personal space and community life started to be explored. Participants often referred to the culture in the scheme but were not easily able to describe what made a good culture. An important aspect for many was the friendliness of the place, and the added value of having a community. This will be explored in more detail in the next section.

5. CHAPTER FIVE: DEVELOPING A COMMUNITY AND SUPPORTING INDIVIDUALS

5.1 DEVELOPING THE COMMUNITY

Ageing well is often contextualised in terms of older people living within their local communities, ageing in place, or having a sense of community. The concept of community has a long history in both sociological and policy terms. The positive role that community, social networks and social support play in



helping individuals feel socially and emotionally connected was explored in Chapter 2. This section sets out how participants in this research experienced the community aspect of extra care housing. The role of community in relation to these findings will be further explored in Chapter 6.

5.1.1 What is community?

Some of the residents described taking part in community life so that they could have company and benefit from interesting activities; be less of a burden on their own family; give something back to other people; and because they were afraid if they didn't use them, the services or facilities might disappear. One resident developed community activities to provide custom for the caterers. They were worried that a possible change in caterers might mean that they had fewer social events at Christmas and commented:

I've organised it all. We are getting a New Year's buffet because I thought we weren't getting a Christmas dinner and stuff like that. So, I went ahead and said, 'can it be paid for?'. So, it is. So, we have got a buffet for New

Year's Eve. So at least we'll have some social gathering. Jeremy is going to put music on and we can all enjoy ourselves.

Residents were also positive when they described reasons why they didn't take part in the community activities, such as being happy with their own company.

One resident, Zoe, said:

A lot of the time we are happy [in their own apartment] but I do like friends when I come down, and as I have said, we have experienced nothing but kindness when we have come down occasionally you know...

For Zoe there was a sense of belonging without having to take an active part in the community, because she felt she had things in common with other people there. The relationship with others in the community was less positive for another participant, as suggested by Audrey in Section 4.5.2 . Not only did the interaction with others not satisfy her own needs, but the exchanges with other people made her feel more isolated. Audrey commented:

I just can't leave him [husband with dementia] on his own at all, and I don't come down a lot [to the community] because he's a bit embarrassing... so I think we stay up there [in the apartment] more than we would normally do.

Provencher et al (2014, p. 4) describe community as having a set of shared interests and shared belongings. This provides an insight to why 'community' might be described as something that sets extra care apart from other forms of generic housing for older people such as sheltered housing. At one of the focus groups a manager said:

You only have to look out there, and the residents really are proud of their scheme. You know, they do all these kind of things, like book stalls, you hear them say 'I've more or less taken over the shop and am doing this now'. You know, it's great, and that's what these places are all about, to actually, to ... for the clients to put something back into the community and actually manage themselves in some respect.

Participants said that individuals living with dementia who were part of the community could live better in extra care than those who weren't part of the community. Residents at one focus group said:

There is community spirit. I think we support one another as best we can. And I think we identify people with needs, and we've had people in here with Alzheimer's who have needed a lot of care and support, and they're not, sort of, segregated. They are part of it, aren't they?

But developing a sense of community isn't always easy. Audrey chose to isolate herself because of her husband, but there were other examples where individuals were alienated by other individuals or groups. As one manager said

It had been reported that the residents had been quite negative towards some other people, and not wanting to speak to them, not wanting to interact with them, excluding them from certain areas....

Stories told by participants in this research revealed that respecting privacy and reducing unwanted isolation, and managing relationships were essential characteristics for a well-developed community. But on their own they weren't sufficient. Participants described how a well-developed community also relied on people being helped to take part in community life, and having the right facilities, which depended on where the scheme was located and what else was in the neighbourhood. Characteristics deemed to be essential in developing a community within this research are shown in Figure 5-1.

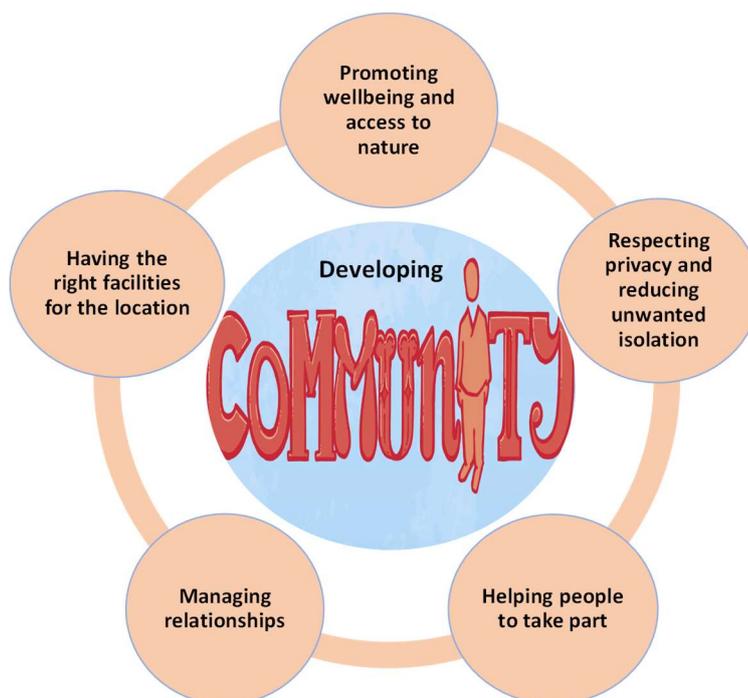


Figure 5-1: Characteristics described as essential to a well-developed community

What appeared to be important when talking about the facilities was not just what the facilities were, but who ran them and how person-centred they were.

One resident commented:

We was promised a café, that was open 24 hours, well 7 days a week really, we was promised a shop. We was promised lots of things that didn't materialise. We had to set up the shop ourselves.

The original intention had been for the extra care housing provider to arrange for the shop to be managed commercially, but this did not happen. Although residents complained that they had had to set up the shop themselves, it was an obvious source of pride for residents who ran it, giving them a role and identity within the scheme.

Some concepts of community define it as being physically bound by its setting. It is interesting to note that this was not the case for one resident, George, who described multiple relationships or communities that were important to him. For George, being able to use technology to keep in touch with his biological family community around the world was as important as the community that was being fostered within the extra care scheme. It was clear that whilst there were some areas of shared interests that promoted feelings of community involvement (such as the film club and activities groups), there were also a range of individual motivations for taking part in community life.

5.1.2 Support for communities

The support provided to help individuals or groups to set up or make use of facilities or group activities within the two extra care schemes was of significant value. There was a marked contrast in the level of community involvement between the two research schemes and a third scheme in the local authority. The third scheme was community-led from its inception, which had a 'massive impact' on the community and volunteer involvement in the scheme. There was a formal 'friends group' who supported community activities. The manager of the independent care agency that provides the on-site support at the scheme said of the 'friends group':

We work together. Sometimes they'll send us for somebody [to take part in an activity], and sometimes they'll go, knowing that a different face would help bring them out.

Volunteers and care staff working together well was described as key to having a well-developed community at this scheme. There was obvious respect for each other's roles and a commitment to providing person-centred responses. The attitude of volunteers was mentioned by participants in both the research schemes. One social worker encapsulated it when they said what helped people to take part in community activities:

It's that volunteer type role isn't it, but having somebody who understands the needs of the tenants, it's not about herding people is it, it's about engaging with people isn't it...

There was also discussion about the nature of the support provided to residents who wanted to set up their own activities within the community. Examples were given of support from wider community links with voluntary groups. One participant, Josie, talked about a group she was setting up in the extra care scheme. She seemed concerned that the person from the local voluntary group was taking over and described the volunteer as patronising.

At the same scheme, housing funds had been used to contract with a national voluntary group to recruit volunteers and support them to work within the scheme. This had not been successful, and the contract had not been renewed. One of the senior managers from a different national extra care provider said that they had provided a volunteering and activities toolkit for managers, which was built around the 'five ways to wellbeing' (Government Office for Science, 2008). The guidance provides managers with information on how to recruit and support both internal and external volunteers, as well as guidance on how best to promote events and activities. They recognised the variety of formal and informal volunteer roles and the range of residents, staff and external people who would volunteer. Significantly they recognised regional variation in approach and priorities to volunteering and described how that can impact on the culture and ability to get the community to come into the scheme.

Commissioners and contract managers who were interviewed also felt that stimulating community, sourcing volunteers, and enabling activities was a local responsibility, with debate about how far the local social work teams should get involved.

5.1.3 Negotiating between private and community living

Being able to work together to develop community activities and encourage resident and wider community engagement was a key issue at both of the extra care research sites, requiring skilful negotiation of public and private space and public and private lives.

The primary community is the extra care scheme itself; but it cannot be divorced from its immediate surrounding neighbourhood, which provides the wider community. Negotiating how much or little neighbours should use the extra care community facilities is an ongoing process. In one scheme a neighbour with visual impairment relied upon the café for his daily meal and was welcomed into the extra care restaurant. Whilst there were examples such as this, that the extra care schemes were being inclusive of people with specific needs from the neighbouring community, there was also a suggestion from participants that more could be done, and that more activity would enhance the viability of the scheme. Participants in both schemes believed the caterers were not operating a business model, and not promoting or marketing their service enough. For example, one manager said, of a scheme that wasn't included in the research:

I think xx scheme is used more by outside people in the community there, the restaurant cafeteria. Yes, it's advertised well. I think they have had some good caterers in there. But the last time I was talking to Janey, it's a while back, but certainly people were using the restaurant cafe from outside. And I live close to where xx is, and I drive past, and I'll see notices put out on the walls, what's happening within the restaurant... you know... got this special on. We've got Mother's Day coming....

There were suggestions that free access to the rooms and facilities could be offered to external groups to run their activities within the scheme if they benefited extra care residents as well.

When talking about the use of public spaces and what might make them more attractive and appealing, one participant, John, suggested light background music might help in the restaurant area. Another participant, Zoe complained that the clatter of plates and noise from chair scraping was too much for her husband to bear. Skilful and sensitive negotiation of ambient noise and noise pollution is required to encourage community participation and make the communal areas attractive to visitors.

Discussions at the focus groups highlighted the use of the external environment and access to nature. Each of the extra care schemes had gardens that were private to the residents, and both schemes welcomed pets. Animals played an important role for several participants. Sarah spent a lot of time in her own apartment, and she recognised that her cat provided a means of her keeping in touch with other residents when she said:

Everyone comes to see me, but they are really coming to see Chaddy (the cat) ... [Laughter]. It's true, and I say, "don't forget I'm here".

Some residents accessed the garden as part of looking after pets or seeing the wild animals. The habits of one of the local grey squirrels was a subject of much discussion after one of the participant focus groups as the squirrel appeared to want to come inside and join the group! Gardening was an extension of a lifelong hobby for George. It was a great sense of pride to George that he had developed the garden from the building site when the extra care scheme was set up. The garden also gave him a link to the wider community when he had to use one of his contacts to help source some of the gardening materials because there was only a limited budget. Gardening kept George fit, it gave him an opportunity to get outdoors, and a chance to share produce with other residents and with the cook in the café. It enabled George to continue with a personal hobby and made him a figure-head within the extra care community.

When talking about gardening and other activities within the extra care communities there was an acknowledgement that the dynamics of the community are affected by the profile of resident's needs and the availability of

people to help them take part. Residents at one scheme said that there were not enough volunteers to help people who were more dependent to take part. Other staff commented that they don't really get involved in the dynamics of setting up groups, of people and their behaviour in the communal areas, that it was more the role of the housing staff. In contrast, care staff at a scheme which was not one of the two research extra care schemes were very positive about the many activities they could do with residents at the weekends when they were on site and not occupied with planned care calls.

It was evident from the range of discussions across the range of focus groups that staff can play an important role in developing friendships. There were comments at both extra care schemes about the café being a place for meeting people and developing friendships rather than just a place for eating. The café staff were important in make introductions and initiating conversations between different people who didn't know each other. Staff were catalysts for individuals to reach beyond their private lives to make connections with other people in safe, public environments. Direction from managers was sometimes described as creating a barrier, with one example given from a staff member who said their manager had told them not to get too friendly with residents, as they didn't have the time. This was particularly hard in one instance where the staff member had known the resident before they had moved into extra care.

There were also comments from both resident and staff participants that the extra care community could provide support for couples living with dementia. One staff member said that the staff are a support to the person who hasn't got dementia, that their support enables the carer to go out and do what they want for a short time, that they have someone to talk to, and don't feel alone. A social worker commented about the benefit of extra care for a couple who are living with dementia:

There's also a little bit about the carer, who is also able to mix normally with other tenants, so it gives a positive normal experience for them, so that's why it's alright for couples [living with dementia in extra care].

Caring for someone with dementia at home can be seen to be socially stigmatising, challenging or an onerous duty, but it can also be an opportunity to have a shared investment in creating liveable arrangements and doing things together (Van Hoof & Kort, 2009; Beard, et al., 2012; Savitch, et al., 2015). The result can be that a couple living together with dementia can become voluntarily or inadvertently isolated from others if they retreat into the private world of their home. In contrast, one participant George, described how the care team had become the community for his wife who had advanced stages of dementia and wasn't able to leave their apartment.

It was clear from discussions with resident participants that even though they may not know each other well, they cared about each other and worried if they did not know what was happening to them. Keeping residents updated on what is happening to others was an issue for residents and staff alike. There was a strong ethos of confidentiality and not sharing information without someone's permission. In practice, lack of information caused residents to worry and be concerned about each other. There was general agreement amongst staff about not sharing personal health information without the individual's permission, but there was also a level of puzzlement expressed by some residents in some situations. Two examples stood out, when someone had died, and when someone had transferred to hospital. For example, one of the residents said they had been concerned about a neighbour they had not seen for a while:

And then there was the person across ... in the very flat opposite us died, and I didn't know he had died at all. It took ages to come out, the news that he had died.

In contrast, at the other scheme there was a notice on the communal lounge to advise residents when there would be a funeral for one of the residents who had died. There was an assumption that the matter of the death was public knowledge, but that the details of how the person had died should not be shared. This was especially important in one instance where the resident had died in unfortunate circumstances. A further example was a comment from a resident that *"We don't get to know if people are in hospital"*. Residents

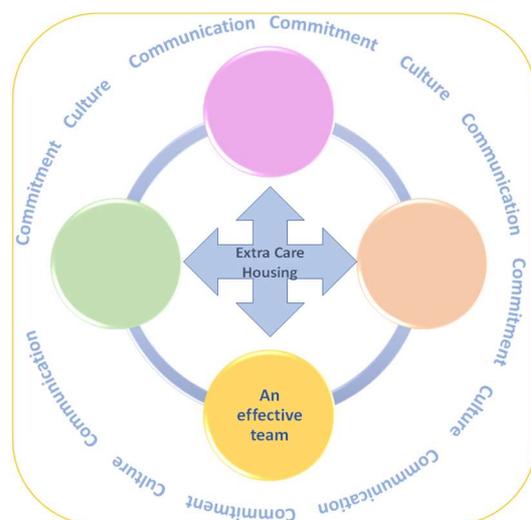
reflected on how the lack of information had made them feel, including sad that the person in hospital may have felt abandoned, and wouldn't have known that the other residents would have wanted to send wishes for a speedy recovery if they had known.

Skilful negotiation of public and private lives and public and private space is required to develop a harmonious extra care community. The level of harmony will depend upon the nature of and culture of different groups within extra care communities and how easily those groups co-exist. A further examination of the role of groups in extra care will be made in Chapter 7, exploring how individual groups contribute to the whole extra care community.

A well-developed community was described as adding value to the extra care schemes. It was what made the difference between living in their previous home or in generic housing for older people. Development of the community involves effective working between residents, staff, and the wider community to make sure that there are the right facilities, and that people can take part as much or as little as they are able or want to. The next section will explore what the different participants thought was important in developing an effective team of people who can support individuals living in extra care with dementia.

5.2 HAVING AN EFFECTIVE TEAM

Most of us are familiar with the expression 'the sum is greater than the parts'. This was especially pertinent in the focus group discussions about how individuals are supported by the whole team in extra care. The teams included care staff, housing support staff, housing management staff, catering and cleaning staff, social workers and other professionals visiting people living in the schemes, as well as family and other



professionals visiting people living in the schemes, as well as family and other

residents supporting each other. Four elements of team work were said to influence the experience of individuals with dementia living in extra care. The four elements illustrated in Figure 5-2 are: strong leadership; managing resources and the capacity of staff and volunteers; developing skills and competence in staff, volunteers and residents; and being clear about staff roles whilst at the same time reducing boundaries.

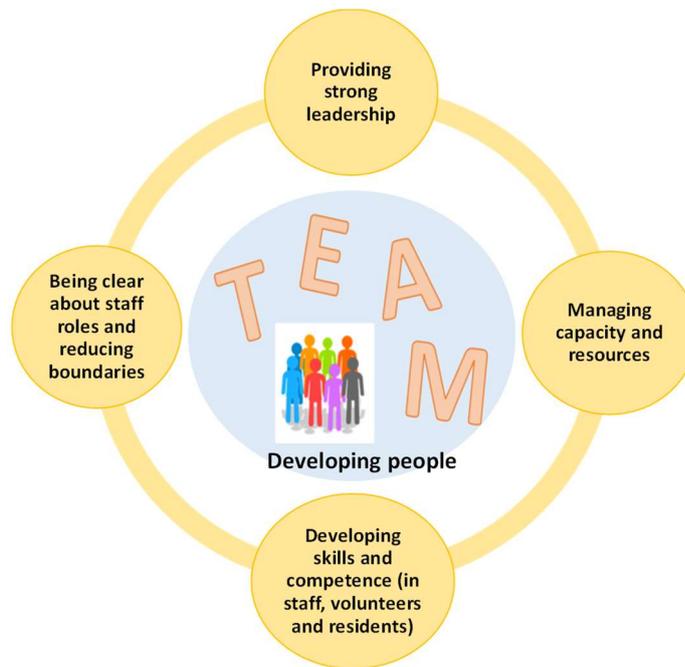


Figure 5-2: An effective team to support individuals in extra care

5.2.1 Leadership within a housing and care setting

Extra care involves several organisations working together to deliver housing, care and other commercial services to a core group of residents and a wider group of friends, family and local community neighbours. Leadership within extra care may be better described as ‘leadership within and across organisations and people to deliver services to residents’, and yet that still doesn’t capture the range of formal and informal leadership styles seen in this research.

The various organisations involved in delivering extra care are not established within uniformly agreed delivery structures. Each extra care scheme seeks to consolidate its working arrangements through contracts, service level

agreements, or joint operating agreements. Leadership across diverse management arrangements can be challenging, particularly if there are not clear operational boundaries between the different organisations involved. A typical example was provided in one manager focus group where it was said:

It's a complex situation to try and unpack, of what the issues are, because you've got multiple different agencies, with different agendas all coming into the mix... with all different priorities as well. But I think there is this kind of cloud thinking. I don't think the reality of it is in line with the expectations.

Extra care is still relatively new in relation to other forms of accommodation or housing with care and support. The extra care environment demands effective leadership within nascent organisational structures, where organisational behaviours are still developing and where there are still varying expectations across the profession. One manager described how she felt when the extra care scheme first opened:

I was extremely green about how extra care worked, and I was very glad of the leadership of the project manager, and I've missed that leadership since the role was lost....

This research revealed that although the vision was for the extra care partnerships to deliver person-centred services, there was a tendency to hold onto single organisational ways of working typical of existing structures for housing and care services outside extra care. This seemed to create a tension for front-line staff members who were trying to work together across agencies each with different operating protocols and guidelines, leading to organisational barriers for cross-agency provision. One manager who recognised the tension between the different partner agencies offered another comment on the value of having a project manager who supported the initial opening of the scheme:

She was the hinge-pin between us and our partners and worked closely with people in partner organisations to pursue things on our behalf...the leadership of that person was very, very helpful.

In this context the project manager provided leadership to address issues faced when the extra care schemes were first set up. The role continued as the schemes became more established, and as changes in the external economic

climate started to impact on availability of resources. The impact of her role was mentioned in a comment about maintaining a balance of residents with different levels of care as set out in vision for extra care:

The project manager was battling [at the allocation panel] all the time, holding them back, and when she left it was a case of ... all of a sudden, the flood gates seemed to open and all of a sudden, the allocation had been done.

After the extra care schemes were established the project manager role was withdrawn and the lead responsibility shifted to local managers to deliver the strategic vision within the scheme. Different types of leaders and followers are discussed further in Chapter 6.

A range of issues arose within the focus group discussions around providing strong leadership and managing the service. For example, the role of managers in setting out whether the scheme was 'independent living' or 'extra care' was frequently discussed:

I think that we've got a lot of people in here that, to me, didn't need extra care housing [...] originally the problem here was that the majority of the independent people here, especially the leaseholders, that invested their life saving or whatever into it, were sold a very wrong picture.

In this example the manager thought that the wrong expectation had already been set before the person moved into the extra care, and that it was then the manager's role to try to match the resident's expectations to their own view of what could be provided.

Within the extra care research there were discussions about the degree of staff flexibility to respond to residents, and the lack of clear direction from management. One staff member remarked:

There is no consistency in management directives and I feel that I am spending more time supporting management than residents, and I could be spending more time with the team and residents.

Management and leadership are two different functions, but both can be undertaken by the same person, as described in more detail in Section 6.5.1. Someone may be designated a manager, but leadership is not a role bestowed

on any one person, rather it will typically emerge within a given situation. Leaders may appear within groups of managers, staff and residents, and will be influenced by those around them. For example, one manager said:

I think it is important not to underestimate the level of power that this residents committee actually has. There are some strong characters on there....

Informal leadership from such groups may not be viewed positively by others. For example, one carer said:

There's a bit of power within that, what we are talking about is members of the tenants committee. So, we have got a group of tenants who actually fund-raise and put on events, and I think slightly, that might have gone to their heads.

This was echoed by residents who said:

We formed a residents' committee and I was one of the main group, I'm not now. So, the onus was on us to make people welcome. So, when we knew somebody was coming in, we would go up to them and say, 'I am xx, etc'.

The conversation then went on to imply that the new residents' committee no longer takes the lead in welcoming people, that new residents "*just sit in their little flats*", with an onus on staff to help them to settle in and develop new relationships with other people. This shift is symbolic of changing relationships between different members of the extra care community, and where the locus of power lies. There was insufficient evidence to suggest residents have become more, or less, empowered and involved in the everyday running and functioning of the scheme because of the reported swings between an independent living model and a more heavily dependent extra care model. It is an area that could be usefully explored in future research.

5.2.2 Staff roles and boundaries

There was some overlap between staff and resident roles in providing support to residents, especially when it came to settle in new residents, and helping less able residents to take part in activities. At times this was seen positively, but

there were also times when it was expressed as an unwanted burden for residents. One resident said:

Fifty per cent of the caring is done by us [the residents], if we see somebody who has got a problem, we help them.

Another resident commented:

It's their [staff] job to persuade people to come down and say, 'would you like to come down and meet'... and join the craft class or whatever it happens to be.

There was also a significant difference across the two schemes. The manager from one scheme said that members of staff bring people down for meals, take them for appointments, and help them to use the facilities of the scheme. The manager from the other scheme expressed surprise at this and said she was very clear from the beginning that they don't do that for individuals unless it is budgeted in their fund and in their plan. Both managers discussed the grey area of who funds such unplanned support to meet identified needs, and who organises the support.

There was an interesting comparison made about housing support available at each scheme. The amount of available support differs across schemes and partner arrangements but has a direct impact on the level of activities and support provided. One member of staff commented:

It's little needs that people have that I expected the housing support worker to do... engaging them to come to groups or determining with individuals about what other needs they might have with housing... it's not care, but it would help them with their whole life if there was more availability for that... and we're looking to each other to bridge that gap, but nobody is....

A housing support worker also described some of the difficulties in knowing where the boundary lies when they said:

We'd remind them to come to activities, because I do wellbeing checks in the morning, and I'd say, 'don't forget there's this coming on'. And even though I have given them that information I would also then ask the team, if we are free, to tell the people that had forgotten that I had told them in the morning, to come to the event. There's a line between telling people and helping them to come down to take part.

There was a grey area relating to the question of whose role it was to help residents to come down to activities. Residents should be able to expect to receive a safe, good quality service that respects their dignity, protects their rights and meets their care needs (Care Quality Commission, 2015). Housing support staff are not registered with CQC and are not able to provide 'personal care', as defined by CQC. Helping residents to come down to activities is not classed as personal care and can be provided by both care and housing support staff.

In practice two main factors affect which staff member provides the assistance. The first factor is whether moving and handling is classed as personal care. Although moving and handling is not one of the activities defined as 'personal care' under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 No 2936, there was nevertheless unanimous agreement from participants that housing support staff could not move and handle people. This common perception prevented housing staff from being given appropriate training that would enable them to attend to specific residents who had moving and handling requirements. One of the residents said:

The thing is they make up silly rules as they go along. Now it's a place where people are going to be either elderly or disabled. Then... ask them to take you somewhere in the wheelchair and they're not allowed to push wheelchairs, they haven't done the exam.

When reflecting on the entrenched positions taken on moving and handling, one of the senior managers commented that:

We've always, I suppose, in historical times, been more risk averse around moving and handling, and there's other people's roles in that, and we don't want to get in a mess doing it badly. I don't think it necessarily needs to be rigid [about not supporting people with moving and handling]. It should be something we should look at.

The second factor that determines who responds to a call is which staff team has the most time, with each staff team thinking their own as busier than the other team. By default, each staff team thinks that the other team should help individuals to come down to activities. One suggestion that occurred in almost

every focus group was that there should be 'floating support'. For example, one resident said:

But the thing is, the carers have got their schedules. And they cannot leave that schedule for every pull cord. They can answer it by the telephone, and check if it is an emergency or not... There should be somebody that's taking charge of the phones so that the onus is not on the carers, because that person can field those phones, and if it's somebody with Alzheimer's that just needs a little bit of reassurance that can be done over the phone or whatever....

Similarly, a manager described the advantages of a floating support staff member in the following conversation:

You have your rotas, but then you also have additional staff that are floaters to address things like that, so that if you have someone that is discharged from hospital, maybe you need extra support for a while, maybe you can stick that in. If you've got someone that has got a UTI and is wandering a bit, or is a bit off colour, you've got someone that can intervene. And, also have the time to build up those relationships.

The concept of a floating staff member, drawn from the many discussions, is described in more detail in Section 6.5. Although a potential floating support role was described variously by housing and care staff, by residents, and by managers, it was implied consistently that such a role could help the teams collaborate better to provide the right support for individual residents.

There was some evidence that residents did not always know, or care, which provider employed individual staff members, they were more concerned about who the staff member was and what they were able to do, which is consistent with other research findings (Cameron, et al., 2014). Figure 5-3 sets out the typical staffing structure in the extra care schemes. Although there were discussions about the difficulties caused by organisational definitions of staff roles, there were no questions raised about whether the staffing structure within or across the partner agencies should be changed.

There is inconclusive evidence of a best practice model for the varied roles within extra care housing, but it is incumbent upon scheme managers to make

sure that they are integrated into a person-centred service. One manager commented:

The structure of the funding does create some inflexibilities, but I think that, with that needs to come some kind of policy around if there was more flexibility around funding, how it would be used, what it would be used for.

A care worker commented that there are divides between housing and care providers that put barriers in the way of team working, creating a “them and us” situation. Another manager commented that lack of experience and lack of understanding of roles can lead to one manager inappropriately treading on another manager’s territory or responsibilities. One senior manager interviewed recognised that currently different partners have different agendas and emphasised the importance of leadership and communication to negotiate and mediate the tensions between managers over boundaries and responsibilities.

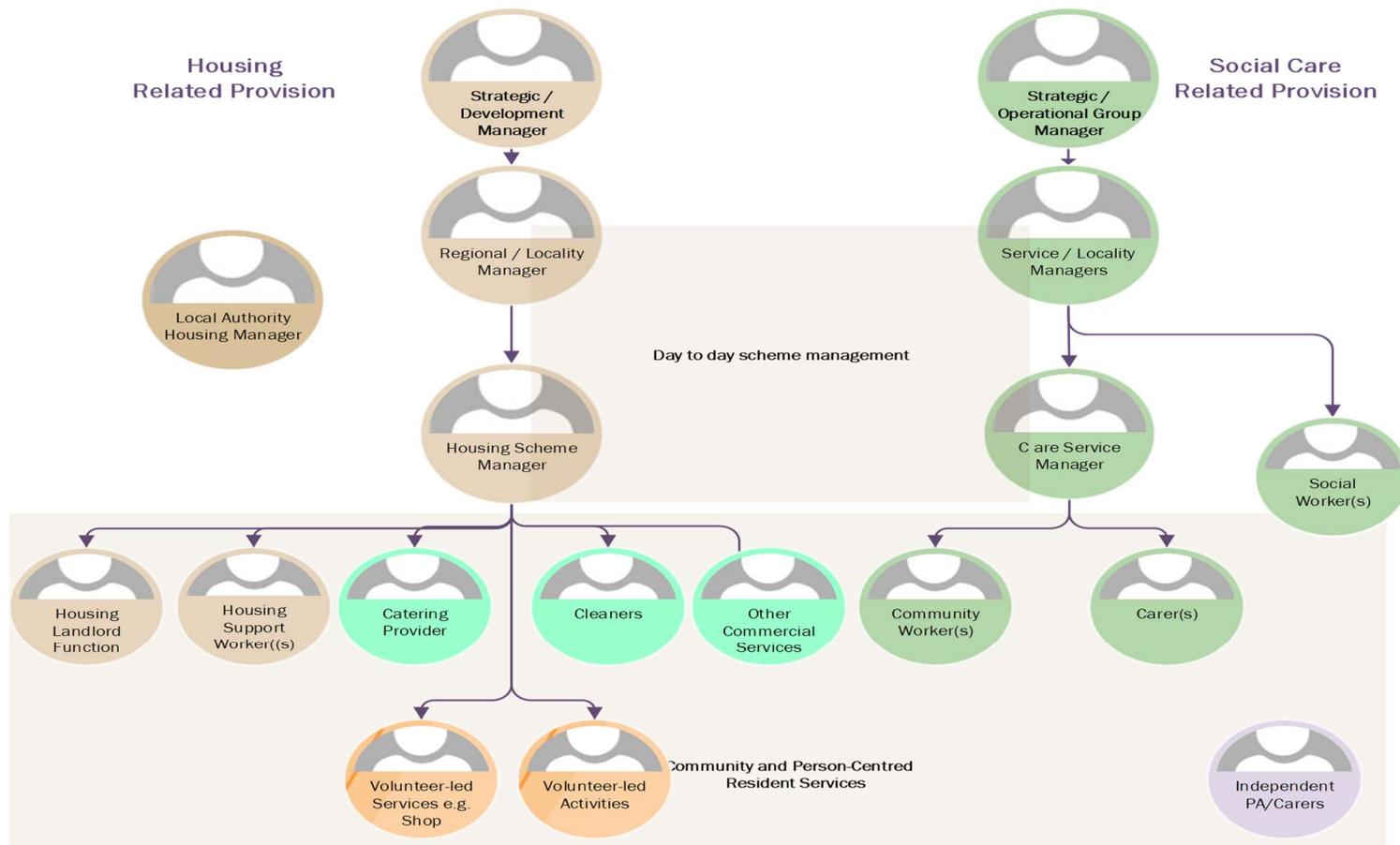


Figure 5-3: Typical structure of case-study extra care schemes

A second role that was frequently discussed was the role of the social worker. Across the two schemes there had been different models of social work used. In both schemes there was a dedicated social worker from the local social work team during the initial opening period of the scheme. Once the schemes were open the models changed. The changes included three different models; having a social worker dedicated to all eligible residents at the scheme; each eligible resident having their own social worker but having a dedicated social worker to attend allocation panels; and having a social worker spend dedicated time at the scheme each week and available if residents have social work queries

Although there was no conclusion in the discussion about what a preferred model for a link social worker would be, the different responsibilities included: visiting the scheme and being available; getting to know residents; signposting or short social work inputs that don't need an allocated social worker; reviews of people in the scheme and identifying or micro-commissioning services that might support small groups of residents together; and safeguarding referrals. One social worker commented that:

If you've got a link social worker, we've got to be clear about how we use that worker. Otherwise they get bogged down in the minutiae that they wouldn't normally know about... and....

There appeared to be value of a link social worker getting to know the scheme, understanding the dynamics of the scheme, and being easily accessible to residents, staff and managers in making a bridge between the different groups involved. Social workers having detailed insights to the scheme dynamics was considered helpful as part of an integrated and person-centred approach that would help individuals with dementia to appropriately move into the scheme, and help the service adapt to any challenges as an individual's dementia journey progressed.

There was less consensus on the potential for a link social worker to stimulate community involvement and take on the 'community worker' role, with further recognition of the constraints of how linked social work posts could be funded and deployed.

5.2.3 Staff, volunteers and service providers working together

As described earlier in this section, volunteers and care staff working together well was identified as key to having a well-developed community in extra care schemes. Their roles can be enhanced if everyone is able to develop the required skills and competence to work effectively as members of the team.

The development of skills and competence in staff, volunteers and residents was considered by the focus groups. Participants identified three main areas where this was important: sharing information, awareness of dementia, and detailed understanding of dementia.

There was much discussion about the advantages and limitations of sharing information about individuals, especially where the team supporting individuals was made up of people employed by many different agencies. There was also discussion about whether and how a team approach can help individuals with dementia to live in extra care. It was evident that information is collected, stored, shared and destroyed appropriately with the right permissions in place to share and protect the resident's information.

All staff members were concerned about sensitive personal data relating to an individual's demographic background and their physical and mental health and wellbeing. Staff were clear of the safeguards so that information is shared only with those who have a legitimate reason to access the information. Some staff found it obviously frustrating, as expressed below:

My view has changed a little since we last met. Yesterday some of the residents accused us of neglect because a resident went out and we let him. This is because of the way the other residents perceive him and how safe they feel he is to do that. The difficulty is that we cannot have a discussion with others about why we have to do that without divulging personal details about him.

Even amongst different staff groups providing support to the same resident there are limits to what information can be shared. This is particularly relevant with staff who are employed by businesses commissioned to deliver a

commercial service within the scheme such as the café or hairdresser. In one scheme it could be seen that catering staff had built up a very good rapport with residents and were providing added value both through the social support and the personalised service they offered. This appeared to be driven by the catering staff taking the initiative and taking time to get to know their customers. The value of business suppliers working with extra care providers and residents is explored in more detail in Chapter 8.

At another scheme the housing and care staff reported that they tried hard to encourage catering staff to provide a personalised service, but it was difficult without sharing confidential information, as was evidenced in the following comment:

I think it's not just us the care staff, there's the hairdresser and the café. Especially the café, we have people with dementia, you know, how they are responded to and how people interact with them. You know a lot of the time I will make sure that I go up and say... 'you know this lady; can you make sure that... can you go up to her because ... I'm always trying to divulge you know, this is what they need... so that they've got that support.

Trust is one of the five themes identified as important and necessary within an older people's care community to support an environment with healthy relations between staff and residents (Grimshaw, et al., 2016). There is a judgement call to be made by managers and staff about what is classed as confidential information and the level of information that can be shared about individuals. Appropriate and inappropriate sharing of information is likely to affect the trust residents have in staff and the level of community belonging that develops in a scheme. The ability to judge whether to share information about an individual living with dementia will be made more complicated for staff as they will have to ensure decisions on sharing information consider the 'best interests' of that person under the Mental Capacity Act (Office of the Public Guardian, 2016).

For others outside the scheme, such as GPs, the issue of whom information can be shared with is equally important. An example of a breach of information sharing was provided where a housing manager asked for private medical information from a GP practice for a review meeting. The surgery gave the

information, even though the individual had previously asked for the information not to be shared. Data protection requirements (Data Protection Act 1988) have been strengthened by The General Data Protection Regulation (GDPR) which came into force in May 2018 (ICO, 2017).

Extra care providers will need to continue to review their approach to data protection and allow individuals to have control over their information and to ensure health professionals, partners and contractors have taken steps to protect information adequately, to be transparent about the use of the information, and to be accountable for their compliance within the regulation. Sharing information about individuals is not always clear-cut, and extra care providers should support open and transparent discussion about the nuances and judgements that must be made by staff, and the impact that not sharing as well as inappropriately sharing information can have.

5.2.4 Developing skills and competence

Much of the rest of the focus group discussion on skill development was concentrated on staff training, but there was an acknowledgement that dementia awareness was needed by everyone involved including residents, volunteers and other service providers. At one focus group a manager commented:

I think there needs to be some level of education for those [residents] that have not got the level of experience of dementia or of anything else... for me it's more, it's the fear of not knowing, and it's obviously the not knowing is the knowledge isn't it? If you don't understand something you fear it [...] So I'm implementing having different services in to do coffee mornings for people. Not just based on dementia, but macular degeneration, diabetes, all those different aspects. Because I'm looking at the kind of clientele we've got here to see who would it be, who these support groups would benefit, and, also if anybody else is wanting to come along, so they can understand it a bit better.

There was a mixed view of training skills needed to help individuals with dementia live well in extra care. The local authority training department provided a highly regarded series of training programmes, ranging from half a

day, a day, to five days depending on staff roles and requirements. Ease of access was limited by budget restrictions, with some of the more detailed courses being targeted primarily at staff within specialist dementia services rather than generic extra care. This created frustration for care staff who commented that:

Individual residents with dementia do get worse... and in the meantime, we're trying to manage something we're not trained for. We do have dementia training but, to that progressive level we don't have the ability and the capacity to care for someone like that. It's frustrating as a carer, when you can't support individuals....

Providers of commercial business within the extra care schemes appeared to have very little training or awareness of dementia, but there was one notable example provided by a national housing association which had developed dementia e-learning materials to improve the knowledge of catering contractors and other sub-contractors.

There was a less clear dementia training pathway for housing support staff, with one comment that one-to-one support for housing managers on dementia would be preferable to training. There appeared to be little joint training across staff teams, except for safeguarding training which was provided on site.

Interestingly, the staff attending the sessions for this research said how useful attending the focus groups had been because it enabled them to reflect, share views and learn across staff teams.

5.2.5 Balancing needs and managing resources and capacity of staff and volunteers

There can be many organisations involved in extra care schemes, including housing support, housing management, care, catering, commercial outlets, and volunteer organisations. Each is likely to have a slightly different view of what extra care is. The relationships between organisations and groups is important in creating an effective team to meet the expectations and needs of residents, especially those living with dementia. The willingness of organisations, staff and volunteers to work co-operatively, to tread the line between enabling someone

to be independent and providing coordinated support, can be an important factor in reducing unwanted social isolation and loneliness, in avoiding or reducing behaviours that challenge the service, and enabling someone with dementia to live in extra care.

The aspiration to have an extra care population with a manageable balance of different care needs was frequently raised by participants. There were numerous debates about what the balance should be, and what it was. The allocation protocol and guidance in both schemes set out that there should be three bands of needs; a third of people with little or no care and support needs, and third with some support needs, and a third with quite substantial support needs.

The balance of needs is considered within the allocation panel each time that there is an allocation of an apartment to be made, taking into account the capacity of the care provider to respond both to each person and to the whole resident population needs. One manager commented:

I think we are certainly trying to maintain a third, a third, a third. When we look at things, the rotas for delivery, the direct care part of it, we are at capacity most of the time, so we are getting ... I think we are getting that balance right, most of the time. I mean obviously it does fluctuate depending on how many people you have lost in a particular time frame....

Another manager recognised the difficulty that swiftly changing needs can have on the overall balance of care linked to the sufficiency and deployment of the staff team, and the resulting impact on service delivery when they said:

I hate to bang on about resources, and I think the difficulty here has been the level of need can shift very quickly, you know. If you get a couple of people that, as I say have just been in hospital, discharged from hospital, their needs have increased, you know... I think what needs to happen in terms of the staff is, you know, there needs to be a resource supporting extra care that can draft staff in, can take staff out. I don't think that mechanism is in place.

They went on to discuss the pressure of care providers nationally in recruiting staff, especially those that may be required to have flexible contracts to reflect changing patterns of demand. There are different models of staffing in

operation in extra care schemes nationally. Many, if not most, operate a model that includes a combination of core hours that enable everybody to have access to limited care and support services, with additional tailored care packages according to assessed needs. Most extra care schemes operate a compulsory resident contribution to the core service as a condition of living at the scheme, and in return they can have unplanned²⁰ or emergency support within agreed parameters.

Limited resources featured in all focus group discussions, in relation to both national and local constraints. When talking about the flexibility of staff to spend time with individual residents one resident, Mary, commented on the constraints of local authority funding when she said:

We know them all [the staff] don't we? [Murmurs of consent from other residents]. It's not like they are in there [the staff room] and they are isolated from everybody, they're not. They haven't got the time... but it's the council funding isn't it? They're limited to what they can do. Its accountability isn't it, all the time.

The resident viewpoint was echoed by staff, one of whom said:

And then it's all down to money really... funding... Because you think with us being extra care, you'd think we have time within our rotas to help with all this, but we don't, we have back-to-back calls. Which you understand because it's a funding issue, we can't be here and not getting paid.

At a local level, the provision of a wellbeing service was intended to provide flexible unscheduled care for those who needed it. Instead it appears to have created rigidity, as one manager commented about the care service:

It's the inflexibility. Because one of the big bug-bears for me is this four-hour thing... you see the problem is the carer service is very much driven, it's very procedural driven. It's driven by rotas, it's driven by... you know... so actually it doesn't allow for that flexible ad hoc support very well. Not without it impacting on the rota, so to speak. And this is where you get to the issue, is actually, someone with say a dementia even, that is possibly doing a bit of purposeful walking, maybe exited the door.

²⁰ Unplanned and unscheduled care are terms that are used interchangeably by participants. They represent the care and support that are provided to residents that are not part of a time-tabled care plan or staff rota. They are also sometimes referred to as 'downtime'.

The manager went on to express some frustration when describing the impact of not being able to respond to the person with dementia who was walking either with or without purpose. Her frustration was because, as she said:

But you know, some of that can be diffused much earlier by just ... To us it seems like common sense stuff, but saying 'let's go in'... or 'let's go and have a brew'.

5.2.6 Sufficiency and deployment of staff

The sufficiency and deployment of staff was a common theme in all focus groups. There is a well-recognised national shortage of care staff (Carter, 2016; Rhodes, 2017; Slawson, 2017), which is impacting at a local level as well as evidenced by the comment from one scheme manager:

I mean xx [this local authority] is under massive issues about recruiting care staff alone anyway.

Innovative ways of encouraging staff to work in extra care were being tried, including staff from the community working periodically as part of the extra care team. The increasing difficulty of maintaining adequate staff numbers, together with increased care needs within the extra care population, was affecting the flexibility of staff to undertake different types of scheduled and unscheduled care. One resident, Mary, was particularly concerned when she said:

But unfortunately, that's what we are living in, today, isn't it? It's wrong, I'm not defending it, it ... because everything is geared to resources... [others murmur agreement] The Council can't support everything what we need to do, xx [the landlord] can't support what we need to do because of the resources, there's insufficient money to pay extra staff, there's insufficient money to get extra care unless there's direct payment²¹, and it's all to do with money.

On the other hand, the staff team at one of the schemes had a long discussion about what they were expected to do, and how the expectations had changed as

²¹ A **direct payment** is a scheme that gives social service users money to directly pay for their own care, rather than the more traditional route of having the care provided or arranged by social services.

the extra care residents had become less independent and needing more care.

On staff member said:

You see, I came in a year and a half after everyone else, and I was told to expect this stuff [laundry, shopping, higher care needs] in my interview. I think when they were recruiting the original staff it was a lot different to when I was recruited.

The managers were equally concerned about the level and type of support that could be offered to residents. There was a perception that personal budgets²² were not flexible enough to meet the non-physical needs of residents. Examples were given of what personal budgets should cover, including:

...well better access to shopping and things like that, and also use of the budget to actually support somebody both physically and emotionally with stuff. With time rather than physical tasks all the time. Because ... a lot of our budget is worked out on physical need. Whereas, with dementia, a lot of the times it can be emotional support and physical support to do things rather than ... the actual physical needs... but they have to be able to have enough in their personal budget....

The allocation of a personal budget is done through the local authority based on an assessment of each person's eligible needs (Department of Health, 2014). Yet the care service commissioned in the two extra care schemes involved in the research was through a block contract²³ which would meet the needs of all people at the scheme who are eligible for a personal budget, unless they opted to take direct payments. Processes were in place to enable the care providers to make small adjustments to individual care packages on a week-to-week basis, but that could only be done from within the total hours available in the block care contract. There were reported difficulties in securing sufficient personal budgets to meet all the individual's needs, partly because of assumptions made by other professionals about what the extra care service comprised.

²² A **personal budget** is the amount of money the local authority allocates for an individual for their care, based on its assessment of the individual's needs.

²³ A **block contract** is a payment made to a provider to deliver a specific, usually broadly defined, service.

5.2.7 Expectations of others

Staff, managers and residents all implied that other professionals and families had high expectations of extra care being able to meet all the needs of each individual resident, either formally through a support and care plan, or informally through the core wellbeing and support service. It was felt that those expectations were not met for numerous reasons. An example included health professionals who thought that extra care was a residential home. One manager said:

Hospitals find it difficult to get their head around the fact that there is staff here, but they are not necessarily going to do what you say needs to be done.

The focus groups also talked more specifically about there being a presumption that extra care could meet all the needs of people with dementia.

That is why people who have got Alzheimer's are being pushed in a place like this rather than making sure that they have got adequate care and support, because it seems to be, on paper, the ideal place for them.

There were reports that some people with dementia might benefit from day care services outside the extra care scheme, but that the social worker assumed that the extra care scheme provided sufficient stimulation through formal or informal activities. One manager said:

People can be just as socially isolated in extra care because of how they have been, you know, and whether that be the ignorance, or budgets, or whatever... we see a lot of people who people think "oh well, they're alright because they live in extra care". And many a time I've had conversations with social workers [where the manager has said] "well they need to go to day care because they specialise in stimulating that person with dementia".

There was also some debate about additional support that could be provided from unscheduled time within the core wellbeing service or block contract. A second debate was whether such support should be provided to everyone, including those who self-fund their own care, or only those people with eligible care needs who have a personal budget. This returns to an issue covered in Section 5.2.5 about the use of the well-being service and starts to touch on some

unspoken assumptions about the differences between self-funders and those in receipt of local authority support, and similarly differences between those who lease properties and those who rent properties.

Many comments reflected that staff worked hard, that there was little spare capacity, and that if there was it was well deployed. That wasn't a consistent view though, as one manager commented:

Some of problems that we have at [...] is the amount of times where we have not got planned support, where care staff seem to be sitting around doing bugger all (just excuse me swearing, it's a technical expression, yes, it is...) and we are paying them to do something you know. We need to find something effective for them to do, because we've had people falling asleep on shift, people sitting around gossiping, and they gossip for hours and they end up getting together and they become the bullies... They become part of the culture then? Yes, and then when we are asking them to respond it's: "well, it's not on the schedule, it's not on the schedule". Well that's not what it is about. So, we have had difficulties, so we are trying to move it across.

There appeared to be a developing culture of resistance from staff about proactively using unscheduled time or 'downtime', which was in marked contrast to the commitment described elsewhere. It was of interest that the dilemma about who could have access to any unscheduled or downtime was not unique to the two research schemes. A comparable extra care scheme within the same local authority area said:

We do a lot of things that, especially at the weekend we have massive gaps where we have to be on site. Where we have two carers on site. So, we do a lot of activities. People that are isolated we try and get them out more. Spend a little bit of time with them... mostly for those that we are contracted to provide care for. But we will support anyone that needs it really [...] the arrangement that we have had, that if there are hours that we have been paid for [by the block contract], that are going to be used by self-funding people, then what we would expect is that it is very clearly explained to the resident or their family, that this is not long term, but ... and you have done things like walking practice²⁴ haven't you?

²⁴ Walking practice is a form of rehabilitation for one resident that was receiving support.

This scheme highlighted the added value that could be gained from a contract where staff and managers from different agencies worked flexibly together to meet the needs of all the residents.

5.2.8 Co-ordination and supporting individuals

One of the strengths about both schemes was the attitude and commitment of staff. Members of staff were valued by both residents and managers, and it was clear that there was a lot of camaraderie to be gained by the staff team working together to support a constant group of residents. When talking about 'that little bit of extra support' one staff member said:

It's just what you see, and the help you would give anywhere in life.

Although there was an ethos from all the discussions that staff would 'go the extra mile' to support individuals, there also appeared to be some discretion about how willingly they would go the extra mile, and for whom. There was a sense that staff thought some residents abused their good will. For example, one staff member said:

You would help anybody. If that buzzer goes, you do what you can, don't you... You go in, and then you realise it's something trivial. You do get tricked... [by residents] playing the system....

There were numerous suggestions that call responses could be better managed if they were triaged first to establish the urgency of the call, and to determine which of the housing and support team could best respond (see also Section 5.2.2 about the suggested role of a floating support staff member).

As well as co-ordination of front-line staff through triage, it was suggested that there was insufficient overall co-ordination of the day-to-day tasks and activities undertaken by the different staff teams. The staff at one scheme said:

There's no-one who's seeing the whole thing, so we're all communicating, but then we kind of like co-ordinate the whole thing [between ourselves]
....

Having an overview of the whole scheme and coordinating activity across both private and public parts of the scheme is key to scheme viability when different services within the scheme are inter-dependent.

5.2.9 Viability of the overall scheme

Informal and formal responsibilities for ensuring the scheme is viable was a nebulous topic of discussion with participants. There were strong views expressed about two areas. The first area covered the need for extra care providers to remain financially viable, and the impact that had on filling vacant apartments. One manager summed up a two-stage approach to filling vacancies; the first was the business need, and the second was the care or housing support needs. In one instance a manager commented from a care point of view:

Then they [the apartments] started coming through onto the open housing market, and that seems to have effected a change. So that I was looking at the allocation panel, I was looking for people with care needs because otherwise I have got carers that aren't having to do anything. And if they haven't got to do anything on the private or the contracted hours, that is just a huge waste isn't it? So many hours per week. Really. So, I don't know whether that is a difference as things move on, but there are people who choose to buy it [the apartment] for whatever reason, and you know they might be 10 years off having care needs.

And a manager at the other scheme commented that viability of the housing provider took precedence:

Because we weren't generating enough sales, it seemed to be that it circumvented the whole system [of allocations] like. They'd just allocate someone, but it was nearly always someone with very low needs who was given the sales [apartment]. So, the balance was all skew-whiff....

The second area was the viability of the catering service. It was quite clear that the caterers were commercial enterprises with a responsibility to ensure they broke-even. Catering is notoriously difficult to manage in extra care (Bailey, 2014a and 2014b). Although catering is managed by the housing landlord, the local authority will also have a vested interest, with some local authorities subsidising the catering service so that it remains viable for residents to use. One senior manager interviewed from a housing association said:

You and I would say the vision is to have a not a catering service, but to have a hub where people can enjoy food, can enjoy a cup of coffee, and all the benefits that that infrastructure of eating and drinking brings. And ideally to draw in the wider community to help sustain it, balanced with the fact that it is people's homes, which is a tension in itself.

The view of catering as a hub brings different agendas which drive extra care partners to support the catering service. A senior manager in a local authority summarised the different agendas; the housing landlord might seek a financial return on their investment in commercial space within the extra care scheme; the housing support provider might seek to have a thriving community to bring the extra care to life; and the care provider and the local authority might look for it to provide opportunities for residents to get nutritious meals and meet their social needs. When there was a problem with the catering in one of the extra care schemes during the research period the local authority senior manager said:

Where there were problems in that particular service [catering], we [the local authority] got involved because we had a vested interest....

Another manager from a care provider commented that if the catering fails you lose a sense of community, and it impacts on members of the care staff who might then have to go to individual apartments to support people to get meals. The manager of the housing association returned to the subject of catering later in the interview when she discussed the responsibility for having a viable catering service:

Ultimately it lies with us, as the landlord, in partnership with the caterer. But I think it is very, very hard to achieve. I think what we found is, and this is with all schemes, catering will normally have to stack up, because people, if they have choice, and rightly so, and then you get into if it's good quality, but that doesn't always translate into practice... so it's just very... it's very hard in reality to get catering in extra care to stack up. And if ... we're on our third one [catering provider], and we've tried different ways... with the pay as you go... you just [...] for example at [name of scheme], you are not getting the numbers, and whilst there have been quality issues, as I say there's not a direct correlation. Because where we have not got quality issues elsewhere, you don't necessarily get the numbers.

Viability of some of the commercial services goes to the nub of what extra care is about, which is to provide self-contained living accommodation, with access to

on-site care for those who need it, and with communal facilities such as a restaurant or café.

5.3 CONCLUSION

This chapter, together with Chapter 4, set out key issues about the possibilities and practicalities of people with dementia living in extra care housing, illustrated with experiences shared by research participants. The analysis has attempted to bring some balance to the issues raised within the focus groups and interviews, which have then been used to describe what would ideally underpin extra care housing. The extra care model that has been developed in this research describes a set of complex inter-relationships between four individual components. These components are; clarity about what extra care is; individuals living well; the existence of a well-developed community; and an effective team to support individuals. Concepts of independence, community, culture, leadership, commitment, communication and partnership working have been integral to understanding how the model works. The complexity and inter-relationship of the different components of the model has meant that at times the findings have not been neatly categorised but have echoed across the different sections of these chapters. The model identified components that will make it easier for people living with dementia to live well in extra care, but the model itself is not exclusive to people with dementia. In providing a model that supports people with dementia the service will also be supporting for people who are not living with dementia. The findings from these chapters will be discussed, together with relevant insights from the second phase literature review, in Chapter 6.

6. CHAPTER SIX: THE LIVED EXPERIENCE EXAMINED

6.1 INTRODUCTION

The findings set out in Chapters 4 and 5 were drawn from focus groups, interviews and other activities in this research which took place between October 2016 and September 2017. The activities were undertaken without any pre-conceived ideas about what might emerge or what the findings might mean. Four inter-related themes identified from the stories told by participants were represented as four components of a model of extra care, set out in Figure 6-1.

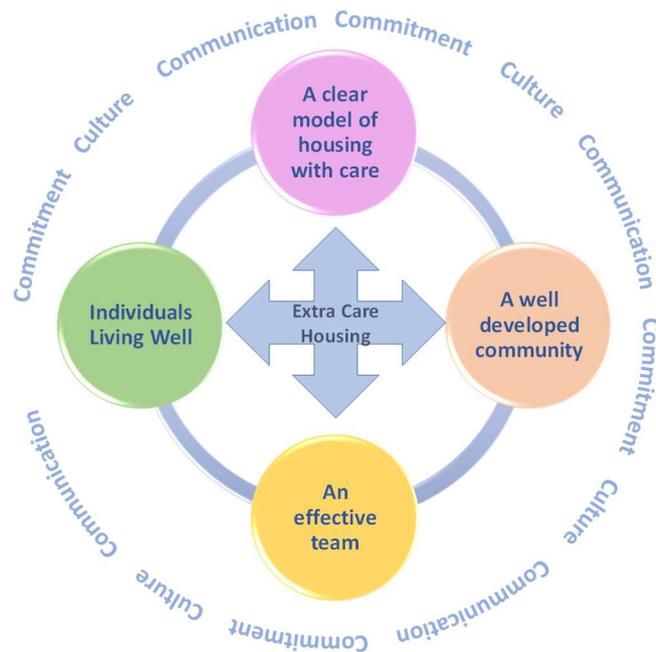


Figure 6-1: Model of extra care housing

It was thought that an individual with dementia would be better able to live in extra care if the four components were in place, and if there was the right culture, effective communication, and a positive commitment from everyone involved in extra care to live and work together. It was recognised that these would support everybody to be better able to live well, not just those with dementia.

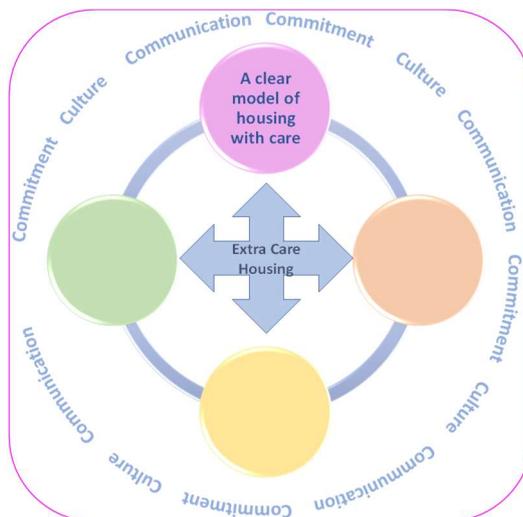
The grounded theory approach used in this research meant that concepts and themes were subject to scrutiny as they were raised by participants. The scrutiny involved reviewing further literature that might support key ideas raised and

considering relevant theoretical frameworks that might be of help in understanding them.

This chapter sets out lines of enquiry arising from each of the four themes identified in the findings; first, the importance of a well-planned vision of extra care housing; second, factors that will help an individual to live well; third, the importance of a well-developed community; and fourth, the effectiveness of the formal and informal team of people supporting individuals. In particular, the lines of enquiry will consider any aspects that are specific to people living with dementia.

6.2 PLANNING THE SERVICE: THE IMPORTANCE OF A VISION OF EXTRA CARE

The first component of the extra care model is having a clear vision that describes the service. There was agreement from all the participant groups on the five factors that have been highlighted as important, set out below in Figure 6-2. Those important to all participant groups included planning a model of extra care that



meets the vision; having policies that support residents, family, staff and other professionals; and having a helpfully designed environment for everyone.

Having a process that supports appropriate moves in and out of extra care was important to staff and managers, whilst managers and other senior representatives of the extra care organisations interviewed also placed high priority on working together in partnerships to commission, operate and monitor viable services.

Some of the focus group and interview discussions gave rise to further detailed examination by the researcher of specific issues as part of the process of developing a model that was acceptable to all participants through a grounded theory

approach. Those issues included examination of what is extra care, and whether extra care could provide a home for life.

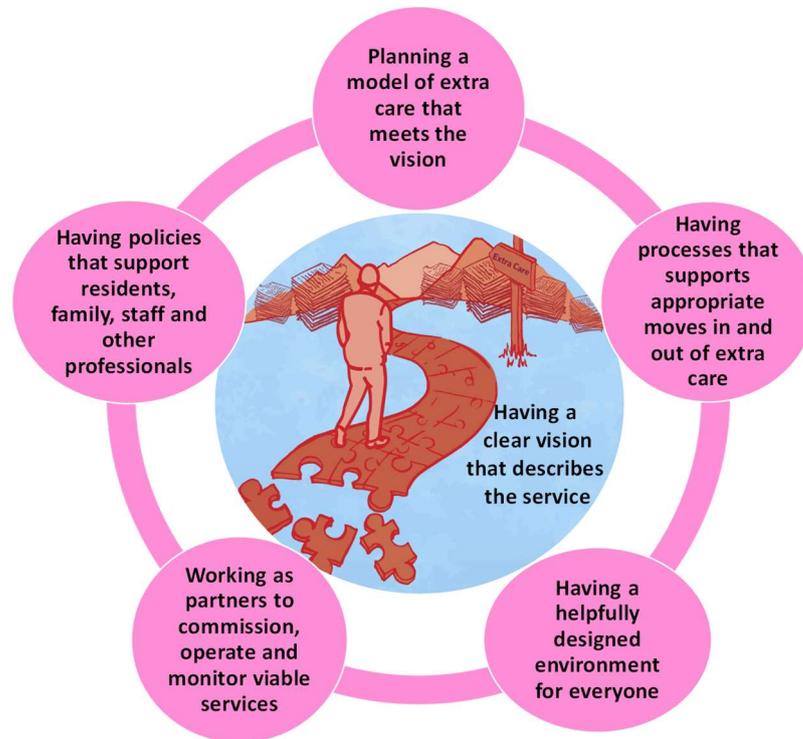


Figure 6-2: Having a clear vision that describes the service

6.2.1 What is extra care?

As reported in Chapter 4, the most important issue to emerge from the focus group discussions was having a clear vision that could describe the extra care service to everyone. The lack of clarity led to a number of misunderstandings about how independent residents had to be when they moved in, about the level of support they would be offered outside an agreed care plan, and about the number of people who lived in extra care who had high levels of need and who might otherwise have been in residential care.

The initial literature review set out in Section 2 revealed that there had been little early consensus on what extra care is and that its development had been opportunistic and piecemeal (Tinker, et al., 2007). As the research progressed, all participant groups repeatedly sought clarity about what extra care was, and what it was not. A review of materials published since the start of this research shows there

is now a commonly accepted view in the housing and care sector that the term 'extra care' is just one of several descriptions for housing with care. The 'extra' in extra care housing is generally recognised by the sector as access to care services that can respond quickly to residents' changing needs and provision of unscheduled support as and when required, in addition to planned care and provision of an emergency response (Riseborough, et al., 2015, p. 3).

The Government's latest policy statement and consultation on funding supported housing (Department for Communities and Local Government & Department for Work and Pensions, 2017, p. 16) described sheltered housing and extra care as:

...housing usually designated for older people with support needs, which helps them stay independent for longer. However, working-age tenants can and do reside in this accommodation, where appropriate. This provision is often described as on a 'continuum', with sheltered housing used to describe housing for residents with lower-level support needs, while extra care is accommodation that has been designed for older people with higher care and support needs. There is little or no expectation for tenants to move on into unsupported accommodation; typically, low turnover of tenants; low to medium housing costs; and high projected demand for increased future provision.

The two publications still leave extra care provision open to wide interpretation of those descriptions. To avoid the confusions described by all participant groups in this research it is imperative that each extra care partnership clearly sets out its vision for extra care, and its strategy for achieving it. The importance of strategy and communication will be returned to in Chapter 8, which explores theories of quality and operational excellence relevant to extra care.

6.2.2 Is extra care a home for life?

The different participant groups discussed the position of extra care in the range of housing with care options available to older people. None of the participants, including resident participants, stipulated that extra care could be a home for life for everyone. Groups highlighted contrasting perspectives depending on participants' own experiences. One participant had supported his wife to live with dementia in extra care to the end of her life; another participant had felt disempowered when

her husband, who was living with dementia and other complex health needs, was relocated to a nursing home after a stay in hospital. There also seemed to be different viewpoints depending on what might be the potential reason for a move from extra care. One resident had planned ahead, and said:

I've got a Right Care Plan²⁵... The right to die here instead of being moved to hospital ... I would imagine that as I deteriorate that my allocated care plan would increase.

Whilst staff had effectively supported some residents to live to the end of their lives in extra care, they also expressed concerns that other people living with dementia should not have been allocated an apartment. Managers spoke of the tension they felt between the rhetoric of being able to provide a personalised care package with full community support to enable someone to remain in their own home as they approached the end of life, against the reality of having limited resources to support individuals appropriately. One manager said:

Everybody is an individual even at the end of their lives, aren't they? You know, some people have the dementia and its manageable right through until the end, given the skills we have got here. But there are other people who perhaps, due to the risk, the assessments that have been done over swallowing, or being fed or, hydration, you know, you can't do it. You can't do it here. Or we could only do it here if there was some extra support from health.

The experience in this research is comparable to experiences elsewhere in extra care schemes. A longitudinal study of extra care by the International Longevity Centre – UK found that, compared to those living in the community in receipt of domiciliary care, those in extra care housing are less likely to enter institutional accommodation (Kneale, 2011, p. 4). Nevertheless, whilst suggesting that extra care housing is a

²⁵ A Right Care Plan is part of the RightCare Scheme. RightCare is designed for patients with long term conditions and complex healthcare needs, including end of life patients. The scheme helps to prevent unnecessary admissions to hospital and attendance at A&E, lower patient anxiety, provides reassurance and allows patients to access the most appropriate healthcare and advice quickly. <https://www.england.nhs.uk/rightcare/what-is-nhs-rightcare/>

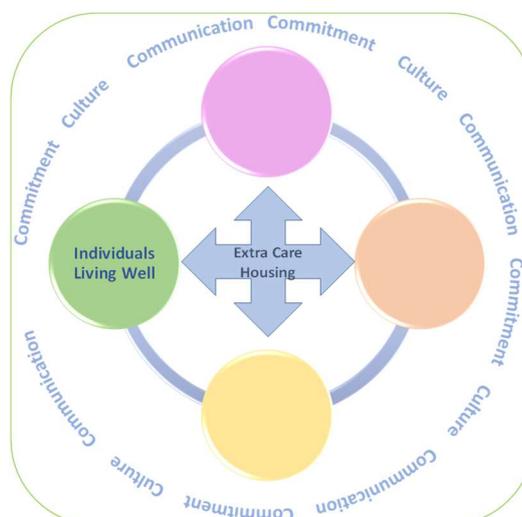
home for life for the majority, the report stated that they would expect 10 per cent of those living in extra care to enter institutional accommodation.

In setting out the vision for extra care it would seem justified to say that the aspiration is to provide personalised care and support to prevent further moves to residential or other institutional accommodation. At the same time, it is important to acknowledge the difficulties that may arise for the 10 per cent of the extra care population for whom this may not be possible.

In keeping with the Care Act 2014, residents were treated as individuals, and any proposed moves would result from a review of the individual's circumstances and revised care planning. This individuality appeared to result in an ad hoc approach to reviewing whether there was anything that the scheme, as a whole, could do to meet the changing needs of its resident population. There did not appear to be a formal process to follow for those 10 per cent of people who might need to move out of extra care. One senior manager suggested that there should be a review at the allocation panel or management group meeting on whether anything more could have been done for those people who leave. This highlighted a possible gap in the approach of the extra care schemes to continuous learning and quality assurance, subjects that are central to theories of quality management and operational excellence.

6.3 LIVING WELL: SUPPORTIVE RELATIONSHIPS, RIGHTS, RISKS AND SAFETY

Section 4.5 set out five characteristics of service delivery that participant groups thought helped an individual with dementia to live well in extra care. The five characteristics include having the right culture, maintaining and reflecting personal identity of the residents, having person-centred teams and providing person-centred support, understanding dementia,



and having a positive approach to managing risk and safeguarding issues, set out in Figure 6-3.

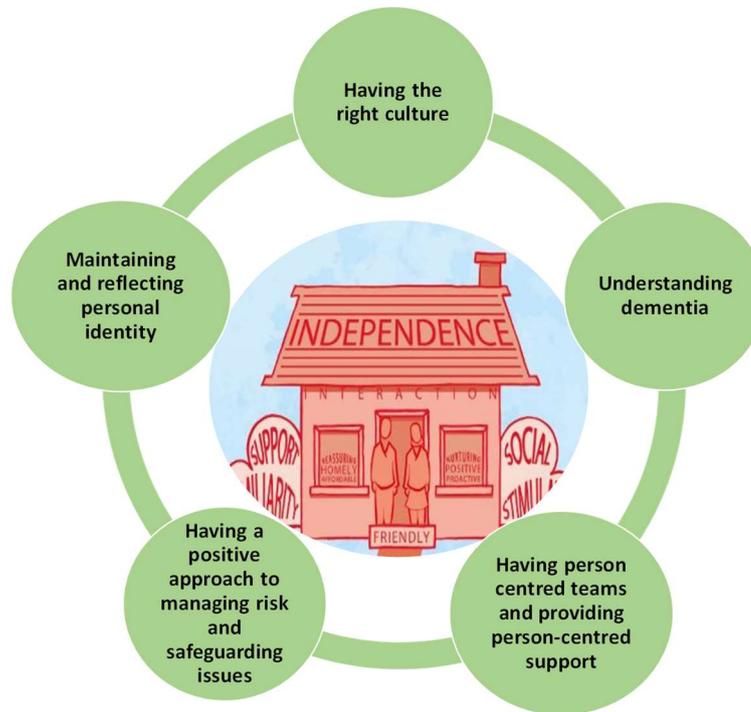


Figure 6-3: Characteristics that help individuals to live well

None of these characteristics are tangible, making them difficult to quantify or measure. The two that gave rise to the most debate were maintaining and reflecting personal identity and managing risk and safeguarding issues. The two issues were further explored by referring to appropriate literature.

6.3.1 Relationships and maintaining and reflecting personal identity

The nature of relationships both between residents and between staff members and residents was an important theme to emerge from the focus groups. The nature of the relationships was closely allied to the culture within the schemes; to the level of mutual support between residents; and to the ability of staff to facilitate relationships between different residents.

The relationships were sometimes described in terms of feelings or impressions, as demonstrated by the contrasting quotes below:

“It’s the friendliness of the place really, that has wowed me, because it is very friendly, and people are so nice to each other on the whole” said Zoe.

“I felt a ‘lack of warmth’ when I arrived at the scheme” said by an external professional about the atmosphere when visiting the scheme.

At other times comments were made about the impact of specific behaviours on an individual’s experience: for example, Audrey described the disinhibition of her husband with dementia as embarrassing, resulting in her choosing to isolate herself and her husband to avoid the embarrassment (see Section 4.5.2).

Croucher et al (2006) noted in their literature review on housing with care for later life that it can offer opportunities for social interaction and companionship. House et al (1998) reported that the mere presence of others and a sense of relatedness appear to promote beneficial health effects. As seen in the example above, the reality can be far more complex. Within extra care housing, an individual’s experience of relationships results from a complex interaction of their own behaviour and the behaviour of others. The experience can be greatly affected by how those interactions are supported or managed within the extra care environment.

Attributes of integrity, compassion, respect, fairness and trust have been identified as important to relational behaviours (Grimshaw, et al., 2016). Grimshaw et al say these five attributes are important in the processes and practices that support a healthy relational environment within older people’s care communities. Lacey and Moody (2016, p. 2) describe relational value as ‘The lifeblood of a system, organisation, partnership or team of people. It is the medium through which our interactions pass that either enhances or distorts our ability to achieve our common goals’. One could hypothesise that Grimshaw’s five attributes of integrity, compassion, respect, fairness and trust should therefore be integral to a model of extra care in which there are healthy relationships, providing the lifeblood of how individuals live well, in a well supported extra care community, supported by an effective team. Table 6-1 sets out how each of Grimshaw’s attributes underpin the extra care model. This hypothesis could be usefully tested in further research.

Table 6-1: Elements of the extra care model supporting Grimshaw et al's (2016) attributes of relational value

Relational value attribute	Themes from extra care research focus groups	Concepts within each theme	Example from the extra care research
<p>System integrity is how things interconnect and function, which is present when the purpose or function of the system is understood and owned by all with clear boundaries within which everybody pulls together with a genuine common purpose.</p>	<ul style="list-style-type: none"> • A clear model of housing with care • An effective team 	<ul style="list-style-type: none"> • Having a clear vision of the service • Commissioning and operating viable services • Having policies that support residents, family, staff and other professionals. • Providing strong leadership 	<p>“I think it’s not just the care staff, there’s the hairdresser and the café. Especially the café, we have people with dementia, you know, how they are responded to and how people interact with them. You know a lot of the time I will make sure that I go up and say... ‘ You know this lady; can you make sure that...? Can you go up to her because ...? I’m always trying to divulge you know, this is what they need... so that they’ve got that support.”</p> <p><i>Quote from resident.</i></p>
<p>Respect is how we treat each other, which is present when each party individual group or organisation has a recognised contribution to make without which the purpose or function of that system cannot be achieved to its full potential.</p>	<ul style="list-style-type: none"> • Individuals living well • A well-developed community 	<ul style="list-style-type: none"> • Having an appropriate culture • Maintaining and reflecting personal identity • Being person-centred • Managing relationships • Helping people to take part • Having the right facilities for the location • Reducing isolation 	<p>“I think the onus is to a certain extent on us [the residents] to care for people. If we see somebody who’s behaviour is worrying, or concerning, it’s up to us to alert the carers....”</p> <p><i>Quote from resident.</i></p>

Relational value attribute	Themes from extra care research focus groups	Concepts within each theme	Example from the extra care research
<p>Fairness is how equity is achieved which is present when no one individual group or organisation is seen to take advantage of a weakness in another which may for example arise through privileged information or political influence.</p>	<ul style="list-style-type: none"> • Individuals living well • An effective team • A well-developed community 	<ul style="list-style-type: none"> • Having an appropriate culture • Being person-centred • Having a positive approach to managing risk • Providing strong leadership • Managing relationships 	<p>“it had been reported that the residents had been quite negative towards some other people, and not wanting to speak to them, not wanting to interact with them, excluding them from certain areas....” <i>Quote from staff about resident relationships</i></p>
<p>Empathy or compassion is how we understand each other which is present when each individual group or organisation is able to ‘live in someone else’s shoes’ and by doing so is sensitized to the risks arising from a lack of integrity respect or fairness being proactive to address someone else’s needs.</p>	<ul style="list-style-type: none"> • Individuals living well 	<ul style="list-style-type: none"> • Maintaining and reflecting personal identity • Having an appropriate culture • Understanding dementia • Having a positive approach to managing risk 	<p>“There is community spirit. We are all ... I think we support one another as best we can. And I think we identify people with needs, and we’ve had people in here with Alzheimer’s who have needed a lot of care and support, and they’re not, sort of, segregated. They are part of it aren’t they.” <i>Quote from resident.</i></p>
<p>Trust is how much we put ourselves in other people’s hands which is present when people act in each other’s interests as a means to achieve the overall purpose and function of the system within which you are operating and are committed to.</p>	<ul style="list-style-type: none"> • A clear model of housing with care • Individuals living well • A well-developed community 	<ul style="list-style-type: none"> • Having a clear vision of the extra care housing • Having an appropriate culture • Managing relationships • Helping people to take part • Reducing isolation 	<p>So, I did that, but if we didn’t have that trust and relationship between us...and I stayed here all day, didn’t I? I couldn’t say, that’s fine, we are doing what we have been asked to do by the social worker. But it doesn’t work like that. You have to have the relationship with everybody, the residents themselves, their family, and the commissioners, the social worker, and we did manage...It is all about the relationship and the trust, and all of us working together. <i>Quote from a manager</i></p>

Participants in the focus groups had mixed views about relationships. Sometimes participants talked about their own experiences and at other times they reported how they thought relationships impacted on other people who they perceived to be more vulnerable than themselves (including people living with dementia). For example, both resident and staff participants expressed strong views about the difficulty of managing negative group dynamics in communal settings, whilst at the same time valuing the community spirit and the level of friendships in place.

Supportive relationships were one of five areas identified by Lee (2006) as being of crucial importance to wellbeing. It was notable that there were visible cliques in both the extra care schemes. As a small close-knit group, a clique can be considered negatively if it does not allow others to readily join the group. In this research, cliques were described by many of the participants as a natural part of forming friendships and social relationships. The normality of cliques was noted by Darton et al (2008, p. 77) who said 'where cliques were developing these were not harmful, and were simply like-minded people forming friendships and groups'. Interviewees in a study by Chandler and Robinson (2014) described how their retirement village provided both opportunities to form new relationships but also divisions resulting in cliques. In contrast to the views expressed in Darton et al's study (2008), the cliques described by participants in Chandler and Robinson's study created exclusion and friction, with resulting ostracism.

Ostracism is likely to erode an individual's sense of self. Bernard et al (2012) write that literature over the last 40 years has consistently highlighted community identity as a basis for self-definition (Sarason, 1974, p. 157) and linked the older person's environment with their sense of self (Rowles & Watkins, 2003; Andrews & Phillips, 2005; Peace, et al., 2005 and 2006; Sharf, et al., 2007; Smith, 2009). The extent to which individuals living with dementia can maintain a sense of self is debated (Kitwood, 1993; Downs, 1997; Sweeting & Gilhooly, 1997; Cohen & Eisdorfer, 2001; Dewing, 2008), however qualitative evidence does suggest that individuals living with dementia are able to live meaningful lives and demonstrate on-going personal growth (Harris, 2008; Wolverson, et al., 2017). Living well with dementia and being

able to live meaningful lives would be enhanced if individuals were positively recognised by, rather than excluded by cliques. Being accepted into a group can be a difficult process fraught with misunderstandings if communication is impaired, as discussed further in Chapter 7.

The notion that individuals are ostracised could mean that they are less likely to identify with or be attached to the community or culture within the scheme. Croucher et al's (2006) review of literature reported that, even where there is evidence of neighbourliness and residents supporting each other, very frail people, or people with sensory or cognitive impairments were consistently on the margins of social groups and networks. Being on the margins of social groups and networks may lead to social isolation. Social isolation and loneliness are separate concepts which are often but not always linked (Davidson & Rossall, 2014; Local Government Association, 2016; Wigfield & Alden, 2017), a view echoed by residents and staff within this research who said that you could be isolated but not lonely and vice versa.

The potential impact of feeling marginalised or isolated for someone living with dementia could be large. Issues of the individual's agency and the duty of care staff to help someone with dementia to develop or maintain relationships within an extra care community were alluded to by resident and staff participants in this research, with the implication that not managing relationships and allowing marginalisation to occur in an extra care scheme could contribute to loneliness. The detrimental effect of loneliness on the wellbeing of individuals is well documented (Windle, et al., 2011), and reducing social isolation may go some way to countering those ill effects for some people. As Chandler and Robinson (2014, p. 16) noted in their study of a retirement village:

...negative impacts on wellbeing are described in the constant reminders of mortality in the village due to death, disability and illness in residents, a sense of being away from society, and the village being cliquey or socially divided.

Individual residents participating in the research wanted very different things from their engagement with, and relationships within, the extra care community. This is consistent with the findings of Lacey and Moody (2016) who suggest the need to

understand and reflect on how concerns relating to each respective area might be translated into actions to help maintain and improve the relational environment. There were many discussions amongst staff and the resident participants about impact of the behaviour of residents who wandered, and how the behaviours challenged relationships within the extra care scheme. The residents were concerned about the wellbeing of the individual, but also wanted support to stop the individual's behaviour from disturbing the harmony within the scheme.

6.3.2 Managing rights and risks

Chapter 4 illustrated some of the tensions between upholding the rights of residents whilst also being mindful of potential risks to resident wellbeing and the responsibility of staff and managers to make sure individuals are safe. That was echoed in a review of extra care schemes in Wokingham (Healthwatch Wokingham Borough, 2017, p. 9), which reported that

...clarity is needed between provider, regulator and local authority, around independent living environments enabling resident choice and free will to come and go as they wish, balanced with safeguarding those who may have diminished capacity.

Risky situations in everyday life are experienced by people with dementia as unfamiliar and confusing, and consequently difficult for them to understand (Sandberg, et al., 2017). Each person's approach to risk and experience of risk is unique to them; what may be acceptable to one person could be unacceptable to another. Residents, staff and family members are likely to have varying levels of comfort or tolerance for the same risky situation. Circumstances, and the relationship between the person and the environment, are constantly changing. Given the complexity of everyday life for people with dementia in extra care, it is difficult to predict how risks will develop.

One of the main risks identified by all participant groups in this research was of the extra care scheme being unable to effectively manage wandering, or walking with purpose, by people living with dementia. As set out in Section 4.5.4 the main concern was that some individuals with dementia become disorientated and get lost

either within or outside the extra care scheme. There were three main reasons for the concern. The first was that the internal layout of the scheme can be hard to navigate, and people both with and without dementia may feel lost. It will be more difficult for someone with dementia who may not be able to retain a memory of the scheme layout. The second was that the scheme is open to the public and doesn't provide a locked secure environment. There is nothing to prevent someone with dementia from walking outside even if they don't know where they are heading. The third reason was that the model of extra care provision and staff structure does not allow sufficient flexibility for staff to provide round the clock supervision of individuals with dementia who may not know where they are, in a way that gives the individual choice and independence alongside a watchful eye and the capability to step in and support if necessary.

Those reasons reflect the interaction between individuals, the environment and the support being offered. A change in any one of those three aspects could alter the balance of perceived or actual risk for individuals with dementia. The potential consequences of someone with dementia getting lost were described by staff and managers who said it was upsetting for individuals with dementia if they are lost, confused and don't understand where they are. They also said it was upsetting for other residents when individuals do not know where they are and try to get into someone else's apartment. Staff said they may feel inadequate or stressed if they are unable to support people who they know need help, and that when residents wander or get lost, either inside or outside the home, it can reflect negatively on the scheme and the public's perception of how staff care for residents.

The perceived risk of someone getting lost were mainly distress either to the person, other residents or staff, with some consideration to the reputation of the scheme. Although the risk did not appear to result in direct harm to the individual or those around them, the consequences of someone with dementia being unable to orientate themselves within the extra care scheme was cited by both staff and managers as a possible trigger for the person to move out of extra care. Before such a move is considered, strategies would be explored by staff, managers and allocated

social workers to minimise the risk or negative impact of wandering. Focusing specifically on the problem of the unlocked environment for people with dementia, an example of the type of tactics that could be used to minimise the adverse effects on someone who is likely to become disorientated are illustrated in Figure 6-4.

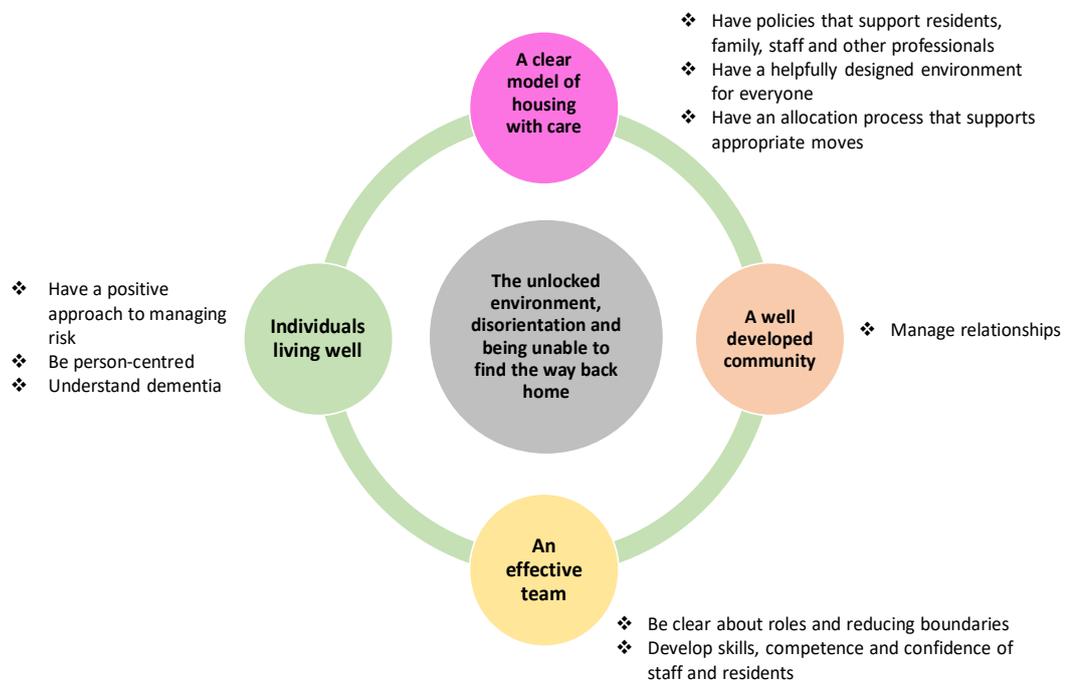


Figure 6-4: Minimising potential problems of an unlocked environment for people who become disorientated

A clearly articulated model of extra care would lead to a strategy for how the building and services would be planned and services delivered on a day-to-day basis. A well-articulated strategy would drive the recruitment and retention of a skilled and competent staff team with clearly defined roles to support individual residents. An implication of the focus group discussions, although not directly articulated, was for residents to have general support for emotional wellbeing and be helped to take part in activities without compromising the independence of extra care living, and without shifting into a more institutional type of setting. The absence of such additional emotional support was one of the main issues raised by staff, managers and residents, and was often cited to be the result of limited or insufficient funding. That is consistent with previous research which suggested that implementing a personalised approach in housing with care is not straightforward (Atkinson, et al., 2014), and that while the goals of personalisation may lead to more choice and

control the reality may be that most of an older persons individual budget may be used for high care needs with little left for supporting wider social well-being (Glendinning, et al., 2008).

A clear strategy and the right staff team would enable public areas of the building to be managed effectively to foster an inclusive and well-developed community. It would enable person-centred support to be provided with a positive approach to managing risks to help individuals with dementia to live as well as they can. In circumstances where an individual with dementia becomes disoriented, each of the areas just described (layout of the building, relationships with other residents, level of person-centred support available, and clear risk management planning) could be reviewed by the staff and managers at the scheme to see if any adjustments are required to support the person to remain living at the scheme.

The model set out in Figure 6-4 takes a holistic approach to resolving the issues associated with being disorientated. It considers the environment in which the extra care service is being provided, the people involved in delivering services and the people affected because of an individual's disorientation. It also considers the processes involved in supporting both the individual and other people in the scheme and the impact of those processes, and subsequent support, on the quality of the service being delivered. How well those issues are responded to will ultimately result in residents being more, or less, satisfied with the service they are receiving. Resident satisfaction is a fundamental concept within quality management and operational excellence, which is covered in Chapter 8.

The acceptability of taking risks featured in many of the discussions reported in Section 4.5.5. Different participant groups, and individual participants within groups, had different tolerance levels for risk-taking. In particular, staff and managers may adopt a more guarded approach to managing risk, shaped by social and organisational preoccupations and policies that overemphasize risk elimination (Evans & Means, 2006, p. 1). Figure 6-5 provides a matrix to help understand how far an individual with dementia is likely to be understood and encouraged to take risks that might support their wellbeing.

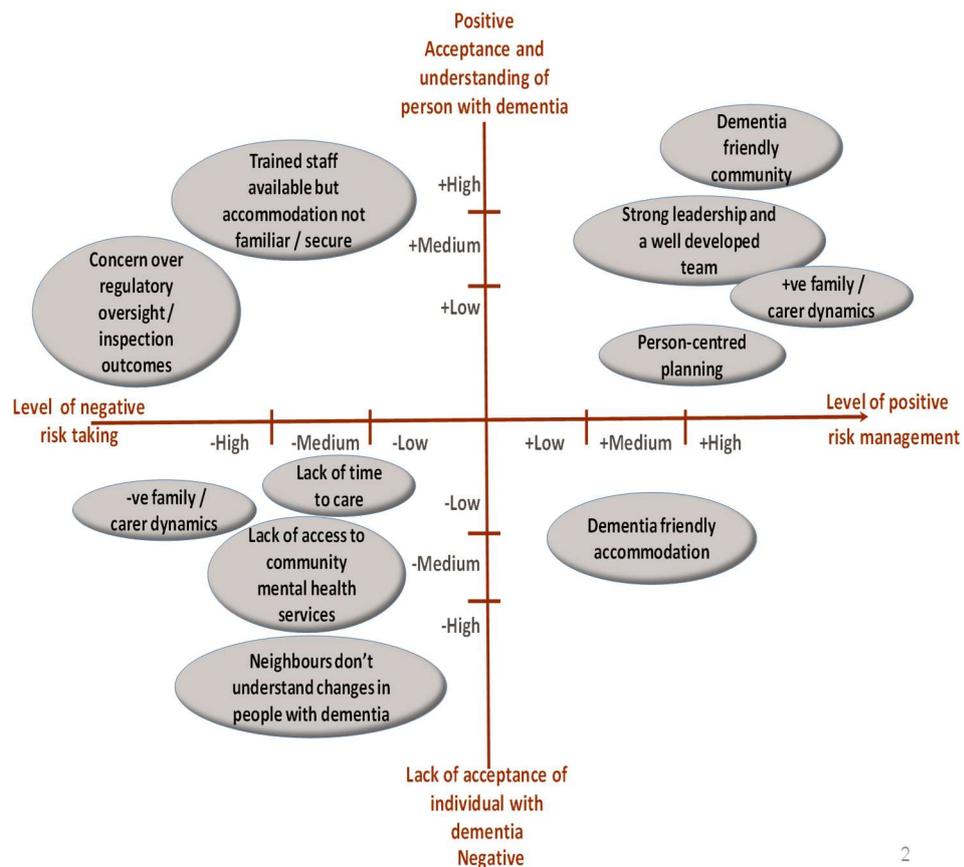


Figure 6-5: Matrix of factors influencing acceptance and risk taking in relationships with people with dementia

The inclusion or absence of the factors placed in the matrix are likely to affect how much an individual is understood and accepted, and how positive or not the approach to risk-taking within the scheme is likely to be. The factors that populate the matrix were drawn from interviews and discussion groups in this extra care research. They are illustrative rather than providing an exhaustive list. Other factors could equally be considered from other situations outside these research discussions.

Staff and managers revealed some inner conflict in how they responded to risky situations faced by residents with dementia. The conflict arose because of the imperative to keep someone safe, whilst neither restricting their freedom nor negatively impacting on other residents. Balancing individual freedoms and personal risk taking against the potential negative consequences of behaviour on other people is not exclusive to an extra care setting. It also occurs when the person

is living in a private home in the community and living in residential care²⁶. Abusive practices or safeguarding issues can develop where principles of individual freedom are not respected or managed appropriately, resulting in risky environments (Penhale & Manthorpe, 2004).

6.3.3 Risks and safeguarding individuals

Manthorpe and Marineau (2016) presented the results of a study undertaken in 2013 which analysed Adult Serious Case Reviews (SCRs) where the people who were the subject of the reviews had been at risk of harm, had been harmed, or had died. Although the focus of the study was not on extra care schemes, it revealed that approximately 25% of the SCRs they studied involved a person with, or most likely with dementia. Some of the themes that emerged included the potential for poor care quality in all settings for people with dementia, and by different staff and family carers; the lack of communication with family members; and poor integration of care for people with dementia.

These are consistent with the factors identified from this research, set out in Figure 6-5, and are likely to result in decreased acceptance of people with dementia and a greater amount of negative risk-taking. Most SCRs involving people with dementia were in care homes, but lessons may be learned for extra care settings which comprise independent living in individual apartments within a communal scheme. The safeguarding lead for the authority interviewed in this extra care research thought individuals were less likely to be vulnerable to abuse in communal areas of extra care than they could be in residential care because there are not such large numbers of people gathering together. Conversely, the provision of domiciliary care within the extra care scheme from just one provider was thought to make the potential for institutional abuse more likely because the closed nature of the domiciliary provision within the scheme may give rise to poor practices going unquestioned. Fragile communication between the extra care scheme, the local

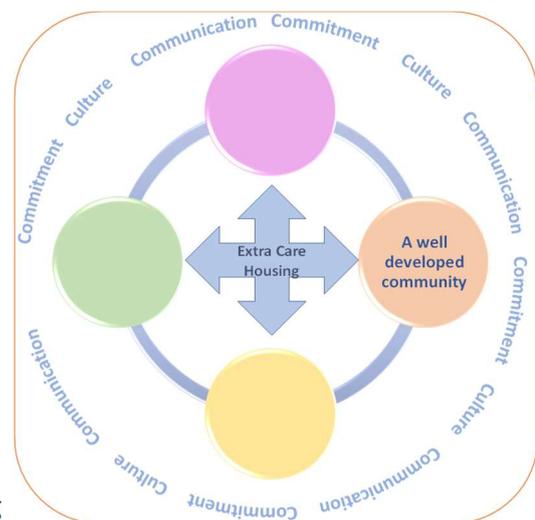
²⁶ People living in extra care have the same protections and legal rights as private tenants under UK law (Evans & Means, 2006). The tenancy agreement refers to the private space of an individual's extra care apartment rather than the communal or semi-public areas of the extra care scheme.

authority social services department, and other professionals, or relationships and cliques developing between managers, staff or residents can both discourage safeguarding or poor practice concerns being raised and reduce the potential for external scrutiny of extra care.

Manthorpe and Martineau (2016 p527) identified ‘fault-lines’ that may exist in dementia support systems, including there being “risk of poor communication, limited record sharing and little sense of shared care between agencies”. That has some resonance with themes from this extra care research about the difficulty in sharing information and the need for good communication. It is also consistent with other empirical research indicating there can be weak systems of communication across care homes and primary care services and lack of case management or coordination (Robinson, et al., 2010; Davies, et al., 2011). Developing effective communication, having robust risk management and building continuous learning would all form part of a quality strategy for extra care housing.

6.4 RECOGNISING AND DEVELOPING THE COMMUNITY

Concepts of community and evidence that community, social networks and social support play a positive role in helping individuals feel they are ageing successfully were set out in Chapter 2. Stories told by participants in this research revealed that respecting privacy and reducing unwanted isolation, and managing



relationships were essential characteristics for a well-developed community. Participants described how a well-developed community also relied on people being helped to take part in community life and having the right facilities in place which depended on where the scheme was located and what else was in the neighbourhood.

Characteristics essential to a well-developed community were described by participants in Chapter 5 and are reproduced in Figure 6-6 below.

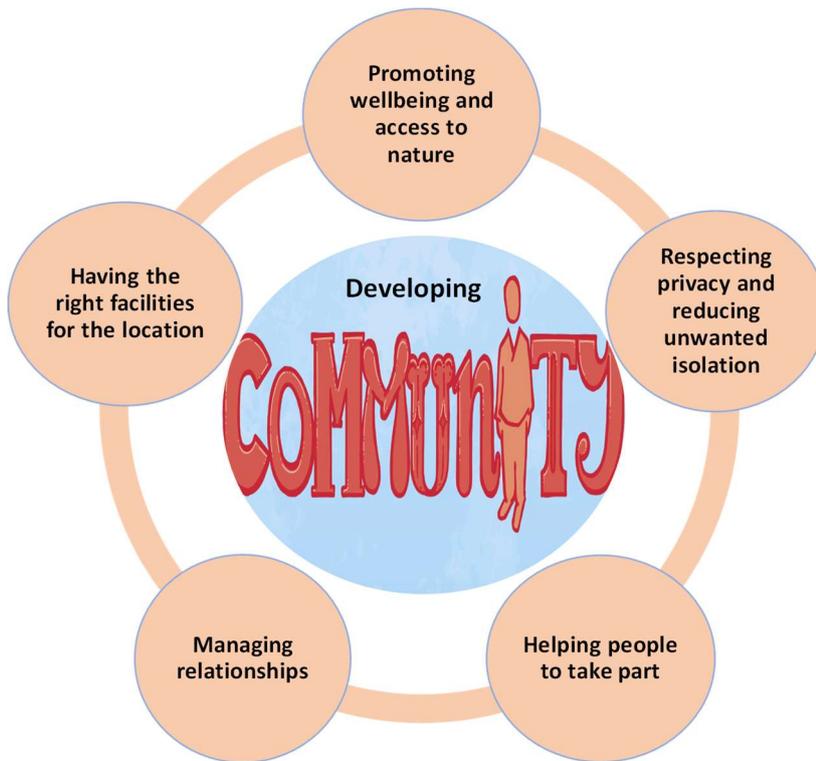


Figure 6-6: Characteristics described as essential to a well-developed community

The grounded theory approach adopted for this research involved analysis of, and insights from, relevant literature about communities. The insights set out below and discussed in more detail in Chapter 7 helped to understand participant interpretations of community and contributed to the conclusion that social worlds theory is relevant to the provision of extra care housing.

6.4.1 What is community?

Rapley and Pretty (1999) view a sense of community as central to a community's psychology, but argue that the meaning of 'community' is 'highly particular and localised: the term 'sense of community' is opaque [...] and where it approaches clarity, it is as the locally negotiated product of an interaction [driven by the research interviewer]' (Rapley & Pretty, 1999, p. 708).

Common community characteristics such as social interaction or shared actions, geographic location, and common ties or social membership, have been described

by authors over the years including Hillery (1955), Chavis et al., (1986), McKeown et al. (1987) and MacQueen et al. (2001).

More recently Provencher et al have conceptualised community 'as a physically bounded place, as a set of shared interests, and as a sense of belonging' (Provencher, et al., 2014, p. 4). Others such as Mannarini and Fedi (2009) and Li et al (2014) suggest that sense of community is not geographically bounded, that community is not restricted to being locally based, but can be achieved by connecting with people located in other places.

Consistent with the critical realist approach of this research, the concept of 'community' in this research is regarded as a socially constructed term that is used pragmatically to represent the various understandings or descriptions of participants. It is helpful to explore the social functions that community appeared to represent to participants, and how community was portrayed by participants through shared social representations²⁷.

It is generally accepted that extra care schemes should be as integrated as possible with their local neighbourhoods (Riseborough, et al., 2015), leading to consideration of whether an extra care community is bounded by the extra care building itself, or by the surrounding neighbourhood. An aspiration for many extra care schemes is that they will be open to people both from within and outside the scheme, suggesting a concentric model of community, as set out in Figure 6-7. For the purposes of discussion here, the primary community of interest is the extra care scheme itself; but as emphasised in Chapter 5 the extra care scheme cannot be divorced from its immediate surrounding neighbourhood, which provides the wider community.

²⁷ A social representation is a system of values, ideas and practices with a two-fold function: first to establish an order which will enable individuals to orientate themselves in their material and social world and to master it; and secondly to enable communication to take place among members of a community by providing them with a code for social exchange (Moscovici, 1973).

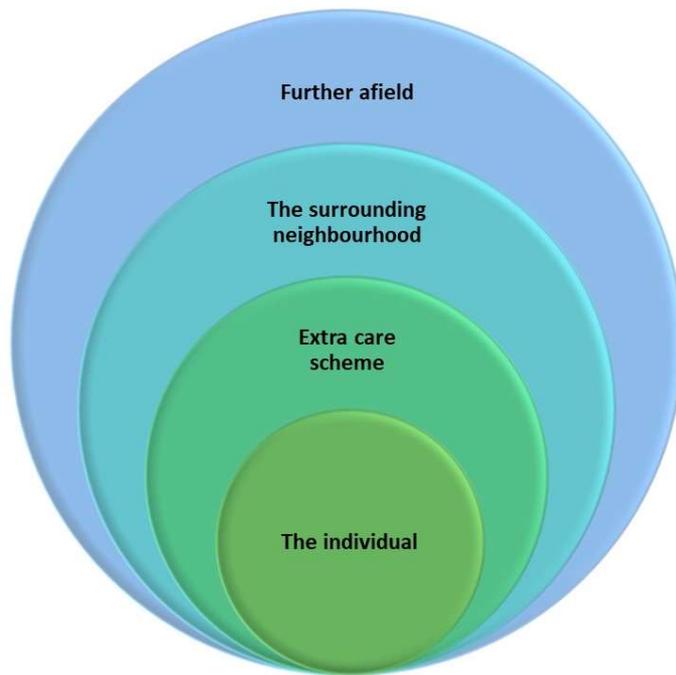


Figure 6-7: Concentric circles of community

6.4.2 Ageing, community and moving to a new house

An extra care community is, by its nature, a setting primarily for older people. The extra care community is defined and shaped by age through eligibility criterion for apartments that are normally allocated to people over 55 years old. It was noted in Chapter 3 that participants varied in age from 59 to 93 years, with an average age of 78. This is consistent with the findings of other research in extra care communities (Cameron, 2016), but is atypical of the population at large, where there is much more inter-generational connectedness. The scope for intergenerational living and promoting age integration by co-location in different housing and care settings is slowly emerging, with intergenerational schemes reported abroad in Germany (Oltermann, 2014), the Netherlands (Harris, 2016), Spain (Homeshare International, 2017) and in the UK (Murphy, 2012; Goddard, 2017; Shephard, 2017). A driver or outcome of many of these schemes has been to reduce isolation and loneliness by fostering inter-generational relationships.

For many residents, living in extra care may be their first experience of communal or community living with shared facilities. There is some evidence that community living is not the main motivator for many of those who move to extra care

(Callaghan, 2008). As residents in this extra care research revealed, the triggers for moving were varied, and included wanting to be near their daughter; not wanting to be a burden on family; wanting to be in a supportive environment away from family; needing more accessible accommodation; needing continuity of care for wife living with advanced stages of dementia; and needing support to help look after partner. Residents in the two extra care schemes in this research had varying levels of need across the age spectrum. Concepts of belonging to the third and fourth age may be more useful than chronological age in understanding the make-up of the extra care community (Heikkinnen, 2000; Coleman & O'Hanlan, 2004; Twigg, 2006; Gilleard & Higgs, 2010; Lloyd, et al., 2014). Extra care is considered to typically target those people in their third age looking to optimise their leisure time, starting to look for some support, and seeking opportunities to continue being fulfilled. The triggers for moving into extra care described by residents in this research suggest that whilst some of the residents could be within the third age, for others the move could be more analogous with preparing for a passage of decline either for themselves or a partner, symbolised by the fourth age. This resonates with work from Johnson (2017) who said that 'for some residents, the boundary between the 3rd age and the 4th age was a permeable one that they were able to subject to forms of control, management, and resistance' (Johnson, 2017, p. 3).

The different motivations for moving in to extra care are likely to affect not only each person's level of control, management and resistance, but also their expectations about community. The importance of community within extra care featured heavily in the focus group discussions. Participants described community as more than just its physical environment; referring to the services or activities provided and the friendships and relationships that developed. The different groups and friendships within extra care were described as fluid, with different residents coming together to develop small social worlds within the arena of extra care.

6.4.3 Support for communities

The support provided to help individuals or groups to set up or make use of facilities or group activities within the two extra care schemes was of significant value.

Croucher and Bevan (2012) identify themes in developing supportive communities including: promoting tolerance and respect; raising awareness of the nature of conditions or aspects of a person's identity to foster greater understanding and tolerance; background support so that residents can participate; brokering opportunities for individuals; linking with wider communities; and respecting autonomy, privacy, choice and dignity. Croucher and Bevan (2012) focussed on the role of organisations, the role of residents and the contribution of wider community links in helping to promote and develop a supportive, inclusive, physical and social environment within housing with care schemes.

Each of the three roles set out by Croucher and Bevan (2012) were evident in the conversations with participants in this extra care research, but there was greater prominence given to the different roles depending on how the schemes were established. Each extra care scheme seemed to have a unique identity reflecting its constituent members.

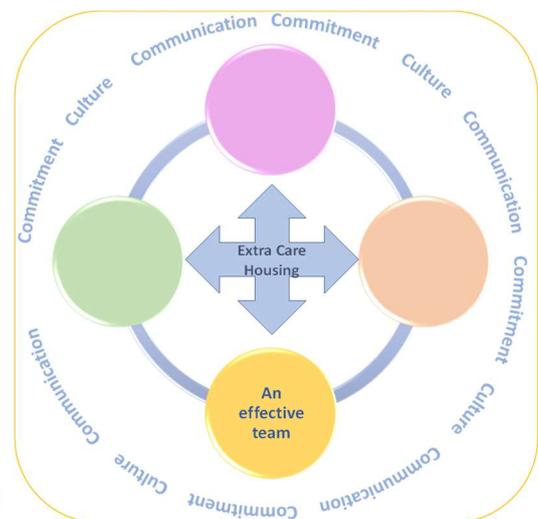
In Section 5.1.2, three examples of developing supporting communities were given, which match with Croucher and Bevan's (2012) three roles. The first example reflected the organisational role, where the care staff and volunteers worked well together to support residents to take part in community activities. The second example was less positive, resulting from conflict between a resident and a member of the wider community. A resident's self-confidence and motivation to set up a peer supported resident activity was undermined by her perception of how a volunteer from outside the extra care scheme was 'taking over' and being patronising. This second example highlighted the damage that volunteers can do if their approach to residents setting up activities and initiatives is either not sensitive or if individuals do not determine for themselves what they do, but rather are constrained by expectations of others (Wehmeyer, 2004; Miller & Das, 2011).

The third example involved a failed attempt by the extra care provider to contract volunteer services. Tetley et al (2017, p. 182) note the challenges associated with the recruitment, management and support of a volunteer-based service when they say ‘local needs, regulatory and bureaucratic restrictions, along with legal regulations, can impact on the goodwill, scope and nature of work that volunteers engage in’. It is difficult to engage people who wish to volunteer but do not want to be part of the bureaucratic world of large complex organisations.

Providing a well-developed extra care community is helped by understanding how boundaries or barriers are put in place or removed as people from different groups or social worlds come together. Insights from social worlds theory and its relevance to understanding the dynamics of an extra care scheme will be discussed in Chapter 7.

6.5 BEING AN EFFECTIVE TEAM WITH THE RIGHT PEOPLE

Section 5.2 suggested that the sum of a team is greater than its individual members. Participants described four elements of team work that have an influence on the experience of individuals with dementia living in extra care, set out in Figure 6-8 below. The emerging issues of leadership, staff roles, developing skills and competence, and managing capacity and resources effectively are reviewed in this section.



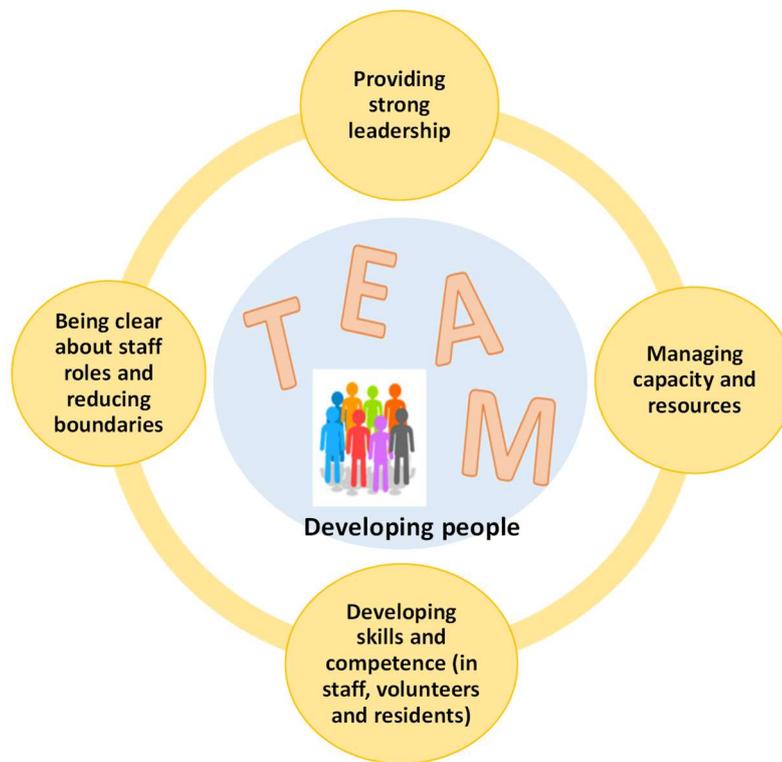


Figure 6-8: An effective team to support individuals in extra care

6.5.1 The importance of leadership

Leadership is a practical skill which results in the action of “leading” or guiding an individual, a group of people or an organisation. Leadership has historically been defined by the characteristics or traits that leaders demonstrated in their interactions with others. In the mid-20th Century a review of evidence from a wide variety of studies indicated that patterns of leadership traits differ with the situation (Stogdill, 1948, p. 60). It became accepted that the qualities, characteristics and skills required of leaders are largely determined by the demands of the situation in which the person is leading, including the needs and interests of followers and the objectives needing to be achieved (Parker Follett, 1942). It is outside the scope of this research to provide an analysis of the increasingly complex leadership models that have since been developed, but a comprehensive review of developments in the last decade is provided by Zaccaro et al (2018), which includes work by eminent authors on both leadership and followership. Zaccaro et al (2018 p35) conclude that:

Leadership researchers must attend more systematically and extensively to leadership context, and particularly how leader individual differences are integrated with situational characteristics... leaders do more than react to situational demands; they choose and shape leadership contexts.

The interrelationship and social construct of leadership and followership is relevant when looking at how organisations behave in developing and delivering services. Defining who is leading whom, within which organisation, and to achieve what goals is imperative in having an effective team in an extra care scheme.

Although there was limited direct mention of 'leaders' in the focus group discussions, views about leadership were assumed from discussions about managers and other key roles. The focus group and interview discussions showed a lack of consensus between local managers and off-site senior managers and commissioners about the source and provision of strategic leadership. This echoes a presupposition that 'leadership is built into positions or people in positions' which Raelin (2004, p. 131) claimed was flawed. He said instead that leadership should be built into an organisational unit or organisation. Consistent with Raelin's view, some of the leadership issues explored by managers within and outside the extra care schemes in this research were about how separate parts of each organisation communicated within the whole extra care partnership, rather than which specific individuals should provide the leadership.

Especially important was the fragmented rather than strategic approach to communicating the aims of the extra care scheme into every day, and consistent, language that could be understood by managers, staff, residents and family members. A clear strategy underpinned by strong leadership are key attributes of organisations that have a well-defined approach to quality management, (Sureshchandar, et al., 2001; Oakland, 2011; Turner, et al., 2016 - 17) and will be explored further in Chapter 8.

In their seminal work on leadership and management, both Kotter (1999) and Mintzberg (2004) said that the jobs of a manager and leader are not neatly segmented, with Mintzberg going on to suggest that we 'stop the dysfunctional

separation of leadership from management' (Mintzberg, 2004, p. 22). Kotter said that getting things done through a large and diverse set of people, despite having little direct control over most of them, is one of the most consequential activities of managers (Kotter, 1982, p. 160).

It has been said by a number of authors that leading in the 21st Century is not easy, and that leaders must challenge conventional wisdom and urge their teams to explore and experiment to move forward (Barton, et al., 2012; Heywood, et al., 2014; Oakland & Turner, 2015). Housing managers and care service managers who took part in the extra care research sought to get things done through a large and diverse set of people. That is not always easy when there are two specialist managers in situ with no overall general manager or figure-head, and when there are insufficient forums in which to creatively share ideas and encourage innovation.

6.5.2 Staff roles and boundaries

The two main staff groups in extra care housing are the housing support staff and the care staff. The different roles of the two groups have been influenced by the service delivery model adopted within the extra care scheme. The dilemmas faced by the managers and staff in this extra care research, such as defining role boundaries between staff groups, are not untypical of other extra care schemes (Skills for Care, 2014 and 2017).

Staff and managers who participated in this research often referred to the concept of a floating staff member. Based on the discussions, a suggestion of what the purpose and tasks of the role might be, which team might host the role, how the role could work across staff groups, and how it could be funded is set out in the illustrative role below.

FLOATING SUPPORT STAFF ROLE – AN ILLUSTRATION

Host staff team: the floating support staff will be members of the care team, working on a rotational basis between floating support and planned care.

Purpose of the post: to provide an effective support service to individual residents to meet unplanned or emergency care and support needs and to promote wellbeing through social inclusion.

The role:

To be the first response to emergency calls from individual residents and provide a triage service if it is not possible to meet the immediate needs of the resident.

To provide ad hoc support to residents to:

- Remember appointments, events and activities that are taking place.
- Come down for formal arranged activities or events.
- Come down to use the café / restaurant, shop and other facilities in the scheme.
- Meet up informally with other residents in the communal areas.
- Feel comfortable to take part in arranged activities or events (e.g. by staying with them for part of the event).
- To provide appropriate support to groups of residents to promote social inclusion and minimise unwanted isolation of individuals.

Working with others:

The floating support worker will:

- Be additional to care staff who are scheduled to deliver planned care through personal care plans.
- Be additional to housing support staff.
- Work closely with the care staff and housing support staff on duty to meet residents planned and unplanned care needs.
- Link with other staff members including commercial providers and social workers to promote the best interests of residents.

Financial considerations:

The number of hours per day/week would need to be determined in conjunction with the size of the scheme and the number of planned care hours in place. Funding for the role will vary depending on the circumstances of each scheme, but may for example, be an element of the wellbeing charge²⁸ made to all residents.

The floating support role could usefully have a broader role than either the care worker or the housing support worker, enabling the floating support worker to work effectively across both teams. The need for care staff working in extra care housing to have a broader and more generic portfolio of skills and an awareness of the

²⁸ Wellbeing services and charges vary across schemes, but typically pay for a core support service available to all residents irrespective of care need.

holistic needs of residents was highlighted by Skills for Care (2014) in their report about new, emerging and changing job roles. Skills for Care reported that only about one-fifth of extra care providers they interviewed appeared to operate a traditional model where providers continue to maintain a separation between roles and do not foresee a 'cross over' (Skills for Care, 2014, p. 14).

Managing capacity and resources was very much seen as a set of complex day-to-day tasks involving matching personal care and support requirements to available staff team members, managing the building, co-ordinating activities, managing catering contracts, and making sure other communal facilities were available etc. Whilst each specialist manager could manage the resources and capacity of their own service, it was more problematic when leadership was required to make changes to enable staff to work flexibly across housing and social care roles to provide person-centred rather than task-centred support. Where ideas are not clear, or not communicated clearly enough, there can be a tendency for staff who are unsure what they are supposed to do to revert to what they know best, which can be a traditional service (Walker & Warren, 1996).

Participants in this extra care research identified that person-centred care and support was needed for individuals with dementia to live well but said little about how it should be provided across the different staff groups involved. McGreevy (2016) discussed the importance of theories of management, motivation and leadership styles on bringing about cultural change to move from task-oriented and person-centred care in dementia care settings. Theories of operational excellence, managing quality and the importance of leadership will be discussed further in Chapters 8 and 9.

6.5.3 Staff, volunteers and service providers working together

Volunteers and care staff working together harmoniously was identified as key to having a well-developed community in extra care schemes. Section 5.2.3 set out how their roles can be enhanced if everyone is able to develop the required skills and competence to work successfully as members of the team. It also identified

three areas that all participant groups described as important; sharing information, awareness of dementia, and having a detailed understanding of dementia.

Residents who participated in the research described how easy or difficult it was to make friendships or be part of the different groups in the extra care scheme. Both staff and resident participants highlighted the benefits of staff 'going the extra mile'. Managers described the benefits to residents when staff and volunteers worked alongside each other, whilst staff described how it was sometimes difficult to work with other service providers because of organisational boundaries or policies. What was being deliberated in these situations was how groups become established and work together.

Some of the deliberations can be examined through a lens of social worlds theory, which explores how societies have multiple social worlds that co-exist. Within extra care the social worlds of residents co-exist with those of the managers and staff, the volunteers, and the other service providers such as the catering staff and the hairdressers. The congruence of these social worlds or groups will affect how easily they are able to address issues such as understanding and supporting people to live with dementia. The extent to which the different groups can operate jointly can be constrained by formal and informal standards and boundaries that they adopt.

Problems in sharing information were discussed by all participant groups and may arise because of the constraints placed upon members of the social worlds in extra care. For example, staff are limited by legislation and by regulatory bodies in the personal information about residents that they can share, but limits to how personal information can be shared may also be self-imposed by the groups themselves as they negotiate and assert their own boundaries and relationships. This can be illustrated best with a scenario from the research. Section 5.1.3 set out two approaches to sharing the news that a resident had died. In both schemes the staff and managers were adhering to requirements of data protection legislation. Different approaches to sharing information about the death of the resident then developed in the two extra care schemes as different interpretations of data protection requirements became custom and practice. This is consistent with social

worlds theory in which people with different outlooks and perspectives define identical situations differently, responding selectively to the environment, and coming to different judgements about the same situation (Charon, 2007).

Social worlds theory, which will be considered in more detail in Chapter 7, can provide a helpful lens for considering how individuals and groups co-exist or work together in extra care, and what the impact might be for someone living with dementia.

6.5.4 Developing capable teams and managing resources

A detailed analysis of skill development and training needs was not within the remit of this research, but the informal discussions that staff and managers had about skills, training and development were not atypical of the findings from Skills for Care (2014). Skills for Care identified new and emerging staff specialisms within extra care as dementia, substance misuse, mental health and learning disabilities, many of which had unmet training needs. Areas particularly highlighted in the Skills for Care research included training around outcomes-based approaches, differences between care and support, dementia, enabling people through care and support, and empowering people. More recent research funded by the National Institute for Health Research School explored how empathetic engagement was used by home care staff when engaging clients with everyday tasks, which helped to reinforce the agency and identity of the person with dementia (Schneider, 2017, p. 12). Schneider concluded that

...in addition to the many and various practical duties of home care, good home care for people with dementia was characterised by four additional activities performed by care workers:

- anticipation of needs on the part of clients with memory loss and organisation to meet these needs;
- acknowledgement and promotion of their clients' identities
- attunement to and consideration of clients' feelings at all time; and
- affordance of pleasurable experiences and opportunities to exercise agency. (Schneider, 2017, p. 12)

These activities require specific knowledge and skills, which would contribute to an individual with dementia living well in extra care, as described in Section 4.5.

Ensuring that people living with dementia are supported by skilled and competent people requires a holistic view of who is providing support, moving beyond the immediate housing and care support.

There can be many organisations involved in extra care schemes, including housing support, housing management, care, catering, commercial outlets, and volunteer organisations. The relationships between organisations and groups is important in creating an effective team to meet the expectations and needs of residents, especially those living with dementia. The culture of an organisation will encourage or discourage different service providers working together as teams to support residents. Having a positive culture and developing capability through competent people working effectively together are key features of organisations that manage the quality of their service well.

6.6 SUPPORTING AN EFFECTIVE TEAM WITH THE RIGHT PROCESSES AND RESOURCES

6.6.1 Having flexible processes to support individuals with and without agreed care needs

Participants in the different focus groups and individual interviews not only talked about the quality and competence of people working together in extra care, but also about having the right processes in place to support effective service delivery. The processes described by staff and managers included allocating apartments, making sure the extra care scheme had people with a balanced set of care needs, being able to adapt to resident changes in care needs, being able to support residents with unexpected or unplanned needs, being able to support residents' social or emotional needs, and being able to refer residents for additional services outside the extra care scheme. Those were mainly internal processes supported by input from the local housing manager or social worker at key points. Other processes that were discussed by residents, staff and managers alike involved the other suppliers of services within the extra care scheme, such as the caterers.

Figure 6-9 sets out a model where the different suppliers to the extra care service work in partnership with the extra care providers to jointly meet customer requirements²⁹ through customer focused processes. There were examples in this extra care research, given by both scheme managers and by commissioners and contracting managers, of the added value that could be gained where staff and managers from different agencies worked creatively together to meet the needs of all the residents and customers.

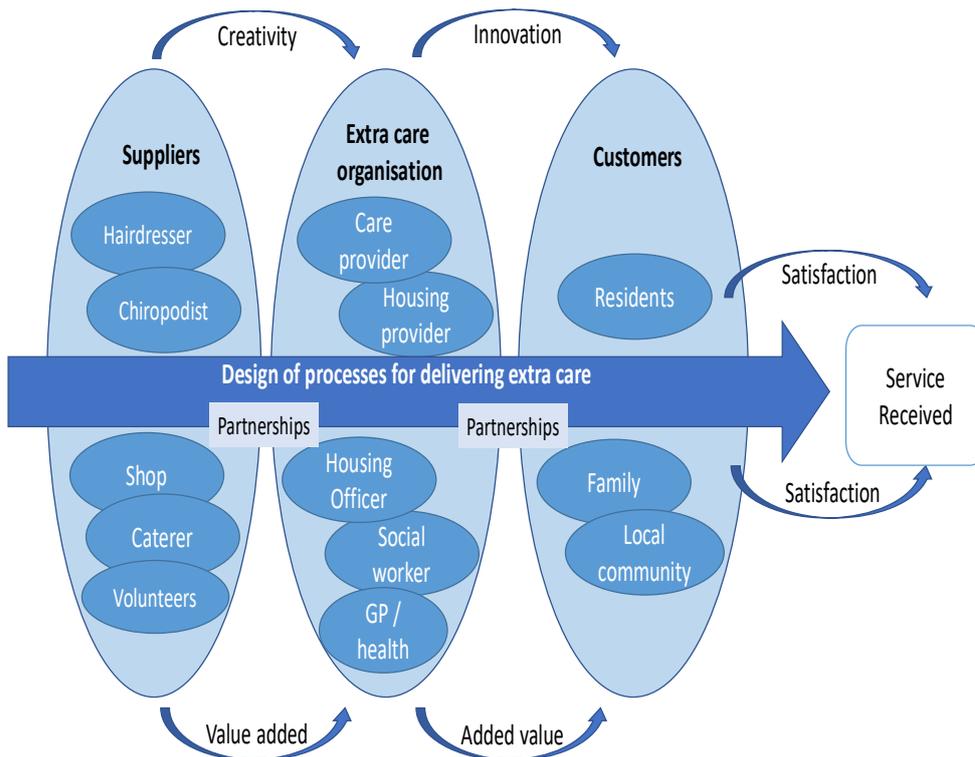


Figure 6-9: Designing processes for delivering extra care services with suppliers and customers
(Adapted from Oakland 2014, p. 110)

The more the extra care providers work creatively with suppliers to provide innovative services to the customers, the more value should be derived from the service. Equally, the more residents and customers are involved as partners in designing the services around their requirements, the more satisfied they are likely to be with the resulting service.

²⁹ In this chapter the term customer is used to refer to residents, users of the community facilities and services, and family members. The concept of the customer is explored further in Chapter 8.

Co-design and co-production are recognised ways of developing and delivering services with customers. Whilst challenging for those involved, co-production and co-design have been championed abroad and, in the UK, and are increasingly being used to develop service provision and social care policy in the UK (Boyle, 2009; Pacey, 2010; Boviard & Loeffler, 2012; Scriven, 2012; Boviard, et al., 2015).

Best practice using co-production is now recognised in legislation and guidance including 'Making it real, Marking progress towards personalised, community based services' (TLAP, 2011), 'A vision for adult social care: Capable communities and active citizens' (Department of Health, 2010), and 'The Care Act' (Great Britain, 2014). The Care and Support Statutory Guidance (Department of Health, 2014, p. 4) defines co-production as:

When an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered.

Within the extra care schemes at this research there were several examples of co-design; in one scheme the residents worked with providers to run the shop, in both schemes the residents were involved in agreeing activities. In another extra care scheme within the same local authority, the extra care scheme was established and continues to be influenced by a group of local people interested in the scheme. These two types of co-production, first those individuals who use services, and second, groups of people who get together to affect the development and delivery of services, are both acknowledged in the Care and Support Statutory Guidance.

Co-production is one element of managing customer relationships. Managing customer relationships effectively requires an organisation and its suppliers to have a central focus on customers, one of the main principles of an effective quality management strategy.

6.6.2 Balancing human resources with assistive technology

Most of the discussion and analysis in this research has focused on service provision in extra care. Extra care also provides a product, the apartment itself, and the

associated communal areas of the building. Participants did discuss the apartments, the bin areas and other parts of the buildings, but mostly the discussion focused on the services that enabled the products to be used well. For example, the responsiveness of the repair service.

The service sector has often been considered to pay low wages, be unproductive, and lack innovation in the jobs. Mounting evidence gained through innovation surveys discredited that view, confirming that services were innovative and, in some areas, more innovative than traditional product manufacturers

Many service providers are being innovative in the way in which they merge their product and service offerings by building the infrastructure for future technology into their schemes. The effective use of resources and alleviating capacity in the current employment climate has been linked to the appropriate use of assistive technology³⁰ to complement hands-on care staff. Assistive technology and telecare³¹ are terms that are sometimes used interchangeably. Telecare devices, or assistive technology, are seen by many as an innovative and effective way to support older people and their carers, who are usually family members. They are reported to improve their quality of life, to improve safety, to improve independent living, to ease the challenges caused by age and to promote autonomy (Cahill, et al., 2007; Botsis, et al., 2008; Topo, 2009; Matlabi, et al., 2011; Cook, et al., 2017). They are also said to save time, provide reassurance, relief and peace of mind for relatives (Cash, 2004; Carretero, et al., 2013).

The Department of Health endorsed the use of telecare and telehealth³², and evaluated such innovations through its Whole System Demonstrator programme

³⁰ Assistive technology comprises products, equipment, and systems that enhance learning, working, and daily living for persons with disabilities (Assistive Technology Industry Association, 2017).

³¹ Telecare has been defined by the Department of Health as a service that uses 'a combination of alarms, sensors and other equipment to help people live independently. This is done by monitoring activity changes over time and will raise a call for help in emergency situations, such as a fall, fire or a flood' (Department of Health, 2009).

³² Telehealth involves the distribution of health-related services and information via electronic information and telecommunication technologies. It has been defined by the Department of Health as a service that 'uses equipment to monitor people's health in their own home... [monitoring] vital signs such as blood pressure, blood oxygen levels or weight' (Department of Health, 2009).

(Department of Health, 2011). Whilst early findings of the Whole System Demonstrator programme indicated that if used correctly telehealth could deliver some savings to the NHS, there was inconclusive evidence that telecare improved outcomes for those who used it (Woolham, et al., 2016).

Some caveats about the use of telecare are emerging from recent research, including whether assistive technology can be used effectively to support people with dementia. Factors to be considered include the individual or their carer having enough knowledge about what is available, agreement on who is going to be responsible to support the individual if the assistive technology requires an intervention, how useful the technology is perceived to be, and how easy it is to use. (Greenhalgh, et al., 2015; Luijkx, et al., 2015; Tinder Foundation, 2016; Cook, et al., 2017).

There was surprisingly little discussion by participants in this research about the use of assistive technology. That may in part be because there is a perceived lack of funding for it. The lack of discussion about assistive technology may also be because it is expected that family carers will arrange and support its use, or because it is not popular. There was some concern that when assistive items had been identified for an individual, there were then sometimes delays due to the ordering and funding approval process.

Other comments reflected an anxiety that assistive technology was seen as cost cutting and a replacement for staff support. The inter-relationship between human and technological interventions was recognised by one of the senior managers interviewed, who said that high levels of care service coupled with use of technology are key to supporting someone with high levels of dementia. Participants' concerns about the role of assistive technology alongside the role of carers are reflected in Greenhalgh's work where it says that assistive technologies will require 'skilled humans, inter-sectorial negotiation and a social infrastructure to ensure that they work' (Greenhalgh, et al., 2015, p. 2).

The social infrastructure appears problematic in extra care, where there is a barrier to staff responding to some of the assistive technology installations, such as the wander alerts described in Chapter 4. Effective assimilation of product and service delivery will require processes to be adapted to focus on how best to meet resident needs, which may involve reviewing current staff roles and boundaries as new technology becomes available.

The different responsibilities and drivers of each extra care partner were discussed in Section 5.2.1. Removing process gaps and aligning financial and non-financial drivers across partner organisations is imperative if all partners are to meet their strategic priorities in delivering the extra care service to meet the needs of residents and family members.

6.7 CONCLUSION

This chapter has explored the key issues expressed by participants in considering the possibilities and practicalities of people with dementia living in extra care housing. Those issues include the importance of having a vision when planning and delivering the extra care service; managing an individual's rights, risks and safety in the delivery of personalised care and support; recognising and developing the extra care community; being an effective team with the right people; and supporting an effective team with the right processes and support.

A further literature search provided insights germane to the different lines of enquiry in this chapter. Two main theories, social worlds theory and quality and operational excellence theory, were relevant to understanding the issues raised when considering the practicalities and possibilities of individuals with dementia living in extra care. Social world theory considers both situation and relationships of social groups, thus providing a strong analytical framework (Baszanger & Dodier, 1997; Clarke & Star, 2008), helpful for examining the relationships of people with dementia and those around them. Social worlds theory has been used by different disciplines, accommodates environmental gerontology and the social model of disability, and provides a foundation from which to examine the tensions and

conflicts within and between social groups in extra care. Its foundation also provides a basis for examining the processes of social and organisational segmentation and connection. Organisational theory also offers insights into individual and group dynamics, in particular theories of organisational culture³³, but it was discounted by the researcher for this study because it was felt they would focus overly on the managerial aspects of extra care to the detriment of the lived experience of residents.

The managerial and organisational aspects of extra care were important to residents however. The juxtaposition of social worlds theory with quality and organisational excellence theory can help understand the experience of those living and working in extra care. The concept of total quality management and operational excellence is recognised internationally, and provides a broad perspective linking quality to the direction, policies, and strategies of an organisation. That broad perspective with a focus on customers³⁴ is guided by different management theories and is adaptable for use across partnership organisations such as those in extra care. Combined use of social worlds theory and quality and operational excellence theory draws out both the sociological and the managerial influences on the lived experience in extra care. These two theories will be examined further in Chapters 7 and 8, which set out how the theories validate some of the early research findings and adds to the suggested model of extra care. The tentative extra care model will be reviewed in Chapter 9, where the social work theory and organisational excellence theory will be brought together to consolidate the extra care model, bringing new knowledge to support those who develop, deliver and operate extra care housing.

³³ Work on organisational culture was introduced in the 1960s when it was borrowed from social sciences including anthropology, sociology and psychology (Reichers & Schneider, 1990). It was pioneered by leading practitioners and authors such as Charles Handy, Geert Hofstede, John Kotter, and Edward Schein.

³⁴ The notion of customers vs residents is explored further in Chapter 8.

7. CHAPTER SEVEN: INSIGHTS INTO EXTRA CARE AS A SOCIAL WORLD – CONTRIBUTIONS FROM A FURTHER LITERATURE REVIEW

The fieldwork part of this study set out to understand how extra care is experienced by individuals and how they make sense of their world when that world is extra care housing. Grounded theory was used to hear the voices of those with both more and less power within the extra care, encouraging and recognising the different perspectives and realities of those involved. The nature of the social worlds within extra care was not defined by the researcher prior to the study. Rather, the inter-relationships between individuals, groups, and the environment were articulated through the voices of those who live and work in extra care. Using an environmental gerontology approach to view the findings of Chapters 4 - 6, and considering dementia within a social model of disability (see Section 0) led to a review of social worlds theory. It has been used to shed light on the findings, giving deeper understanding of how social groups develop, how they function, and how belonging or not belonging to them can affect the experience of someone living in extra care. This extra care research does not give 'proof' to validate the use of social worlds theory, rather it offers explanations of social worlds theory in the spirit that they add to the emerging body of knowledge about how extra care communities function, including those individuals who live and work in them. This chapter also highlights areas where the application of social worlds theory to extra care might usefully be subject to further research.

7.1 AN INTRODUCTION TO SOCIAL WORLDS THEORY AND ITS RELEVANCE TO EXTRA CARE HOUSING

The concept of social worlds was developed within social interactionism at the Chicago School of Sociology (Argyle, 1973; Maine, 1991). It is outside the scope of this thesis to give a full history of the development and deployment of social

worlds theory³⁵. It is important however, to recognise its salience to this research, which is set out below.

First, social worlds theory originated from work on social groups which later became known as social worlds (Thomas, 1914; Mead, (1938) 1972; Strauss, 1978a). The value of social worlds theory for this research is that it goes beyond social groups to consider both situation and relationships, which provides a strong analytical framework (Baszanger & Dodier, 1997; Clarke & Star, 2008) to explore the relationships of people with dementia and those around them, relevant to an extra care setting.

Second, social worlds theory conceptualises society with multiple and interconnected social worlds that focus on collective action or 'doing things together' (Becker, 1986) by focusing on shared discourses; exploring how social groups make meanings together, and how they act on those meanings within a social world. Mead ((1938) 1972, p. 518) talked particularly about the meanings of phenomena lying in their embeddedness in relationships, in universes of discourse. In this context 'discourses'³⁶ are used to articulate joint commitments and actions that develop within a social world, which vary amongst the different members of multiple and interconnected social worlds.

Third, social worlds analysis takes into account 'problematically bounded and contingent discursive as well as organizational arrangements' (Clarke & Star, 2008, p. 117). This enables a broad study of people living with dementia in extra care to embrace the perspectives of the different players and participants involved. As described in Section 6.7, an alternative approach using organisational theory was considered in which the structuring and management of the different groups in extra care to meet collective goals could have been explored. This was discounted by the researcher as it was felt it could focus too

³⁵ Clarke & Star (2008) provide a full account of social worlds in the symbolic interactionist tradition

³⁶ Concepts of discourse within social worlds theory are compared to concepts of discourse analysis stemming from European phenomenology and critical theory by Clarke and Star (2008).

much on the managerial aspects of extra care rather than the lived experience of residents.

Fourth, social worlds theory recognises different types of actors including those who are physically present but who may be ignored or generally silenced by those in power (Star & Strauss, 1999). This is of importance in considering how the voice of the resident, and the voice of people with dementia are heard by those perceived to have more power within the extra care social world. Another recognised group of actors are those who are not physically present in a social world but who are discursively constructed and discursively present (Clarke & Star, 2008), of some relevance to extra care, where people with dementia may have limited ability to take part in groups and represent themselves in the social world.

Fifth, the concept of boundary objects developed by Star & Griesemer (1989) provides a vehicle for exploring some of the non-human aspects that affect how social worlds function and how different members of social worlds can negotiate different issues of mutual concern. Boundary objects can provide an opportunity to share different discourses that are in play and provide an opportunity to analyse the different perspectives in the situation.

In their work on a social worlds framework Clark and Star (2008) describe social worlds studies from a range of disciplines and highlight some of the controversies that were encountered. They highlighted that both co-operation and consensus can be problematic citing, amongst others, work on 'disciplinary worlds colliding' by Tuunainen (2005). Co-operation and consensus will be further explored in Chapter 9. Being aware of some of difficulties experienced by others in the application of social worlds theory helps in considering its usefulness to a model of extra care for people living with dementia.

Extra care housing was developed through collective action to tackle housing and care problems. Chapter 2 set out how limited public funding, a skills shortage, a lack of care staff capacity, and an unsuitability of many UK

households culminated in interested parties working together to resolve the housing with care problems being faced by the increasing number of older people. Extra care emerged as an important option to support older people with health and social care needs, offering a solution that bridged social care and housing sectors. Social worlds often, but not always, entail people coming together within a shared space or territory (Baszanger & Dodier, 1997). Figure 7-1 sets out how a social world of social services, with an interest in providing care to people in accommodation that enables them to live as independently as possible, came together with a social world of housing providers who have an interest in making best use of scarce accommodation for a growing population.

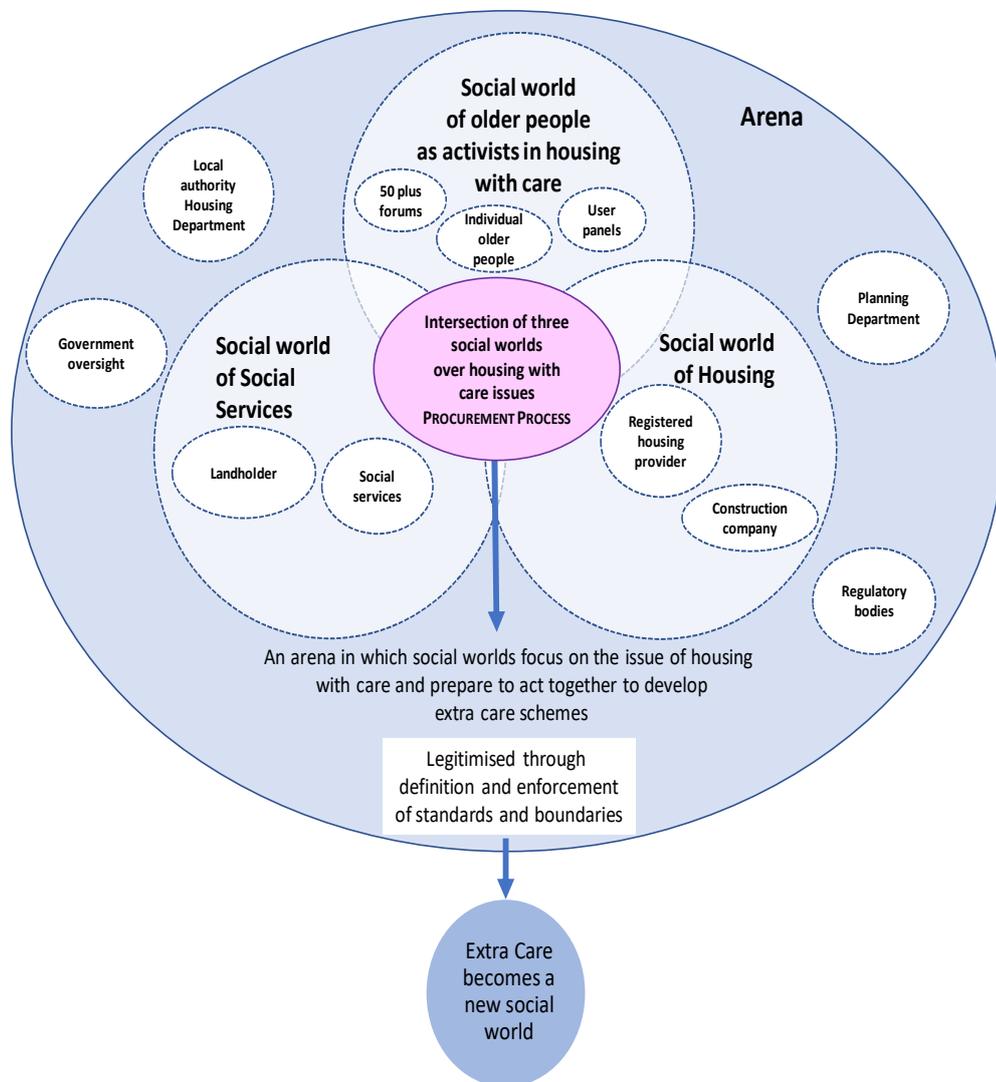


Figure 7-1: A framework for the emergence of a social world of extra care

A cross-agency approach to deliver a local strategy for accommodation, care and support provided an arena for action that included members of the 50+ forums from the social world of older people as activists in housing with care. Within that arena, the main interested parties with authority to act on this issue were brought together through a formal procurement process, initiated by social services and including a community reference group of older people. The community reference group and representatives of the 50+ forums used their experience of home and their expectations of housing with care to influence and provide a reference point for commissioners of extra care. Other parties such as the local authority housing department, the planning department, and regulatory bodies were brought into the arena to provide expertise relevant to the development of extra care. Over time the concept of extra care was refined and developed into a brief for how an extra care scheme would be developed, built and operated. Standards and agreements were put in place and legitimised both formally through a contractual arrangement, and informally through shared understanding and practices between social services and the housing partners for the new extra care developments³⁷.

The procurement of extra care housing resulted in multiple extra care schemes, with each one providing an extra care social world. The social worlds of extra care have continued to mature, clarifying their boundaries through ongoing negotiations between the housing and social care partners involved. Building on the original work of Strauss (1978b) about intersections between social worlds, Tovey and Adams (2001) introduced the idea of strong and weak intersections between and within social worlds, reflecting the negotiating skills and relative strengths and weaknesses in social world power relationships. Effective intersections are sought through periods of detailed negotiations between different participants, which are often repeated over a prolonged period, as demonstrated in the length of time it takes to set up extra care as a housing

³⁷ The description of strategy development and procurement of extra care is based on the researcher's prior knowledge of procurement of extra care provision by local authorities and verified with the local authority in which the extra care research sites were located.

solution³⁸. The need for effective negotiation was exemplified by one social care manager who said:

I was extremely green about how extra care worked, and I was very glad of the leadership of the project manager... she was the hinge-pin between us and the housing provider and worked closely with people in housing that could pursue things on our behalf.

In this research participants described how the extra care developed over time, with changes brought about by extra care partners, staff and residents variously coming together to address common issues through joint management meetings and resident meetings as well as by individuals acting together. This processual change is a key strength of social worlds theory, allowing for fluidity and for the changes in social worlds to become apparent and to be legitimised over time (Strauss 1978a and 1982, Clarke 1990).

Individuals typically have many different roles; as family member, friend, colleague, associate, club member, etc., moving from one social world to another as they assume different roles, participate in different activities, often in different places. Although extra care provides a social world for those who live and work there, most people belong to other social worlds as well, reflecting their history and current identity. Their sense of self and sense of connection to others results from interactions with other significant people around them (Bernard, et al., 2012). People form smaller groups within any social world where sub-sections of people come together in a specific sub-world³⁹ around common areas of interest. Such divisions or groups usually exist within an arena where they can develop an acceptable status quo both within and between the different worlds.

The community elements of extra care such as the café and lounge areas provide focal points for forging new relationships and connections when people enter

³⁸ Approximately 3 years, based on 12 – 18 month time elapse from contract advert to close of procurement for a typical extra care procurement through the Official Journal of the European Union (OJEU) process in a local authority in the East Midlands, followed by 12 - 18 months build programme (Dence, 2018).

³⁹ The terms social sub-world and groups will be used synonymously in this chapter.

the social world of extra care. Section 5.1 described how individuals had different views about the nature and role of the community in extra care, which is consistent with the findings of Stephens' (2007, p. 105) work on community and social representations. He wrote that:

Thus, 'community' is seen as constructed in multiple ways by people using socially shared representations that are deployed according to their social function.

Each sub-world group has its own shared outlook. Mobility between worlds may require someone to change their outlook or adopt the same outlook as other members of the group. Shared outlooks adopted by a social world's members constitute a frame of reference for individuals (Shibutani, 1955), helping them to belong to the group or community.

In Section 5.1, participants described how some residents chose not to fully embrace the community, but to live in relative isolation within extra care, not taking part in community activities. Shibutani (1955, p. 566) portrays social worlds as having boundaries that are 'set neither by territory nor formal membership, but by the limits of effective communication'. In this research Zoe, one of the participants, was able to effectively convey to other residents why she and Alan had made a positive choice not to take part in day-to-day community life. Although this made Alan and Zoe seemingly invisible as members of the community, Zoe said that they still felt welcome members of the group when they did choose to take part in something specific. Conversely, staff and manager participants described how some residents with dementia could be marginalised by group members, consistent with the finding of Raymond et al (2014) that older people with disabilities can be marginalised from community participation.

Groups and friendships that developed in the extra care schemes appeared fluid, with residents coming together within smaller groups in the social world of extra care. As described in Chapter 5, having effective teams to support well developed communities and help individuals to live well are key components in

the extra care model agreed by participants in this research, set out in Figure 7-2.

Support for communities to develop, and for both formal and informal activities to take place within extra care, appeared to influence how easily different groups co-existed and how individuals could move between groups.

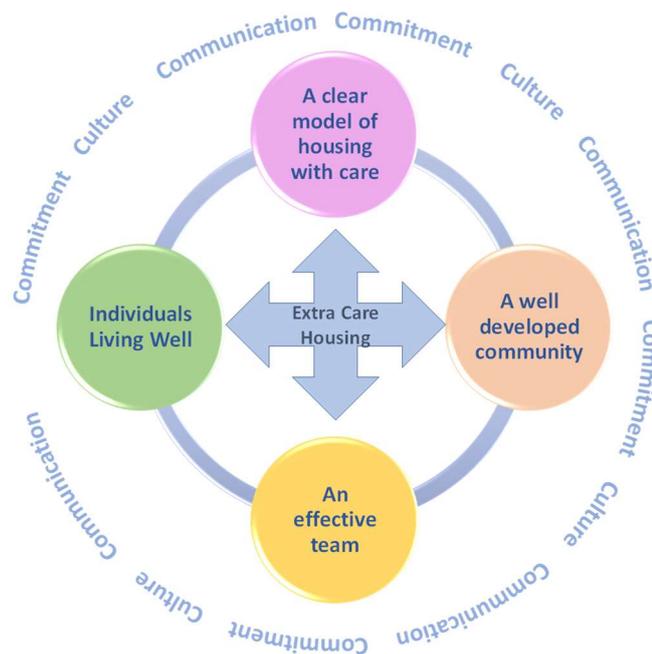
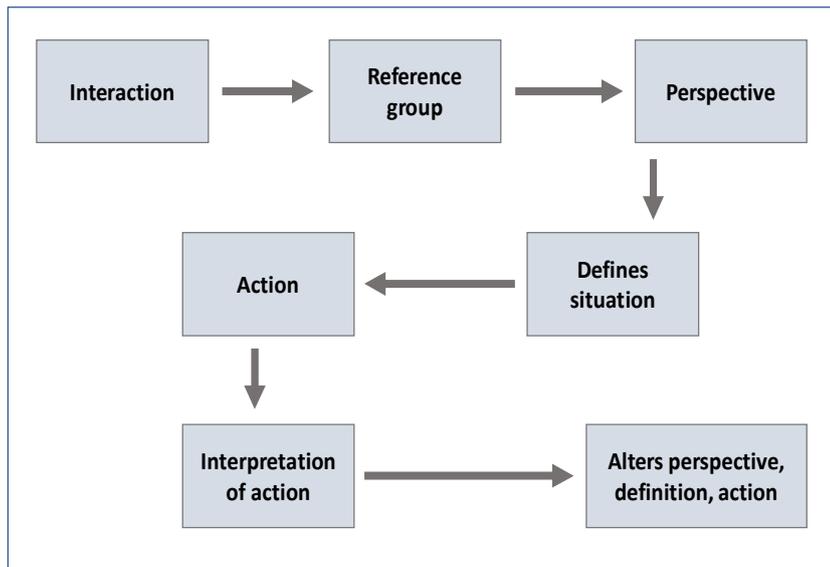


Figure 7-2: Model of Extra Care

Shibutani (1986) suggested that groups in social worlds each have a culture that is used to frame the group's response to situations. He asserted that culture is not static, but a continuing process in which norms are creatively reaffirmed through social interactions on a day by day basis. Those taking part in such symbolic interactions confirm and reinforce each other's perspectives leading people in the group to take actions or respond to others in expected ways as set out in Figure 7-3.



Burbank and Martins (2010), adapted from Charon (2007)

Figure 7-3: Symbolic interaction processes

Where actions are unexpected they will need to be reinterpreted, which could alter the group's outlook and redefine its culture. Schein's (1990) description of how culture grows when shared assumptions develop within groups of people solving problems together is pertinent to the shifts in extra care culture that can be brought about by processual change. He said:

Culture is what a group learns over a period of time as that group solves its problems of survival in an external environment and its problems of internal integration. (Schein, 1990, p. 111)

The contribution of group learning to culture highlights the importance of effective local relationships, which resonates with issues raised by participants in Chapter 5 where it was revealed that leadership, culture, commitment, communication and partnership working are integral to understanding how the extra care works. If the right culture is not already there, having a commitment to develop it and to create a sense of belonging through changes to how the community functions will require resources and infrastructure (Lehning, et al., 2012). Leadership, culture and change will be explored further in Chapters 8 and 9.

7.2 SOCIAL GROUPS AND SOCIAL WORLDS IN EXTRA CARE

The last section gave an overview of social worlds theory and its relevance for extra care. It said that individuals vary in how they choose to belong to social groups and that the culture of a scheme is a determinant of how easy it is for individuals to participate in and be members of social sub-worlds. This section will explore in more detail the definition and development of multiple social sub-worlds in extra care, and their implications for individuals living both with and without dementia.

7.2.1 Defining the extra care social world

As a phenomenon, extra care is described as both a physical building and a service, which provides housing, care and support for individual residents and facilities and activities for a wider community. Using Baszanger and Dodier's (1997) definition of social world as a geographical space or territory, the social world of extra care would be the building and its grounds, and its constituent members would be those who live and work there, and those who use its community services.

Using Shibutani's (1986) broader definition, social world is represented by more than geographical territory, its constituent members could extend to other people with a legitimate role in extra care who are not based at the scheme, including senior managers across the extra care partnership who have line management accountability for the scheme. For the purposes of this study, the social world of extra care consists of the geographical setting, its immediate occupants, and the wider group of people who have a vested and legitimate role in it.

Membership of the extra care social world is conferred on individuals by their work role or because they choose to live or use services in extra care. As described in the previous section, the different groups of people involved in the social world might split themselves into sub-worlds of common interest, as

illustrated in Figure 7-4 which shows the sub-worlds of residents, care providers, housing providers and commercial service providers as examples.

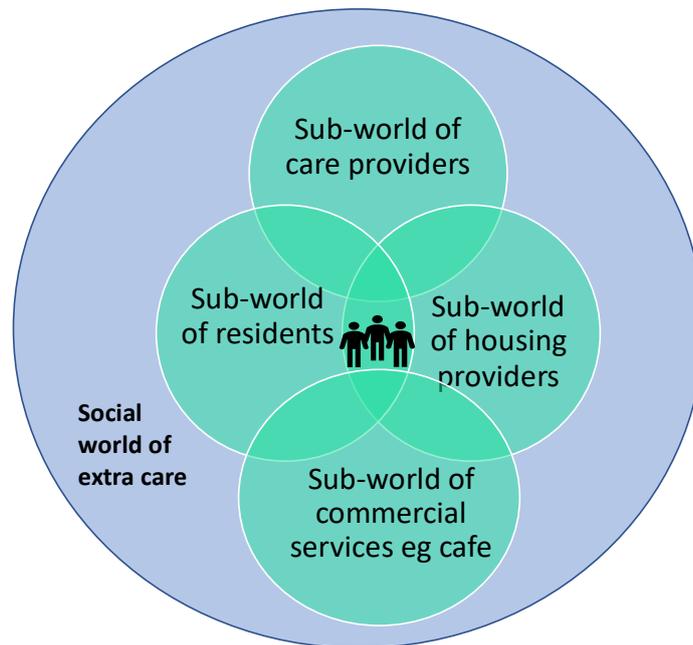


Figure 7-4: Social world of extra with examples of possible sub-worlds

Entry to extra care, and thus access to the extra care social world, is dependent on individuals meeting certain membership requirements. For example, membership of the staff sub-world is defined by work role, and membership of the resident sub-world is defined by allocation criteria for an apartment. The rest of this section focuses primarily on how residents access the extra care social world and its sub-worlds.

7.2.2 Becoming a resident member of the extra care social world

The allocation of apartments in extra care was a topic of discussion across the participant groups. There are formal access criteria that individuals must meet, which are set out in the allocations policy and nominations protocol⁴⁰. Interested people make a formal application to rent or purchase an apartment. The application includes a summary of their current circumstances and why they want to move to the extra care scheme. Those applications are considered by an

⁴⁰ An allocation policy and nomination protocol are typically part of the contractual arrangements put in place between the landlord, the local authority commissioners, and the local district or housing department when an extra care scheme is agreed.

allocation panel comprising representatives of the landlord, social work, care provider, and local district or borough housing departments. The panel collectively considers each application on its merit, and prioritises them based on factors set out in the allocation policy.

Those factors include the individual's support network, whether that support is stable, and whether the support would continue if the person did or did not move into extra care. An applicant's network, and their resulting membership of different social worlds may reflect the strength of support they are likely to be able to draw on. Judgements⁴¹ are made by the allocation panel about how well the applicant 'fits' with the current cohort of residents, as well as judgements about how independent the applicant is and whether staff have the capacity to respond to the individual's needs. The allocation panel uses the allocation policy and nomination protocol to assess how appropriate it is for someone to move from their current setting into a new social world of extra care. Figure 7-5 sets out how the allocation panel acts as a boundary between the applicant's current social worlds and their move into a new social world of extra care, with managers at the allocation panel as gatekeepers who authorise any moves.

⁴¹ An allocation panel will make decisions on applicants based upon achieving a balanced community at the extra care scheme.

Key factors typically taken into consideration when a vacancy arises are:

- The applicant's (and their partner's or members of their household's) level of care and support needs;
- whether and to what extent the applicant is in housing need;
- the suitability of an applicant's existing accommodation;
- the overall mix and levels of dependency in the extra care scheme at that point in time;
- whether the resources available to each scheme can reasonably meet the applicant's care and support needs; and
- the strength of the applicant's links to the locality.

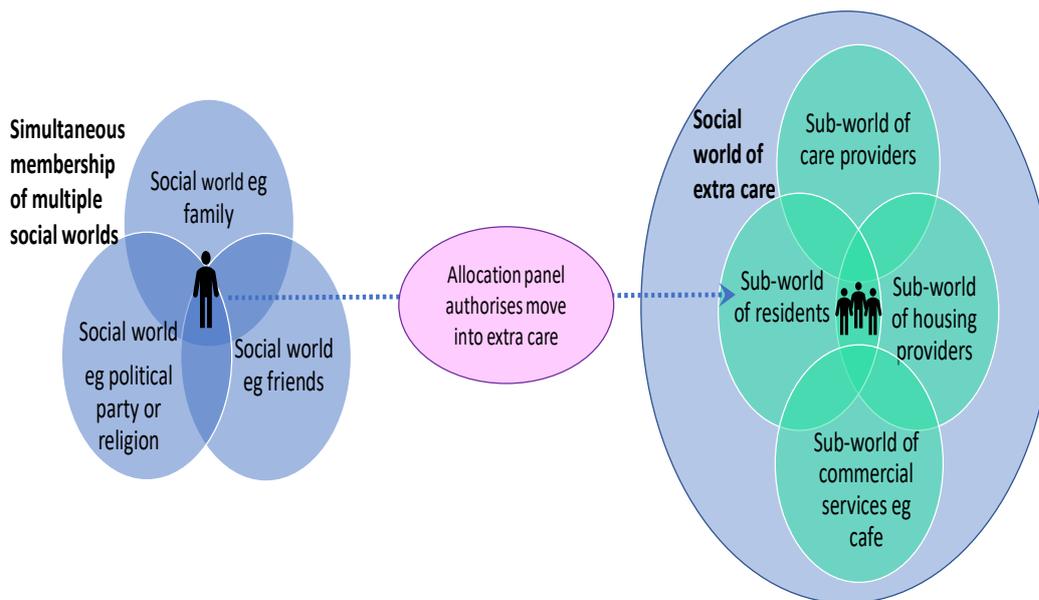


Figure 7-5: Moving from external social worlds into the social world of extra care

When making decisions about whether individuals can or should be allowed access to the extra care social worlds, managers in this research described how they considered whether someone could manage their daily lives when they first move in. As described in Chapter 5, that involved being able to establish new routines, being able to settle into new surroundings, and being able to manage new relationships with other people in the extra care. These considerations did not automatically exclude someone with dementia as each application was judged as a unique set of circumstances. In Chapter 4, participants expressed views about not setting up individuals with dementia to fail by letting them move into extra care if it was not appropriate for them. One of the participant managers talked about the allocation panel and said:

But that is not really that helpful, when it comes around the table to discuss somebody. You want somebody to move out of their environment which is not working properly: they are at risk or they are not caring for themselves. Or they are unkempt, they are unsavoury, they are all those things that you know are going to be a bit of a difficulty living in a setting like this. But nevertheless, that's the challenge for us yes, yes, So I am not saying they shouldn't be here, what I am saying is there should be more openness, openness so that, and if there was, then I think the allocation panels should have more... Because in the busyness of our week, I see the allocation panel in my diary. And I think, oh, the care service manager will manage that... because the issues... their decisions are about have we got capacity for staffing? What is it like in terms of balance of care? How are

we going to manage those risks if they are transparent at that time? But if people were more honest about what the difficulties were at the time, then I think there would be... there is more importance on the panel to discuss those things that perhaps might not come to light. If they were honest and open at the time ... like... well... it's going to be difficult for tenants to accept some of the issues of this person, so we need to look at how we handle the transition, how we make that transition. Or ... it's going to be difficult for the tenant moving into this kind of... how do we help them more, and whose job is it?

In effect these were the unofficial, unwritten but important factors that influenced whether someone would become a member of the extra care social world. They relied on professional judgement and integrity of managers in their capacity as gatekeeper to ensure fair application. There are implications here for setting up and monitoring quality assurance of those professional judgements to ensure they are ethically sound, of good quality, and ensure fair access to the social world of extra care for people living both with and without dementia.

7.2.3 The importance of relationships and culture

It was proposed earlier that as someone moves into the social world of extra care they may become members of several social groups. Figure 7-5 illustrated the main sub-worlds that relate to the various roles an individual may have within the scheme; resident, care provider, housing provider or commercial service provider. Sub-worlds themselves are not homogenous groups, they will split into multiple groups of common interest such as those shown in Figure 7-6⁴².

⁴² The examples of multiple resident sub-worlds in Figure 7-6 are not an exhaustive list.

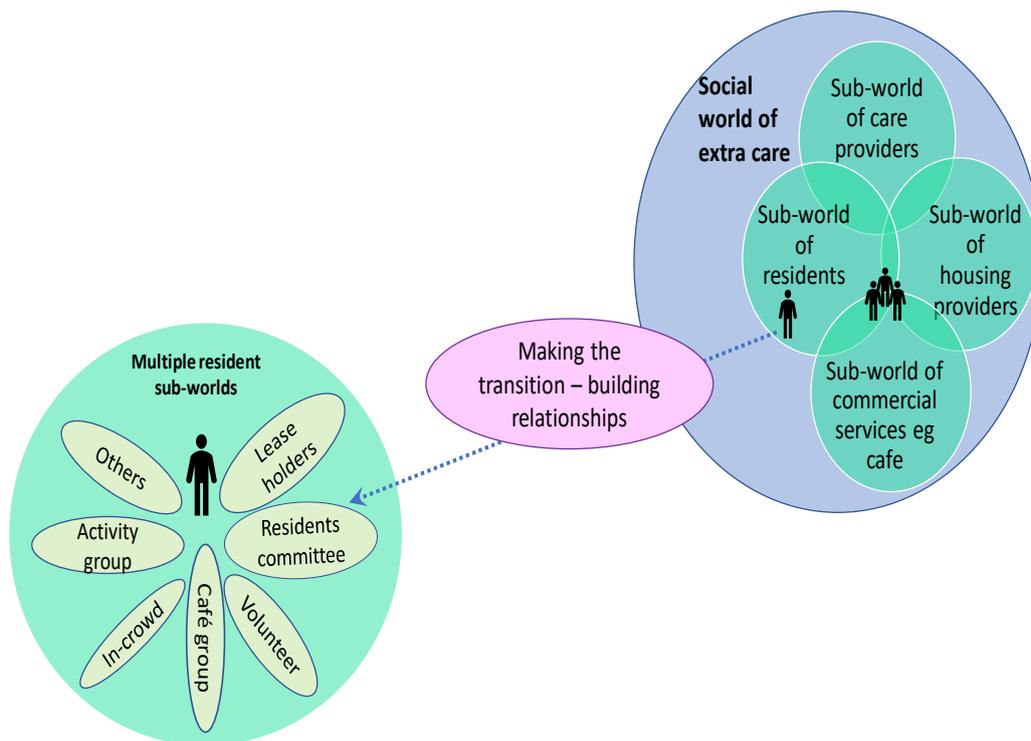


Figure 7-6: Being a member of different resident social sub-worlds

Membership of resident sub-worlds is not an automatic right. Extra care communities are made up of microcosms of wider society, and a person's readiness or ability to engage socially should not be taken for granted (Shaw, et al., 2016). Being able to build relationships with other group members will help residents be active members of the extra care world. But just as in wider society, existing members of an extra care sub-world may not be willing to admit new members to their group. Important to being accepted within a group is the ability to develop reciprocal relationships (Brown Wilson, 2009; Killett, et al., 2015). When personal interaction is initiated there is usually a reciprocal positive response, such as the attempts described by Mary, Audrey and Connie to make new residents at their extra care scheme feel welcome. Reciprocity⁴³ can also be negative though, as exemplified in both the extra care schemes studied. In the first example staff were asked by the researcher whether a

⁴³ Reciprocity means that in response to friendly actions, people are frequently much nicer and much more cooperative than predicted by a self-interest model; conversely, in response to hostile actions they are frequently much more nasty and even brutal (Fehr & Gächter, 2000).

person with dementia would be welcomed into the group of residents who congregated in the café area and was told:

Care staff 1: "I think initially they would until they started making issues for them..."

Care Staff 2: "Until they knew! [that the person was living with dementia] ... initially ... the chap who has got dementia - he wouldn't be allowed at that table. Oh God no!"

Care staff 3: "No, no they wouldn't like him sitting there"

Care staff 2: "Oh no. Not at all. No way, it wouldn't be happening."

Care staff 3: "They occasionally tolerate xxx [women from earlier discussion] don't they?"

Care staff 4: "It's like 'the mean girls' the film, isn't it?"

In this example there was no direct display of negative reciprocity, rather a general attitude. In the second example, there was a general lack of understanding of what a person with dementia was trying to communicate, which led to a negative response. The carer gave the following example of how communications can be misconstrued:

Things that are said, something that was said the other day, one of the residents that has got dementia. She says, well she called one lady a midget. But in her era people who were small were called midgets. But the lady she said it to, and her daughter didn't like it, so that caused a lot of chaos. And then the other day she said she'd got new teeth. There was a lady that is quite disabled, and she said to her, "you need to do your teeth, you can have some like mine". The lady took it the wrong way, thinking that she was calling her because all her teeth were crooked where she fell as a kid. But [the resident with dementia] said, "I've got some". You know we tried to explain that to her, and I think now that the lady understands it a bit better, but there is still the issue with the mum and daughter....

In the third example staff described a more direct negative response involving a person who exhibited behaviour that other residents didn't like:

Care staff 1: "...and I think when he came into a room and everybody else backed off. If he was seen eating in a carpeted area he would be told to move, but then somebody else wouldn't. And you know, he wasn't stupid, he could pick up on that, and it did absolutely nothing for his self-esteem or his mental health.

Care staff 2: He was a victim of his own behaviour really

Care staff 1: And it was horrible, so he was spending more and more time in his own apartment, so completely missing out on the social side.

The consequence of the negative reciprocity in this last example resulted in the man being excluded from the group, whereas in the first example the negative attitudes described appeared to have developed into a culture of the group responding negatively. The strength of a prevailing culture will influence whether patterns of negative reciprocity become the norm or whether they are challenged.

Organisational culture forms when a group of people have a common history and have become stable (Schein, 1990, p. 111), which is the same process as the formation of a social world. The strength of culture will depend on the history the social world group has shared, and how the group has learnt over time to solve any problems it has faced either within the group or with others outside the group. Exclusion of individuals that challenge the status quo of the group is one remedy open to members of a social world. The exclusion of the resident in the second example appeared to have become an acceptable practice within the group, which went on to petition for a resident to be moved from the extra care scheme, as described here by a social worker:

I've been involved in actually moving somebody out. He didn't have dementia, he ... I feel quite strongly that his face didn't fit, and there were a couple of things that happened that weren't addressed quickly enough. And actually, since he has moved, reflecting on how he presented whilst he was here...it was chalk and cheese how he presented in a few days of being in this new place. I think for him, there had been, because he is quite social, but there were some altercations in the communal areas, and it ... you know... yes, he can be a little bit bolshy shall we say, but I'm quite sure other people can be too. And it got to the point where I think, I mean there was petitions formed to have him removed from here by the residents...

The staff, manager and social work participants did not say whether the attitudes resulting in the exclusion had been challenged or not. Schein's (1990) definition of culture would suggest that patterns of shared basic attitudes or assumptions are developed by a group, and when those assumptions are found

to work they are then taught to other people joining the group so that an equilibrium is maintained. In their work on residential care, Killet et al (2015, p. 2) reflected that:

...the strength and internal consistency of such a culture will relate to the stability and longevity of the group, the intensity of shared experiences, and the strength and clarity of assumptions held by leaders.

Further discussion in the staff and manager participant focus groups revealed that not all residents had agreed with the people who petitioned to have the man removed, raising questions about how sub-worlds gain prominence and acquire sufficient agency to bring about change with limited or insufficient challenge. A group's collective agency for action was illustrated in a comment a manager made about the resident committee:

When you get problems, the resident committee will all get together and there will be this 'tit for tat' kind of discussion that goes on. Which can actually be quite an oppressive environment if that is being aimed at you.

Complaining about, or excluding, people who did not conform to their idea about who should be in extra care seemed to have become part of the frame of reference for the residents' committee. One participant, Mary, told the researcher that she had left the residents' committee, implying that it was because the nature of the group had changed and was no longer welcoming. The researcher understood from this that Mary was experiencing conflict between the group's terms of reference and her own values. From observing and talking to Mary during the fieldwork the researcher concluded that Mary's innate characteristics meant that she usually chose groups in which she was able to contribute and help people to be involved. In the resident committee Mary appeared to be experiencing conflict between her own and other members' approach to people who were 'different' from them. Social worlds and their sub-worlds are not static; membership changes, and frames of reference and shared perspectives are continually being reconstituted (Shibutani, 1986). It is unclear whether Mary tried to change the culture or negative frame of reference within the resident committee. It was assumed by the researcher that Mary's action to leave the group reduced her inner turmoil and removed any

dissonance that her malcontent may have been causing within the social world of the resident committee. This potentially allowed the negative perspectives within the group to be more easily reinforced.

None of the participants offered a solution for the difficult issue of managing different cultures or reducing the impact of negative relationships. On the one hand managers recognised the need for intervention, with one saying:

But that's a massive role, (managing) the dynamics of the relationships between the people actually living here... they need someone to mediate.

But on the other hand, managers also returned to the issue of being unclear what the vision for extra care was when they debated the limits of their roles as mediators and the nature of extra care as an institution. Extra care is unlike residential care, where staff are available round the clock to support people in the communal areas. The role of staff in developing a positive culture in residential care is clearer. Brown-Wilson (2009) highlighted the importance of staff in care homes being sensitive to residents' initiation of reciprocal relationships. Killet et al's (2015) study of reciprocal relations in care homes considered the role of staff in connecting with residents to help them contribute within the residential community.

In extra care however, residents live in individual dwellings with no formal staff support for residents when they are in the communal areas. In the focus group discussions one manager often referred to a point of reference she used to help judge how best to respond to difficult situations. She would say:

You've got to come back to that; what would we do if they lived on a street?

This dilemma, reflecting the lack of clarity about what extra care is, was prevalent throughout the focus group discussions in this research. Extra care is neither living alone in the 'community'⁴⁴, nor is it residential care. One staff

⁴⁴ Community as used here represents someone living in a private dwelling in the same locality as others, often with a common cultural or historical heritage. It is shorthand for the home they occupied before moving to extra care or residential care.

member made a comment following a focus group discussion about how much support care staff should give to residents in between their planned care calls. She said:

Well, technically we're community workers, it's just that this is our base.

This comment supports a view of different and unconnected groups within extra care; a social world where staff and residents belong to different sub-worlds. This view appeared to be reinforced by managers at both the extra care schemes. In one there was an example of a difficulty faced by one staff member when she was advised not to get too friendly with residents; she was being asked to distance herself from one resident she had known for a long time before they moved into extra care. The staff member had wanted to make a connection between the resident and staff sub-worlds but faced a culture of separateness instilled by the manager.

In the other scheme staff were also discouraged from making connections with residents as evidenced in the staff comment:

Like when we first started, I don't know... before it got really packed, we could go out there with them (in the lounge), and be with them.....
And then we were told not to. Not to do it because they're not your friends... and so we stayed back in the staff room.

How staff and residents connect with each other across their different social sub-worlds will affect how well staff are able to support relationships and help people take part in a well-developed community. The impact will be more or less pronounced if, as was discussed in Chapter 5, there are staff shortages which cause staff to work in silos and to focus almost exclusively on the planned elements of care packages. Deterring staff from making friendships and connections with residents appeared to detract from a sense of community where there is a positive commitment from everyone to live and work together, and to support each other.

A lack of connection and sense of community is likely to reinforce separation rather than integration between the housing and care staff groups and their

respective social sub-worlds. In turn, this could encourage each to develop and reinforce their own customs, practices, attitudes and frames of reference which influence how they work. Harmony across different social sub-worlds in extra care should engender a positive commitment from everyone living and working in extra care to support one another as part of the extra care community. That requires strong leadership, which will be discussed further in Chapter 9.

7.3 MOVING INTO AND BEING ACCEPTED IN EXTRA CARE

The last section described how building relationships can help individuals to make connections with different social groups in extra care and explored its importance in determining how groups operate. This section further examines resident moves into extra care and the role of staff in providing emotional and social support to become members of the extra care social world.

When individuals move into extra care, they usually move from their own home, although some residents do move from residential care or hospital. All the residents in this research study except Sarah had moved from their own homes. Sarah had previously stayed in residential care. One couple, Alan and Zoe, had moved some distance to be nearer family and the remaining participants had moved from relatively nearby. Shaw et al (2016, p. 2) suggest that moving to new extra care accommodation may be experienced as an ‘anxiety-provoking, ontological – or existential – challenge’. Like this study, they found that learning to live in an extra care community involved negotiating new relationships, which wasn’t straightforward. All participant groups in this extra care research described how new residents needed emotional and social support to move and settle into extra care, and Shaw et al said that maintaining friendships outside the community became more difficult as capacity declined.

Help with emotional and social support needs, especially for people living with dementia, was discussed in Chapters 4 and 5. For individuals to develop relationships with other residents and with staff, all participant groups believed it was important to understand the person with dementia and to see beyond the

dementia to the person they are. Members of staff were identified as catalysts that could help individuals make connections with other people in safe, public environments. Chapter 6 then went on to discuss how organisational boundaries can make it difficult for the existing housing and care staff teams to support individuals. It was suggested in Section 6.5.2 that a floating support worker might help overcome some of the difficulties, with the floating support worker having a broader role than either the care worker or the housing support worker.

Although the floating support role was described variously by housing and care staff, by residents, and by managers, it was implied consistently that such a role could help the teams collaborate better to provide the right support for individual residents. Section 7.2 used social worlds theory to illustrate how the multiple groups operating within extra care become established. Figure 7-7 below shows where the floating support worker could focus their work across the different groups in extra care to provide a more effective service to individual residents. By working across sub-worlds, the floating support workers should be able to enhance communication between individuals and groups and help develop a more integrated, person-centred response for residents.

Previous studies found that although there are considerable benefits of extra care with its socially accessible communities in comparison to other forms of housing, social isolation can still occur (Biggs, et al., 2000; Bernard, et al., 2007 & 2012; Evans, 2009a & 2009b; Liddle, et al., 2014). Section 6.3.1 described how, even where there is evidence of neighbourliness and residents supporting each other, very frail people, or people with sensory or cognitive impairments were reported as being on the margins of social groups and networks (Croucher, et al., 2006).

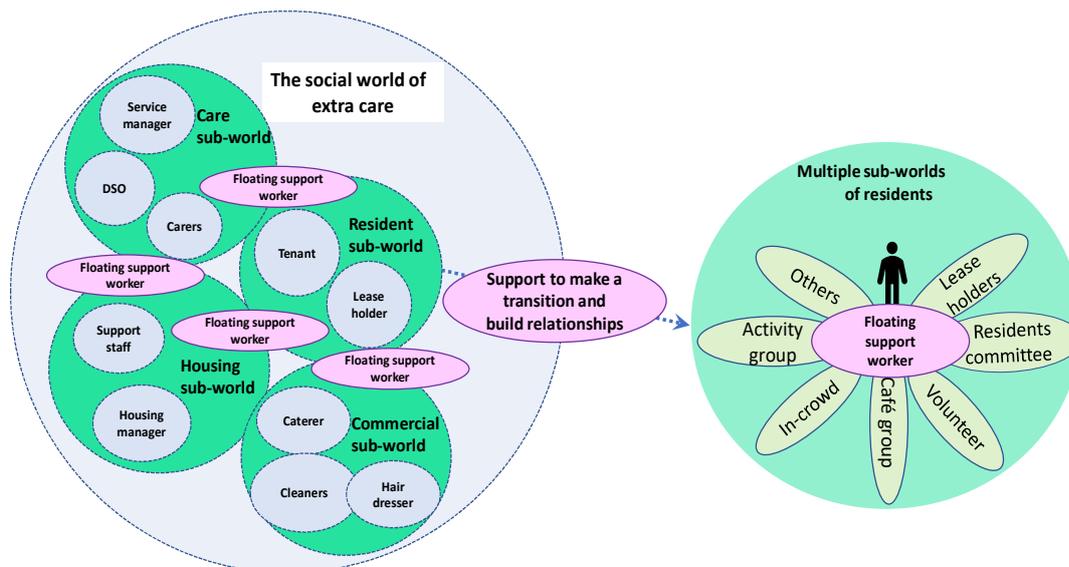


Figure 7-7: Floating support worker crossing the boundary at the intersection of social sub-worlds

A critical element of the floating support worker’s role could be to help residents, especially when they have just moved into extra care, to build relationships with other residents and to become part of the community through formal and informal activities. Taking part in activities and building relationships would give the chance for residents to find out with whom they had shared interests, and to then become a member of relevant social sub-worlds. The floating support worker could help individuals living with dementia retain a sense of their past self by supporting their social interactions with other residents or helping them engage in activities which reflect who they are and what they enjoy, contributing to what Galvin and Todres (2011) described as existential well-being⁴⁵. The floating support worker might also be able to help people with dementia to interact positively to others if their cognitive decline starts to cause difficulties, and to identify when individuals may need more deliberate and skilled support to maintain relationships and continue to be accepted as members of social sub-worlds.

⁴⁵ Existential wellbeing refers to a person’s present state of subjective wellbeing across existential domains such as meaning, purpose, and satisfaction in life, and feelings of comfort regarding death and suffering (Ownsworth & Nash, 2015)

Although all participant groups in this research were positive about the benefits of being part of an extra care community, some residents also communicated disappointments or complaints. This finding resonates with work by West et al (2017, p. 5) who wrote that residents in their research into extra care complained that:

Standards of care and service had slipped; that too many frail older people were being admitted; that management were placing too many restrictions on their capacity for self-organisation; that there were too many people using mobility scooters; or that too many other residents had withdrawn from collective life, preferring instead to remain within their own apartments.

A lack of willingness by extra care residents to embrace people who were different, or who challenged the residents' sense of self was reported in Section 4.5.2. This was attributed in part to ignorance and fear of what might lie ahead for themselves. Fear can occur when someone is approaching her or his fourth age⁴⁶ which can include having dementia. Approaching fourth age can involve a fear that self-expression, choice, and autonomy will diminish, with an associated reduction in pleasure and increase in negativity. As Gilleard and Higgs (2010) said:

The fear of the fourth age is a fear of passing beyond any possibility of agency, human intimacy, or social exchange, of becoming impacted within the death of the social, a hyper-reality from which there is no reality to return.' (Gilleard & Higgs, 2010, p. 125)

The fear of what might lie ahead, and wanting to shield oneself against it might help understand a comment made by a manager about residents:

What I pick up from this place, is that the people with no needs are the ones who are the complainers, in a way, about the people who do have needs.

The people who are complaining could be trying to preserve their individual identities rather than get subsumed into a collective identity of people who are perceived to have more needs (Aleman, 2001). Developing Aleman's work

⁴⁶ A critique of the third and fourth ages are given in Chapter 1, for a detailed description of third and fourth ages see Gilleard and Higgs (2010)

further West et al (2017) suggested that complaints made by people in extra care who are in a liminal state moving between the third and fourth ages can be read in three ways. They suggested first that complaints could simply be about things that have been altered; second, that they could also be used as an illusory support for their identity as they move between the third and fourth ages; and third, they could be used as a form of bolstering for their individual and group identity.

Social worlds theory may explain why a group of people who are currently active in their third age with relatively few needs might complain in an extra care setting. There may be an unrecognised sub-world of third agers, whose members complain about those with more needs than themselves. The complaints may serve to reinforce their identity as people with relatively few needs and bolster their belief that they remain active in the third age. West et al (2017, p. 10) say that extra care's public spaces are where third age themes of choice, independence and self-fulfillment through activity are dominant and it is in the public spaces that residents seek social contact, social approval and fulfilment. It is in these public spaces that a social sub-world of third age residents could seek affirmation from others, as typified in both extra care schemes by the 'in-crowd'⁴⁷ who congregate in the lounge or café areas. Complaining may become the means of reinforcing the groups view of themselves as active third agers, especially if there are not enough people who can reinforce their image or help resist the gravitational pull of the fourth age. This was also evident in Mary's complaints about the craft activities when she said:

I've stopped going to Craft because it's not what I want to do because I don't want to sit and colour... So, the people who are more able are expected to be a volunteer and support the people... rather than it being a craft thing. If we want to do any sewing for example, we'd have to do it ourselves.

⁴⁷ "In-crowd" is being used here to identify a social sub-world within extra care that consisted of strong characters. They were variously described by research participants as the 'in-crowd', 'inner circle', and 'clique'. One such group was prominent in each extra care scheme, meeting together at various times of the day.

It has been noticeable from the focus group discussions and informal observations that Mary's identity is tied up with being an active participant of the extra care community. Her complaints about the lack of support from staff could be an attempt to bolster to her own identity as an active person using the complaints about others as a counter-balance to her own diminishing ability to help others. The complaints could simply reflect the reality, that the complexity of staffing arrangements and lack of resources impact on helping people to take part in meaningful activities, as described in Chapter 5. Alternatively, it could be both, reflecting a concern about lack of support as well as bolstering her own identity as an active person. On the one hand there is a sense of wellbeing that residents such as Mary can gain from helping other people. On the other hand, if not managed effectively, the demand for too much peer support can negatively impact on the resident support-givers wellbeing by reinforcing their growing proximity to and the pull of the fourth age.

Chapters 4, 5 and 6 highlighted that staff have a role in supporting residents with greater needs to take part, which should also address the perceived imbalance for extra care residents with fewer needs, like Mary. Conversely, Shaw et al (2016) concluded from their study that even residents with fewer needs required emotional and social support to live through the transition and challenges of becoming aged. In terms of social worlds theory that would suggest timely support may be needed to help residents whose needs are increasing significantly to move from the third age social sub-worlds to join a world of fourth age residents, or as described by Gilleard and Higgs (2010, p. 121) to join the perceived social or cultural 'black hole' of the fourth age.

Not everyone perceives the fourth age to be the black hole described by Gilleard and Higgs. There is a body of research demonstrating that individuals with dementia can be helped to retain personal identity and self-expression (Kitwood & Bredin, 1992; Brooker, 2007; Buron, 2008; Dewing, 2008; Hughes, 2013; Smebye and Kirkevold, 2013; and Zeiler, 2014). Grenier and Phillipson (2013 & 2017) go on to suggest that in the case of conditions such as dementia it is

possible to see how autonomy and agency within the fourth age may differ from interpretations such as those of Gilleard and Higgs. In considering dementia within the fourth age Grenier et al (2017, p. 319) posit that:

...current ideas and practices organised around the 'fourth' age – including taken for granted discourses, practices and the 'imagined' – risk reinforcing unequal power relations in late life, with the potential of further marginalising persons with dementia.

They put forward that dementia and frailty, described as opposites to a healthy and active later life, risk being interpreted negatively as failed old age. Building on the work of Butler (2006) and Standing (2010), Grenier et al (2017) use the concept of precarity⁴⁸ to challenge the conventional approaches to agency, accentuating the need for agency to be considered differently, which includes responding to vulnerability and fostering conditions for a sustainable lifestyle. The concept of precarity was helpful to this research in considering the experiences described by residents, staff and managers about how some of the vulnerabilities associated with living with dementia in extra care were being experienced. The concept of precarity was also helpful in challenging practices that had developed in response to some of the behaviours of people living with dementia, especially where those responses might impact on the person's independence or lifestyle. Grenier et al say that:

...a key issue which arises is how to incorporate the recognition of the vulnerabilities associated with ageing and dementia into frameworks which translate into an acceptable response that gives scope for agency (or some variant thereof) and the maintenance of human dignity. (Grenier, et al, 2017, p. 326).

The role of managers, staff and other residents in developing a framework that fosters conditions in which individuals living with dementia have agency and are part of the extra care social world will influence how precarity in late life at the juncture between third and fourth ages is experienced. It will also influence whether residents in the fourth age live in relative isolation or collegiately as

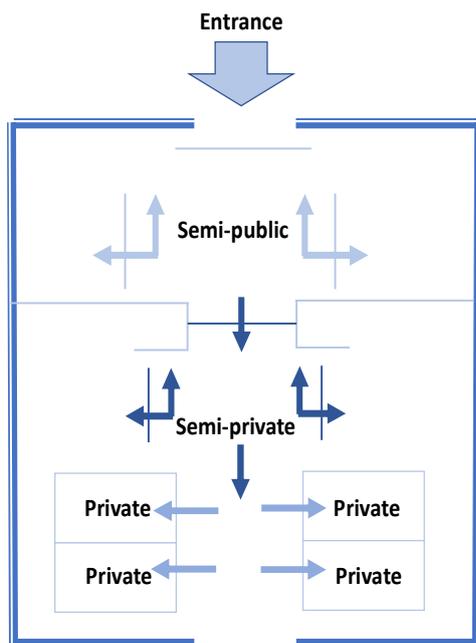
⁴⁸ The concept of precarity has been used in a number of contexts to draw attention to rising insecurities in the context of global economic and social change. Grenier (2017) gives a critique of precarity as a means to reconsider experiences of dementia in which she draws substantially on the work of Butler (2009) and Standing (2010).

members of extra care social sub-worlds. There is a paucity of research on whether or how groups of people in the fourth age co-exist as a functioning group or social-subworld. This subject would merit further research.

7.4 THE IMPORTANCE OF SPACE FOR SOCIAL INTERACTIONS AND FORMING GROUPS

The importance of dementia friendly design for ageing in place was discussed in Chapter 2. It was suggested that using thoughtful design would make accommodation more accessible and easier to use with less need to relocate with either age or the onset of dementia. There was little evidence of existing research which evaluated the impact on the spatial experience of people living with dementia in extra care. The findings in Chapter 4 revealed some limited information on the spatial experience, with all participant groups raising concerns about people both with and without dementia being able to navigate their way around the building without sufficient design prompts. This section sets out some of the implications of spatial design for social interactions and for the formation of social sub-worlds in extra care.

The space within extra care environments typically includes a mix of semi-public semi-private and private spaces in which individuals live and communities meet, see Figure 7-8. That mix of spatial use requires sensitive handling to ensure that those areas that are open to the community are easy to get to whilst those areas that are private to individuals are safeguarded from the public.



Progressive privacy: Understanding the challenges

- **Semi-public:** Partially 'open door' through which anyone within the community can pass, who has a reason for doing so, for example, using the meeting rooms within the scheme, or to meet someone for a morning coffee within the café area or to ask for advice etc
- **Semi-private:** Closed to outsiders and only open to people who have a reason to be in the residential area e.g. residents, staff and visitors
- **Private:** Accommodation, open only to the individual resident. No else should enter without first seeking and gaining permission, this includes staff and visitors.

(Ref: 'A Better Home Life', Centre for Policy on Aging 1996)
In Nicholls P (2014), Design Brief, Glancy Nicholls Architects Unpublished

Figure 7-8: Progressive privacy design principles

Meeting the progressive privacy requirements of residents can be a challenge. For example, staff participating in this research described how key fobs and security systems designed to stop members of the public from entering private area could also become a barrier for people with dementia entering the communal or public areas. One staff member said of people with dementia:

They can't freely rein, they can access the part they are in, but if they wanted to go to a different bit, unless someone was going that way, they couldn't.... [because they can't use the fob system].

It was suggested that individuals lost their key fob or could not operate the key fob system as their cognition declined, becoming a barrier for those individuals to remain independent and take part in community life or group activities.

The functions that the environment is intended to fulfil can be complex as extra care provides a home for residents, a visitor centre for the local community, and a workplace for a range of different staff groups. The architect's design ethos (Nicholls, 2014) for one of the extra care case study schemes stipulated that the design should add value to the service by having safe, comfortable and homely environments with layouts that encourage social interaction, reduce anxiety and frustration, maximise independence and choice, and provide excellent working

environments for staff. Kenkmann et al (2017) say that how physical space is used and how its meaning is defined within the complex and contradictory nature of care environments need negotiation. Negotiating and valuing space within extra care is an important part of how social sub-worlds work. Strauss (1978a, p. 121) claimed that

...some [features of social worlds] are inseparable from given spaces; others are linked with sites but are much less spatially identifiable.

The use of social space may be affected by the social worlds that residents bring with them when they move into extra care as well as the new social sub-worlds that they may join or create. Strauss (1979) further considered spatial implications for social worlds in suggesting that the study of spatial processes can profit from being linked with the idea of arena, where social worlds focus on specific issues and then act on those issues. His analysis of site finding, site invasion and site abandonment are all relevant to the issues described by the participants in this extra care research, as set out in the following sub-sections.

7.4.1 Searching, discovering and assessing sites

Section 6.4 positioned extra care as a community within a wider community, illustrated as concentric circles of community, see Figure 6-7. The importance of location and the surrounding neighbourhood are considered by partners when choosing a site for extra care. The assessment and choice of extra care sites influences how easily residents can feel part of the local community. It also affects how easily the social world of extra care can interconnect with other social worlds outside the immediate extra care environment. In talking about an extra care scheme that was used as a comparison for the two case study sites a manager said:

The café is just unbelievably superb. Not because of the café particularly, but because it is such a community resource. In that they get school children in, they get workmen in, they get people coming in just for a coffee or whatever. It is slap-bang in the middle of town, and if you go in at lunchtime, it is heart-warming really to see somebody who is a 15-year-old at school coming in and just saying hello to their grandma who is across

the other side with her friends. And that for me is just fantastic, but we are very lucky to have that right in the very middle of town.

In this instance the location of the extra care scheme helped one of the residents to more easily remain connected to the social world of her family after moving into extra care.

In addition to the geographical setting of an extra care scheme the design of the building will influence how easily groups or sub-worlds within extra care can make space their own. A variety of communal spaces with the semi-public areas of extra care will make it easier for sub-worlds to create private spaces for their own use without being in competition with each other. Both the extra care schemes in this study had a variety of communal spaces in the semi-private areas but these did not appear to be used by residents on a regular basis. The viability of non-commercial communal space in extra care has been the subject of debate in extra care procurements (Dence, 2015), which may impact on how much is included in future schemes. The availability and use of semi-public extra care communal space could merit further research using social worlds theory to consider its impact on the development of social groups, levels of social interaction, and the wellbeing of potentially marginalised individuals.

7.4.2 Competing for space to situate social sub-worlds

In one of the extra care schemes the film club provided a social group for its residents and neighbours. The film club met in the semi-public area of the scheme, accessible by neighbours who wished to join the group. It was effectively the open plan lounge area, which was also used by the 'in-crowd'. The 'in-crowd' acceded use of the lounge to the film club for the designated show times. This shared use between the two groups is consistent with the findings of Kenkmann et al's (2017, p. 14) work in care homes which reported that spatial boundaries within care environments are:

...drawn and violated or respected, domains are created for certain purposes, sometimes negotiated, sometimes imposed or sometimes the result of common usage.

In contrast, the researcher had an interesting experience when the same lounge was used to feedback the findings of the research. The meeting was open to all residents and staff as well as and invited managers and social workers. It was notable that half-way through the meeting members of the 'in-crowd', who had chosen to not attend the meeting, assumed their regular position at the edge of the lounge spilling over into the corridor. Although nothing was said by the group, the researcher interpreted the action as signalling that the group may have felt their 'space' had been used without their permission and were reasserting their authority by their visible presence.

7.4.3 Spaces or sites that are abandoned by sub-worlds

Spaces used by sub-worlds can be abandoned as well as acquired. In one of the extra care schemes the 'in-crowd' abandoned its preferred site of the café area during the afternoon period. The café area was accessible 24 hours a day, even when the cafe was not operational. During the research there was a period of some weeks when the catering function was disrupted, and the in-crowd relocated to the foyer area. At the time residents complained about the changes to the catering, and the way it was being managed. It was unclear to the researcher whether the café site was abandoned in protest at the change of service or whether it was abandoned because the foyer provided the group with an opportunity to be more visible and to better assert their sub-world within the extra care scheme. Staff participants in the research said that although the in-crowd group included a number of people with physical impairments the group tended to complain about residents with cognitive impairments. There is no direct evidence to confirm it, but the choice of location for the group could have reflected their need to reinforce their sense of normalcy and wellbeing as third agers, as discussed in Section 7.3.

Instead of a sub-world abandoning a space or site in extra care they can take a space over for their own use, which may result in the space being abandoned by other people. Care staff in one extra care scheme described how this process occurred:

There's a group now at the moment that's very clicky, very... And nasty towards people... We have had tenants who have said they don't want to go down... Because when they were there they thought like...they were not pushed out, but they weren't welcome. They all said 'inner circle' which... to be fair... you know that's how they do socialise.

This can negatively impact on the wellbeing of the people who stop using a favoured area of the scheme where they had been able to benefit from social interactions.

7.4.4 Dynamics of space and social groups

Once a social sub-world has appropriated a space for its group there can be a further redesign of the area to better suit the group's needs, which may also exclude those who are not part of the group. This was illustrated at one of the extra care schemes by the in-crowd, who used lounge chairs and their own wheelchairs to define their 'space' at the entrance to the main lounge and corridor. The space offered an optimum vantage point to see and comment on the comings and goings of the scheme. A member of staff said:

There is a group sitting outside here [main lounge / corridor], and you know I think sometimes it can be quite intimidating. I've walked past sometimes, and you're looking around, you know with a visitor, they are not very welcoming. Or they are welcoming when it suits them. You know they are not inclusively welcoming like we would be as staff, regardless.

The lounge corridor space was not created purely by architectural design, rather it developed into a defined space by being lived in by residents and being passed through by staff and visitors. The space represented value and meaning in relation to the in-crowd group and gave potential for the in-crowd to exercise power. This glimpse of the environmental gerontological intersection between the social sub-worlds of the in-crowd and the 'others'⁴⁹ in extra care suggests that the dynamics between design and social world arrangements are complex. Social worlds theory uses the concept of boundaries and boundary objects to

⁴⁹ 'Others' is used here as a generic term for people who participants said were seen by the in-crowd as different, comprising mainly people with cognitive impairments such as learning disability, dementia or other mental illnesses.

develop and maintain coherence across intersecting worlds (Star & Griesemer, 1989, p. 393). A boundary object provides information that is common enough to link separate social worlds together around a common task or issue. One staff member described how they had used the tenancy agreement as a reference point at a tenancy meeting to indirectly address an issue where members of the in-crowd were not respecting others' differences, including those people living with dementia. The example brought together two boundary objects: a concrete object in the form of the tenancy agreement and an abstract object in the form of the meeting. They were used together to provide a focus for shared action between the sub-worlds. Figure 7-9 illustrates a range of both concrete and abstract boundary objects, including tenancy agreements and meetings, that can be used by the sub-worlds in extra care to help achieve a shared understanding of how each will support the other on common tasks or issues.

Social worlds theory suggests that boundary objects are developed and adapted through the actions and interactions of stakeholders from different stakeholder worlds. It is:

...fundamentally an exercise of negotiated order and a robust boundary object achieves this status by satisfying both the particular, local demands of users and the wide arena demands of all the worlds involved' (Clarke, 1991, p. 134).

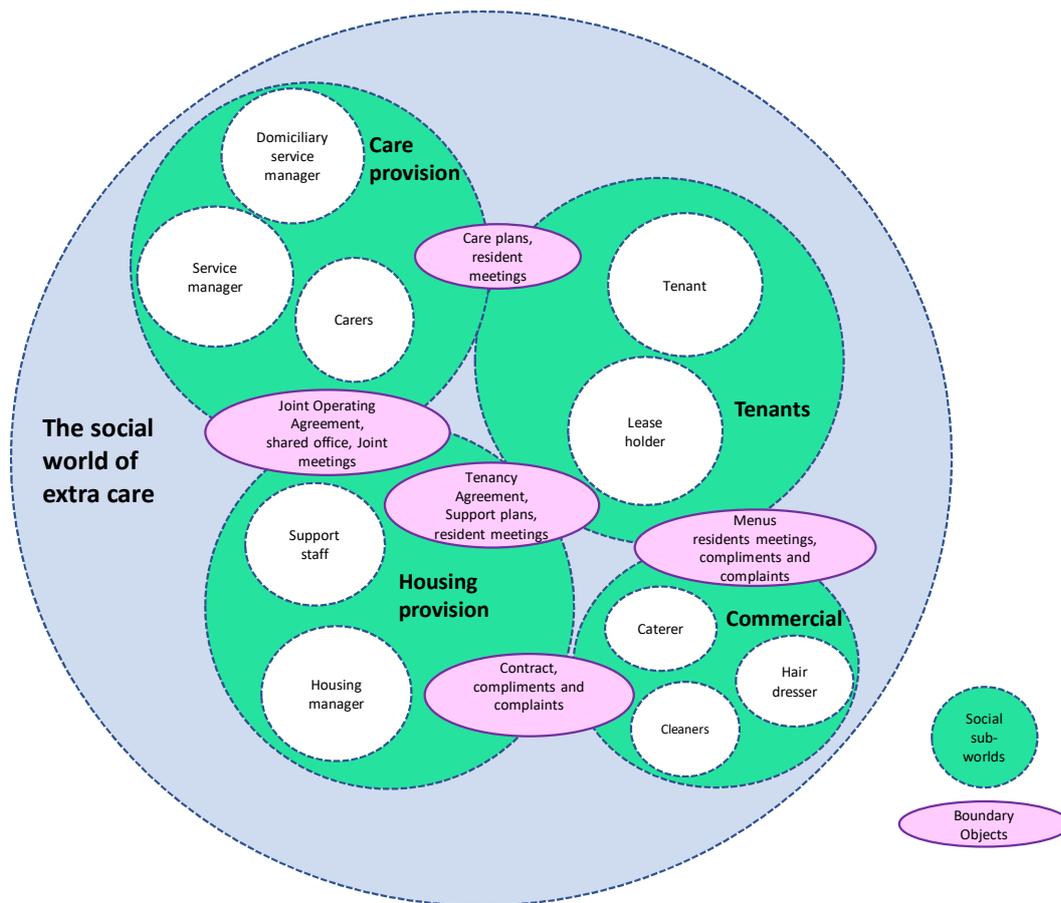


Figure 7-9: Boundary objects used to negotiate order

The descriptions of both extra care schemes in the research revealed that, even with boundary objects such as the tenancy agreement and resident meetings in place, there was not a smooth intersection between the sub-world of the in-crowd and the wider extra care population. It is unclear from a social worlds perspective whether individuals who are marginalised by the in-crowd, such as those people with cognitive impairments, can form a sub-world of their own. Although there was some evidence of staff helping people come together to make friendships it is not certain whether those small friendship groups of people with dementia could meet Fujimura's (1988) description of interested parties who come together in a social world to resolve issues. Grenier et al (2017) in their work on rethinking dementia as a 'fraild' old age put forward a challenge to develop a framework to give scope for agency whilst recognising the vulnerabilities associated with dementia, but there was insufficient evidence in this extra care research to conclude, that on their own, people with dementia

had sufficient agency to develop or use the necessary boundary objects to address issues of mutual concern (Strauss, 1978a & 1982; Star & Griesemer, 1989). The authenticity of a social sub-world where groups of individuals living with dementia could have sufficient agency to act on common issues would merit further research.

Even though it was unclear whether the group of 'others' was an authentic social sub-world within extra care, staff in focus groups described a role for someone to help intervene between different groups, to support individuals to take part in the different activities, and to make sure that individuals were not excluded from communal spaces. This would seem in keeping with Grenier's (2013) suggested framework, placing the responsibility for developing and supporting sub-worlds within the extra care organisation. The role initially described by staff and managers was of a floating worker who would mainly remind someone or help them physically to take part in events or move from one area of the building to another, as described in Section 6.5.2. On its own, that was deemed insufficient support for someone to become part of a group, as told by one carer who said:

I'll bring someone along and I'll say, 'ooh let's go and sit with these' and I'll get the looks and the tuts.

Manager participants recognised the need to help individuals and groups live harmoniously together. One said:

...that's a massive role, [managing] the dynamics of the relationships between the people actually living here... they need someone to mediate

Whilst acknowledging that it might be helpful to have an intermediary who could help members of the different groups or sub-worlds to make effective connections and accommodate each other, there was also an implicit assumption that there were insufficient resources available to develop such a role. With or without a dedicated role of floating support worker, culture is important in maximising formal and informal activities and the use of space in extra care for the benefit of the different social sub-worlds. The prevailing culture will affect whether there is encouragement to be creative in the use of space, and will affect how the meaning and use of space can be renegotiated in

empowering ways that promote residents' sense of wellbeing (Kenkmann, et al., 2017, p. 15). The role of culture will be the subject of further discussion in Chapter 9.

7.4.5 Space as an intermediary between the inside and outside worlds of extra care

The social world of extra care was described at the beginning of this chapter as comprising the building and its grounds, with constituent members who live and work there, and who use the extra care community services. The social world of residents was placed 'inside' extra care, with residents belonging to other social worlds situated 'outside' the extra care scheme. In their study about negotiating and valuing space in care homes, Kenkmann et al (2017 p 10) suggested that the design of buildings and their grounds could provide transitional or liminal spaces which were part of the care home, but were treated as outside spaces. Such liminal spaces would be valuable to residents with declining physical abilities who are increasingly unable to access the 'outside' world. The larger extra care villages, which were outside the scope of this research, seem to have built this liminality into their design. West et al (2017) report that in the larger villages the possibility of corporeal ageing and disability is anticipated, with the ideal written into the physical layout of the buildings in, for example, communal areas of the ground floor looking like streets. Borrowing on Kenkmann's work, the researcher of this extra care study considered whether the focus group discussions shed any light on how the use of semi-public spaces and semi-private spaces within the extra care scheme afford opportunities for extra care residents to bridge their different social worlds. There was insufficient evidence available to draw any conclusions for smaller extra care schemes, but the subject could merit further research.

7.5 CONCLUSION TO THE INSIGHTS OF EXTRA CARE AS A SOCIAL WORLD

Social worlds theory has been used in this chapter as a lens through which to explore insights from the fieldwork into how individuals and groups of extra care

residents experience living in extra care, and how they make sense of their place within the extra care world.

Each extra care scheme was defined as a social world, and the multitude of groups that emerge and disappear were defined as social sub-worlds. The concept that social worlds and sub-worlds develop shared outlooks and perspectives was examined. Whilst social worlds are primarily positive, bringing together people with shared interests, there was recognition that some people could be marginalised. The importance of individual agency and ability to take part in reciprocal relations was explored. It was recognised that a perceived lack of agency and negative reciprocity may cause individuals with dementia to be excluded. Concepts of active third and frail fourth ages were explored, especially in relation to the culture and behaviour of the in-crowd. It was suggested that there may be an unrecognised social sub-world comprising those in their third age, which could include those experiencing the gravitational pull of the 'black' hole of fourth age. There was insufficient evidence to conclude whether it was possible for people living with dementia or frailties associated with the fourth age to form a meaningful sub-world. It was suggested that staff support would help individuals to join and be accepted in social sub-worlds. The current economic climate and resource limitations were recognised as some of the precluding factors to developing a dedicated role within extra care.

Organisational culture was described as central to how social worlds operate. Culture and professional judgement affected how boundary objects such as allocation panels, allocation agreements, tenancy agreements and resident meetings were used by staff and managers to ensure individuals were appropriately admitted to the extra care social world. They were also used to mediate tensions and seek harmony between the different groups.

Organisational culture was shown to affect connections and relationships between staff and resident social worlds and appeared to influence the flexibility of staff supporting residents to be part of the extra care community.

The complex interaction between organisational structure, social sub-worlds and the spatial design of the scheme was explored. It was recognised that flexibility of communal space can foster a wide range of groups to develop both formally and informally, and that visible appropriation of space can lend power to groups. The role of staff in mediating membership of groups and use of space was not clear, reflecting the findings of Chapters 5 and 6 about the confusion about the purpose and vision for extra care.

The application of social worlds theory to the findings of this extra care study adds to the body of knowledge about how extra care communities function. Chapter 9 will draw together the insights from social worlds theory with the insights in Chapter 8 on quality and operational excellence to propose a new framework for extra care development. The application of social worlds theory has also highlighted gaps in knowledge which would merit further study. These include whether or how groups of people in the fourth age co-exist as a functioning group or social sub-world in extra care, and whether groups of individuals living with dementia in extra care could form an authentic social sub-world. Further research could also usefully explore how communal or semi-public space can be used to bridge the social world of extra care and other social worlds external to extra care.

8. CHAPTER EIGHT: INSIGHTS INTO MANAGING QUALITY AND OPERATIONAL EXCELLENCE IN EXTRA CARE – CONTRIBUTIONS FROM A FURTHER LITERATURE REVIEW

Discussion with each of the participant groups about the findings set out in Chapters 4, 5 and 6 confirmed that extra care schemes were considered to be good places to live, and that the support of individual members of staff was hugely valued. An extra care model that included a set of complex inter-relationships was identified by participants and is repeated in Figure 8-1 for ease of reference.

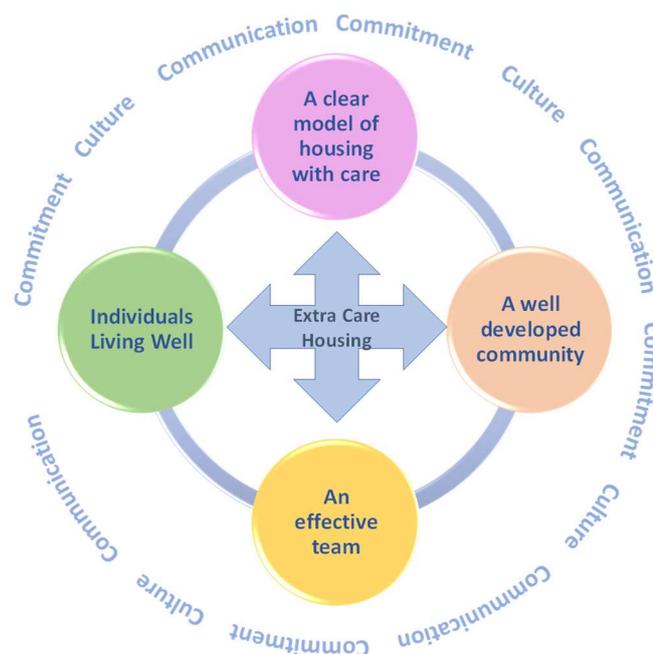


Figure 8-1: Model of Extra Care

The model was developed to support individuals with dementia to live as well as possible, and in doing so should also provide an environment conducive to those without dementia to also live as well as possible. Participants across all the focus groups also agreed that how residents experienced living in the schemes was affected by two areas. First, the nature of social groups and individual relationships, and how they are experienced in the extra care environment. Second the clarity of the vision for extra care service, how the service is

delivered, and the way the partner organisations operated both separately and together to deliver it.

This chapter considers the second matter from an organisational perspective with the resident at its heart. It positions service delivery and a drive for operational excellence in extra care housing within a broader framework of quality management. It considers how a quality and operational excellence approaches might be adopted by extra care partnerships to address some of the issues raised by participants in this extra care research.

As described earlier, concepts of independence, community, culture, leadership, commitment, communication and partnership working have been integral to understanding how the extra care model works. During the focus groups and interviews it became clear that there was a variable understanding of different quality management approaches both within and across partner organisations. For that reason, and in the spirit of making this thesis a useful reference point for others, this chapter has included a relatively detailed account of the concepts within quality and operational excellence.

To help understand the notion of quality the first section of this chapter outlines different approaches to quality management and operational excellence that have developed since the early 20th Century. The second section then looks at an approach to managing quality through the Total Quality Management (TQM) model, selected because it is a recognised industry model which has been used across both public and not-for-profit sectors. The third section looks at the European Foundation of Quality Management for Excellence model (EFQM) that can be used to implement TQM and explores whether it can be tailored to individual sectors such as housing. The fourth section examines how performance measures might help organisations with their approach to quality, and the final section explores in more detail factors to be taken into consideration when extra care housing partners choose an approach to implementing a quality and operational excellence strategy in extra care housing. Core to choosing an approach is the extent to which residents, staff

and managers have agency and opportunity to influence the design and delivery of the extra care service.

8.1 APPROACHES TO QUALITY MANAGEMENT AND OPERATIONAL EXCELLENCE

The word 'quality' is a term often used to describe excellence, in both products and services. The term not without difficulty; two fundamental issues are what is meant by 'quality' , and who is the customer of the product or service.

Within health, social care and housing the term 'quality' is often used to mean 'quality of life'⁵⁰ for customers, patients, clients or residents. Quality of life is used as a proxy measure for how well resident outcomes, needs or requirements are met within housing settings (Evans, 2009; Bygrave, 2010; Golant, et al., 2010; Percival, 2010; Matlabi, Parker, & McKee, 2011; Barnes, et al., 2012; Orrell, et al., 2013). The measurement of outcomes or needs will be returned to later in this chapter.

Over the last thirty years, many of the well-known gurus such as Crosby (1970), Taguchi (1979), Ishikawa (1985), Deming (1988), Juran (1988) and Feigenbaum (1991) have put forward different definitions of quality. An understanding of quality has evolved within the quality profession⁵¹. In the second half of the 20th Century Feigenbaum first used the term 'total quality' and Ishikawa introduced 'total quality control' which later became 'total quality management' and then 'business excellence', 'organisational excellence' or 'operational excellence'. These umbrella terms have come in and out of fashion but are used in this thesis to describe an overall approach.

⁵⁰ WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (WHO, 2018).

⁵¹ An understanding of quality was developed initially through leading authorities such as Shewart, Deming, and Juran who developed quality mainly within manufacturing industries. Juran, Deming and Feigenbaum helped consolidate quality control and management in Japan; and Deming and Ishikawa popularised involving employees to solve problems.

Hoyer and Hoyer (2001) helpfully categorised two levels of quality relevant to service provision; at one level the nature of the service must satisfy a fixed set of specifications, and at the second level the customer must be satisfied. Within quality and operational excellence theory there is a narrative of ‘the customer’; the customer voice, the customer experience and whether the product or service provides customer satisfaction. This is in contrast to the narrative within extra care housing where it is common to talk about ‘the resident’; resident satisfaction and resident needs. This significant difference in defining who is at the centre of service provision indicates a potential schism between the care and support (sociological) and managerial approaches to an extra care model, which is addressed further in Chapter 9.⁵²

Service specifications and performance management frameworks were introduced to public sector service industries in the late 20th and early 21st centuries, at the same time extra care provision was being consolidated as a housing with care option within public policy. A range of models, tools and frameworks were introduced to support the development of quality management, which remain largely in use today (see Appendix 15). One tool developed to help public sector and not-for-profit organisations to manage their performance is a Public Sector Scorecard which will be discussed in Section 8.4.

Performance issues in extra care, identified from the lived experience of participants described in Chapters 4 and 5, are set out in Table 8-1 below. They include having a shared vision for extra care housing with clear leadership within and across partnership organisations, aligning financial and non-financial drivers to meet the needs of residents in a person-centred way, focusing processes on meeting resident needs whilst maintaining their rights and managing risks, developing staff into skilled and competent teams with clearly defined roles, and having opportunities to learn and improve the service together.

⁵² For the purposes of this study, the primary customers of extra care were the residents. The terms ‘customer’ and ‘resident’ may be used interchangeably in this chapter, depending on whether the managerial or care and support approach is being highlighted.

	Issues arising from the research findings	Where the issue was raised
1	Partner agencies should work closely together to agree and communicate its strategic vision.	Section 6.2.1 What is extra care? Section 6.3.3 Risks and safeguarding individuals Section 4.5.1 The importance of leadership
2	Financial and non-financial drivers should be aligned across partner organisations to make sure that all partners can meet their strategic priorities in delivering an extra care service to meet the needs of residents and family members.	Section 6.6.2 Balancing human resources with assistive technology Section 6.2.2 Is extra care a home for life?
3	Clear leadership within and across partner organisations is critical to ensure there is a culture in which person-centred care can be delivered.	Section 6.3.3 Risks and safeguarding individuals Section 6.5.1 The importance of leadership Section 6.5.2 Staff roles and boundaries Section 6.5.4 Developing capable teams and managing resources
4	A strategy should be in place to drive the development of skilled, competent and capable staff teams with clearly defined roles that can work together to support residents.	Section 6.3.2 Managing rights and risks Section 6.5.2 Staff roles and boundaries Section 6.5.3 Staff, volunteers and service providers working together Section 6.6.2 Balancing human resources with assistive technology
5	Gaps in the process of service delivery should be identified and removed.	Section 6.5.2 Staff roles and boundaries Section 6.5.3 Staff, volunteers and service providers working together Section 6.5.4 Developing capable teams and managing resources Section 6.6.2 Balancing human resources with assistive technology
6	Processes should be in place to value and develop the best possible service with contributions from volunteers, residents, and commercial suppliers.	Section 6.4.3 Support for communities Section 6.5.3 Staff, volunteers and service providers working together Section 6.6.1 Having flexible processes to support individuals with and without agreed care needs
7	Processes should be in place to maintain residents' rights and to manage risks.	Section 6.3.1 Relationships and maintaining and reflecting personal identity Section 6.3.2 Managing rights and risks
8	Partner organisations should have opportunities to learn together about why the service might fail to meet the needs of some residents, and see if there are any improvements that can be made.	Section 6.2.2 Is extra care a home for life? Section 6.3.2 Managing rights and risks Section 6.3.3 Risks and safeguarding individuals

Table 8-1: Quality and operational excellence issues arising from the research findings

The emphasis in Table 8-1 is primarily on matters of organisational quality. It is now about 30 years since the initial extra care housing schemes were introduced in the UK. Over that time extra care has developed and changed, but strategic approaches to quality of service delivery in extra care services is still not high on the agenda for those who commission it (Darton, 2018). Although driving up quality and performance within public sector services has been the focus of The Modernising Government programme (Cabinet Office, 2001), it did not define what was meant by quality.

In considering quality expectations there may be a gap between what a customer wants and what a customer needs to be satisfied, and the two may even be diametrically opposed. A commercial organisation might be concerned with giving a customer what it wants and will pay for, whereas public sector organisations are generally responsible for agreeing with customers what they need, and then negotiating what can be provided, which might be constrained by what can be afforded. Chapters 4 and 6 revealed that there is not a shared vision about what extra care is for, a view which is replicated with the ECHO project study on the provision of social care in extra care housing (Porteus, 2018). It could be argued that, as a proxy, meeting resident needs in extra care is comparable to having a service in place that enables residents to lead their day-to-day life in a way that maintains or improves their wellbeing. A list of outcomes that should be used as measures for individuals who need care and support to lead day-to-day life in a way that maintains wellbeing is set out in the Care Act guidance (Department of Health, 2014). Those outcomes state that an individual should be able to:

- Maintain a habitable home environment and make use of their home safely
- Manage and maintain nutrition, maintain personal hygiene, manage toilet needs, be appropriately clothed
- Develop and maintain family or other personal relationships
- Make use of necessary facilities or services in the local community
- Engage in work, training, education or volunteering

- Carry out any caring responsibilities the adult has for a child.

The statutory framework of the Care Act 2014 enables individuals who are deemed 'eligible'⁵³ to receive care and support to meet those outcomes. Given the personalisation agenda set out in the Care Act, there is no service blueprint⁵⁴ or specification for how partners working together in extra care will meet those outcomes or residents' needs.

Even where an agreed specification is in place to meet resident needs through a contracted extra care service, ensuring residents are satisfied may require a service to go beyond the agreed specification, to provide other desirable services elements that residents 'want' or would like to have. This was articulated by all participant groups who frequently referred to services which are set up to provide planned care through tailored care packages, but with little scope for staff to support the activities sought after by residents. There is potential to have dissatisfied residents if there is a gap between the agreed specification to meet residents' needs and what they would like. Thus, defining, achieving and measuring a quality service for extra care residents is not a simple business.

Three different but complementary quality models are critiqued in this chapter to see whether they provide a helpful approach to managing quality in extra care housing, including how far they provide a focus on the issues identified as important to participants in this research. The three different quality models are the Total Quality Management (TQM) Model; the European Foundation for Quality Management (EFQM) Excellence Model; and the Public Sector Scorecard (PSS). They were selected because they all three use a business philosophy

⁵³ The eligibility threshold for adults with care and support needs is based on identifying how a person's needs affect their ability to achieve relevant outcomes, and how this impacts on their wellbeing. Under the Care Act (2014), local authorities must consider whether the person's needs: (1) arise from or are related to a physical or mental impairment or illness; (2) make them unable to achieve two or more specified outcomes; (3) as a result of being unable to meet these outcomes, whether there is likely to be a significant impact on the adult's wellbeing. An adult's needs are only eligible where they meet all three of these conditions.

⁵⁴ A service blueprint is an operational planning tool that provides guidance on how a service will be provided, specifying the physical requirements, staff actions, and support systems / infrastructure needed to deliver the service

founded on customer satisfaction, have been subject to previous research studies, and have been variously promoted in the UK through the Department of Trade and Industry and other local government or quality bodies.

8.2 AN INTRODUCTION TO TOTAL QUALITY MANAGEMENT (TQM)

This section considers how TQM developed, how it has been adapted to service industries including the not-for-profit and public sectors, and how relevant it might be to extra care housing.

8.2.1 The development of Total Quality Management

A model of Total Quality Management was initially developed in the 1980s based on a broad understanding of total quality management, providing a perspective that linked the TQM approaches to the direction, policies and strategy of an organisation (Oakland, 2014, p. 22). The model suggested using teams of people to address quality issues through quality circles, problem solving and other process control tools, and quality systems such as British Standards or International Standards Organisations (ISO). Customers and suppliers were core to the TQM model, but emphasis was also placed on the need for a culture that was inclusive, empowering and open, having effective two-way communication in place, and having commitment from everyone in the organisation including both senior managers and those operating most closely to the customers.

Research undertaken at the turn of the century by Dale (2001a) and Zain (2001b) concluded that TQM was in the early stages of theory development⁵⁵. They reviewed Oakland's updated model and were encouraged that all areas of TQM

⁵⁵ Over the last three decades management literature on excellence and quality management in organisations has covered different approaches to total quality management (TQM) and organisational or operational excellence. Critics have described some of the approaches as fads (Van der Wiele, Williams, & Dale 2000; Babich, et al., 2016; Lucas, 2016), but there is a consistent theme running through them; the search for an approach to help the organisation to succeed. The TQM model has been updated over time, including two further iterations by Oakland (Oakland, 1993 & 2011).

‘have had their share of scrutiny and this, in some way, shows some degree of academic maturity’ (Zain, et al., 2001b, p. 607).

Successful development and implementation of TQM requires an organisation to be clear what it needs to do to achieve its mission or vision, to be clear what factors are critical to its success, and to integrate TQM activities into the business or organisation strategy (Yousof & Aspinwall, 2000; Wali, et al., 2003; Oakland, 2014)⁵⁶.

TQM as a whole system approach has been adopted to a greater or lesser extent within public sector and health care services (Koch, 1992; Joss & Kogan, 1995; Welch & Allen, 2003; Heidari Gorji & Farooquie, 2011; Talib, et al., 2011; Antony & Rodgers, 2016). Stupak and Garrity (1993) speculated that perceptions of how compatible TQM is to public services were affected by misunderstandings of public sector culture, including the important sub-cultures that are found in large and diverse public sectors. They went on to describe how public services were changing with greater focus on listening to the voice of the customer when defining outcomes for services; more decentralisation of decision making; and more recognition that long term leadership commitment would lend TQM to public sector organisations. Supak and Garrity concluded that there was no one way to design and implement TQM but said it provides a useful template for organisational success (Stupak & Garrity, 1993, p. 8). There are similarities between what Supak and Garrity described for the public sector, and the environment in which extra care housing is operating in the UK today.

Although there has been little research on the use of TQM within the UK housing sector, lessons can be learned from TQM implementation in the NHS and health care services. Use of TQM in the NHS was partly driven by Government NHS reforms in the early part of the 21st Century (Department of Health, 2000; NHS Modernisation Agency, 2003). The reforms did not explicitly say that TQM should be adopted, but rather embraced some of the TQM principles (Adamou &

⁵⁶ Aquilani, Silvestri, Ruggieri and Gatti’s (2017) general analysis of literature on total quality management critical success factors showed both that customer focus has gained importance in recent times and that there has been a positive impact of TQM on performance.

Hale, 2004). Whilst TQM has not been a wholly positive experience in health care and public services either in the UK or abroad, it is reported to have potential to be adapted to local organisations for more successful implementation (Huq & Martin, 2000; Theodorakioglou & Tsiotras, 2000; Lee, et al., 2002; Adamou & Hale, 2004; Mosadeghrad, 2015).

8.2.2 Adaptations to Total Quality Management

As part of a study of crucial factors for successful implementation of TQM in the Spanish public sector, Pimental and Major (2016) reviewed the effectiveness of the latest 'Oakland TQM model' (the 4P's and the 3C's set out in Figure 8-2). In this model, the people-systems-techniques of the 1990s model has been replaced by people-planning-process, with an additional element to cover performance. Pimental and Major concluded from their research that the model remains appropriate but advocated for additional factors such as 'power' and 'collective involvement' to be included.



Figure 8-2: Oakland TQM model
(Source: Oakland, 2011, p. 529)

There has been debate about the nature of collective involvement, managing the relationship with customers, understanding true customer requirements and their interrelationship with performance within the TQM model (Crossley, 2017; Oakland, R., 2017). Whilst no consensus has been reached on whether Pimental and Major's refined model is more useful than the Oakland model, issues of collective involvement and power are important to this extra care

research which recognises the differing experiences and agency of people working and living in extra care, as discussed in the previous chapter about social worlds theory.

Participants of this extra care research described the importance of the physical environment in which extra care is provided, consistent with ageing in place illustrated in Section 0, and further illuminated in Section 7.4 on the importance of space for interaction within and between social worlds. The 'place' where extra care is situated and the design of the physical extra care scheme were described by participants in this research as critical in helping people with dementia to live well, in keeping environmental gerontology and other studies on the impact of the environment on the functioning of people with dementia (Jones & Van der Eerden, 2008; Fleming & Purandare, 2010; Orrell, et al., 2013; Waller, et al., 2013; Fleming, et al., 2016, Waller, et al., 2017).

Within the discipline of management there is a body of research on the impact of the physical environment on both customers and employees in relation to service industries (Kotler, 1973; Rapoport, 1982; Shostack, 1984; Bitner, 1992; Wakefield & Blodgett, 1996; Walter, et al., 2010). Bitner (1992) pioneered a framework identifying environmental dimensions of a servicescape⁵⁷ with dimensions including; ambient conditions such as temperature, noise and air quality; space and function such as layout, equipment and furnishings; and signs symbols and artefacts such as signage and style of décor. The management discipline focusses on how a customer's perception of the environmental servicescape triggers cognitive responses which influences how someone experiences a service, and affects their view of the quality of the service. Servicescape and service culture, which are important in social worlds theory, were two dimensions of managing quality identified as missing from a review of empirical literature of TQM (Sureshchandar, et al., 2001). Sureshchander suggested these two domains were unique to service organisations and put

⁵⁷ Servicescape is a model that emphasizes the impact of the physical environment in which a service process takes place.

forward a conceptual model for TQM in service organisations which included the two additional domains of servicescape and service culture. Critically, neither the Oakland (2011) nor the refined Pimental (2016) TQM models include a 'P' to reflect place; the physical environment where a service is delivered, or the space within it.

8.2.3 Total Quality Management and extra care housing

Extra care housing often brings together housing and care partners to provide a range of activities which include the landlord service to support the actual apartment building, housing support to oversee activities associated with managing a household, and other care and support services (Twyford, 2016). They operate as extra care schemes through a contractual partnership arrangement with the local authority⁵⁸. There is still relatively little literature on how quality is managed within extra care provision, especially across the diverse models of partnership that operate⁵⁹. Managers in four different regional and national housing associations were interviewed in this research about quality approaches adopted within their own extra care organisations. One described a quality framework which was developed internally; one had responsibility for quality management within their job function; one described using a quality assessment from the Association of Retirement Community Operators (ARCO); and one said they struggled to describe how quality was embedded into the heart of their organisation because they were newly appointed into a temporary

⁵⁸ Extra care schemes in this study are not provided by the public sector. They are run by registered landlords as a form of social housing in the not for profit sector, with some similarities to public sector housing provision.

⁵⁹ Specific literature around quality management and the housing sector started to emerge in the early 1990s. Encouraged by the Housing Institute, Catterick (1992) proposed TQM as the best route for quality improvement as part of a quality strategy for social housing. Commissioning for quality has taken prominence since the reform of public services and the introduction of social care markets in the 1990s (Knapp, et al., 2001). The quality of commissioning for outcomes has been subject to both government policy and scrutiny in social care and housing sectors (Glendinning, et al., 2008; Macmillan, 2010; Lucas, 2012; Harlock, 2014; Slay & Penny, 2014).

contract. Only one association appeared to have a relatively mature model of quality management, with the other associations appearing less mature in their approach. Whilst Total Quality Management can offer a model approach for organisations to follow, there is not yet a general or shared model for successful implementation (Aquilani, et al., 2017). The matter of implementation is addressed in the next section.

8.3 THE EUROPEAN FOUNDATION FOR QUALITY MANAGEMENT (EFQM) EXCELLENCE MODEL

TQM set out an approach to quality management and the EFQM Excellence Model sets out an implementation framework to manage quality. The aim of EFQM⁶⁰ is to offer total quality management a business excellence philosophy that can be applied to all organisations regardless of their size, sector or location (de Domartin, 2000). It comprises nine criteria which are described in the model in Figure 8-3, separated into ‘Enablers’ and ‘Results’, with the enablers describing what an organisation delivers, and how. The results cover what an organisation achieves through its performance in relation to customers, people and society.

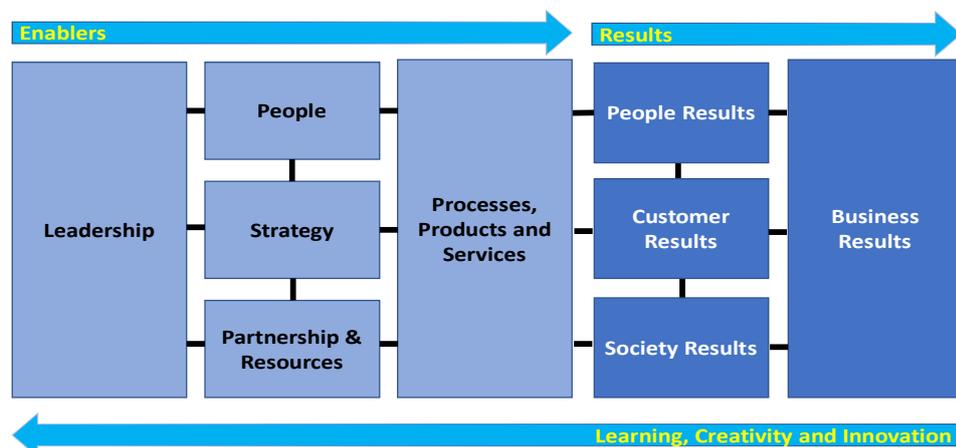


Figure 8-3: The European Foundation for Quality Management (EFQM) Excellence Model (Copyright EFQM (2012))

⁶⁰ Research conducted by the Centre for Organisational Excellence Research (COER) revealed that there are over 90 award schemes for business excellence models, with the EFQM Excellence Model the most popular in the world with use throughout Europe and the Middle East. The second most popular was the Baldrige Excellence Framework, used primarily in the United States and parts of Asia. (Ahmed, 2015).

The EFQM Excellence Model (EFQM, 2012) suggests people, processes and partnerships need to be developed or improved to add value to services that are delivered to an organisation’s customers. That reflects the discussions of participants in the focus groups which portrayed overall satisfaction at the extra care service but a desire for improvements in issues such as gaps in what is provided, partnership working, and development of staff roles. Table 8-2 below illustrates which EFQM criteria are relevant to the issues highlighted by participants in this research.

	Issues arising from the research findings	Relevant EFQM Criteria
1	Partner agencies should work closely together to agree and communicate its strategic vision.	Strategy enabler; leadership enabler; and partnership and resources enabler
2	Financial and non-financial drivers should be aligned across partner organisations to make sure that all partners can meet their strategic priorities in delivering an extra care service to meet the needs of residents and family members.	People results; customer results; society results; and business results
3	Clear leadership within and across partner organisations is critical to ensure there is a culture in which person-centred care can be delivered.	Leadership enabler; people enabler; and customer results
4	A strategy should be in place to drive the development of skilled, competent and capable staff teams with clearly defined roles that can work together to support residents.	People enabler; and customer results
5	Gaps in the process of service delivery should be identified and removed.	Strategy enabler; and processes, products and services enabler
6	Processes should be in place to value and develop the best possible service with contributions from volunteers, residents, and commercial suppliers.	Processes, products and services enabler; partnership and resources enabler; people results
7	Processes should be in place to maintain residents’ rights and to manage risks.	Processes, products and services enabler; people results
8	Partner organisations should have opportunities to learn together about why the service might fail to meet the needs of some residents, and see if there are any improvements that can be made.	Learning, creativity and innovation

Table 8-2: Issues arising from the extra care research mapped to the EFQM criteria

The EFQM model supports sustained success or improved performance through strong leadership and clear strategic direction, both elements that were the focus of participant discussions in this extra care research.

Although the EFQM Excellence Model was recognised at the turn of the century as an appropriate framework to guide the systematic implementation of Total Quality Management (Eskildsen, 1998; Der Wiele, et al., 2000; Bou-Llusar, et al., 2009), as a generic model EFQM but does not suit all organisations⁶¹. It has been used within some housing associations, such as Glasgow Housing Association and Wakefield and District Housing (EFQM, 2017) but there is a dearth of evidence on how the criterion have been adapted, or its general effectiveness within the housing sector.

Housing management participants interviewed in this research were asked about frameworks or models that had been adopted within their own extra care organisation's approach to quality management. A couple referred to quality industry recognised methods such as Lean Management⁶². Individual managers described quality tools, which were used to a greater or lesser extent. The lack of take up of recognised frameworks is consistent with research by Moxham (2010) who studied the uptake of quality performance frameworks across a range of not-for profit organisations. Although her study was small she reported that 'in practice, only the EFQM was used, and that was only used by one non-profit organisation in the study' (Moxham, 2010, p. 349).

Table 8-2 showed that many of the issues raised by participants were relevant to more than one of the EFQM criterion. Rusjan (2005) said that understanding the inter-relationship within and between the results and enabler criterion is critical to being able to understand and improve performance⁶³. Research indicates that EFQM is enhanced when it is used with other tools, such as a balanced

⁶¹ Some sectors have adapted the criteria to better meet their own industry standards (George, et al., 2003; Vallejo, et al., 2006; Jacobs & Suckling, 2007; Bou-Llusar, et al., 2009; Lui & Ko, 2017). The model remains an appropriate framework where it has been used in specific service settings such as the hotel industry (Lui & Ko, 2017), local authority services (George, et al., 2003; Jacobs & Suckling, 2007), and healthcare (Vallejo, et al., 2006).

⁶² Lean management is an approach to running an organization that supports the concept of continuous improvement, a long-term approach to work that systematically seeks to achieve small, incremental changes in processes to improve efficiency and quality.

⁶³ The EFQM model provides a self-assessment framework which can be employed to benchmark performance (George, et al., 2003; Vallejo, et al., 2006; Jacobs & Suckling, 2007; Bou-Llusar, et al., 2009)

scorecard⁶⁴, which can help understand those inter-relationships (Jacobs & Suckling, 2007; Bou-Llusar, et al., 2009).

Van der Wiele et al (2000) suggest that readiness to self-assess against an excellence model such as EFQM is synonymous with an organisation's TQM maturity⁶⁵. That is of relevance to extra care housing, which might be assumed to be immature in its adoption of TQM because of its own relative youth. The findings of the research interviews with housing association managers suggest that extra care schemes are in the middle of Dale's range of maturity⁶⁴, with all four housing associations appeared motivated to improve but describing compliance with regulations as the main driver for quality rather than continuous improvement. Lack of internal resources and the level of external regulation were cited as barriers to moving beyond compliance to a more proactive continuous improvement approach.

There is general recognition that EFQM is a useful model, but researchers have also warned that it has some limitations, and that some organisations face difficulties when trying to move beyond assessing performance to identify strengths and prioritise improvements within action plans (Kanji, 2001; Li & Yang, 2003; Rusjan, 2005; Moxham, 2010). This could pose a barrier to EFQM being adopted within extra care. The housing association managers interviewed in this research described general processes they used to help understand the root cause of problems, such as discussions with residents and care staff or sampling the quality of care and support plans. During the research interviews some of the language used by the researcher in describing aspects of quality models and approaches was unfamiliar with the interviewees, for example, some interviewees struggled to reply when asked about performance measurement systems, but were easily able to describe different methods used to evaluate resident satisfaction and regulatory requirements. At least three of the housing

⁶⁴ A balanced scorecard sets out key performance results in four main areas; financial results, customer results, people results and society results.

⁶⁵ Dale and Lascelle (1991 & 1997) identify 6 levels of TQM adoption or maturity; from organisations being uncommitted to total quality management through to being world class.

association manager participants appeared to have moved into senior roles from a housing or care professional background, which may suggest that their origins were not from within a managerial discipline. They appeared more at ease talking about the quality of extra care and meeting resident needs, perhaps reflecting greater familiarity with a care and support discourse from a sociological perspective. Having a shared language and terminology around key concepts will be essential to understanding and adopting quality approaches (George, et al., 2003; Vallejo, et al., 2006; Moxham, 2010; Turner, et al., 2016:17).

8.4 FRAMEWORKS, DIAGNOSTIC TOOLS AND PERFORMANCE MEASUREMENT

Over the years organisations have used various frameworks to help define measures to assess performance. They traditionally consisted of financial measures but have been expanded to include non-financial measures and revised to highlight links between cause and effect of performance (Keegan, et al., 1989; Fitzgerald, et al., 1991; Brown, 1996). Brown's (1996) work was important for the service industry, and particularly for the public sector, as it distinguished between outputs and outcomes, a key requirement for government policy as set out earlier in Sections 8.1 and 8.2. Brown's performance measurement model has some limitations that may affect its use within extra care settings; it doesn't link the different types of performance measures; it doesn't prioritise the separate requirements arising from the different stakeholder perspectives in the organisation, and it doesn't link performance directly to an organisation's strategy.

The importance of linking strategy to performance has been highlighted by a range of authors (Cross & Lynch, 1988; Keegan, et al., 1989; Kaplan & Norton, 1992; Kloot & Martin, 2000; Ittner & Larcker, 2003; Moxham, 2010; and Oakland, 2014). The balanced scorecard developed by Kaplan and Norton (1992 & 1996) provides a logical framework which enables an organisation to describe its strategy through focussed, strategic objectives and measures through four

linked perspectives, as shown in Figure 8-4. Each perspective is driven by an organisation’s vision and strategy, and together they provide a comprehensive set of performance measures to monitor and evaluate achievement of the organisation’s strategic objectives (Kaplan & Norton, 1992; Kloot & Martin, 2000; Niven, 2003; Oakland, 2014).

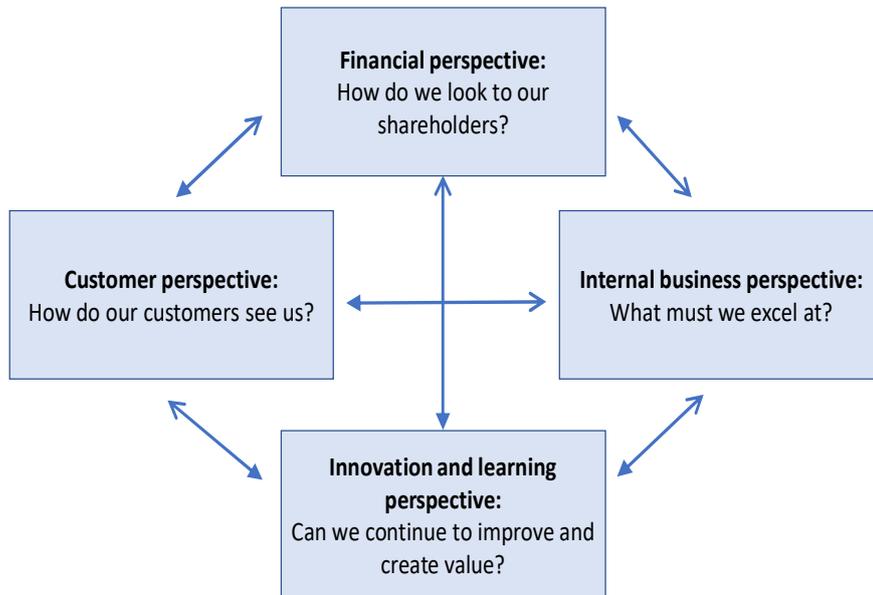


Figure 8-4: The Balanced Scorecard
(Source: Kaplan & Norton, 1992)

Although the balanced scorecard is popular⁶⁶ there are mixed views about its use and efficacy. Criticisms of the balanced scorecard in previous studies (see Appendix 17) include that it is over simple, the range of perspectives are not sufficient, do not cover all aspects of performance, and it can cause the wrong things to be measured. Over the years the balanced scorecard has been adapted to overcome some of those criticisms, leading to revised balanced scorecards (Cobbold & Lawrie, 2002), and to the development of multiple scorecards in complex organisations (Shulver, et al., 2000).

The extent to which the financial perspective is useful to not-for profit organisations and public sector organisations that do not have company

⁶⁶ The balanced scorecard was cited as having been adopted by 57 per cent of organisations in the UK by 2001 and has since been confirmed as one of the most popular tools used for measuring performance (Neely, et al., 2007;(Rigby & Bilodeau, 2011; Vukomanovic & Radujkovic, 2013).

shareholders has also been debated in parallel with the change in public sector management that started in the 1980s. A potential disincentive for using the balanced scorecard was reported by Moore (2003) who said that its emphasis on organisations succeeding by adopting a competitive strategy could distort its use in public and not-for profit sectors. A Public Sector Scorecard, developed for public and non-profit organisations, has been used both in the UK and abroad (Mouillon, et al., 2007; Lundin & Winqvist, 2010; Moullin, 2017). The Public Sector Scorecard is typified by a bottom-up approach to defining and measuring performance, with an emphasis on service user involvement, risk management and the need to work across organisational boundaries (Mouillon, 2006 and 2017).

The change in terminology from 'customer' in the balanced scorecard to 'service user' in the Public Sector Scorecard demonstrates a shift in the discourse about the role of customers who use public services. Within the research focus groups there was some discussion amongst all the participant groups about whether the people living in extra care were called 'tenants' or 'residents'. The term 'customer' did not appear to be much used, even when talking about the commercial services within extra care, such as the café and hair-dressers. 'Resident' appeared the preferred term across both schemes, and across all participant groups. Further research may be useful in more fully understanding whether different terminology gives more prominence and agency to the 'customer' or 'resident', either within or across different professional disciplines.

The promotion of collaborative working across organisational boundaries within the Public Sector Scorecard appears to make it more suitable for public and not for profit services such as extra care, whose aim often is to co-operate with one another to deal with the social problems they are trying to solve rather than compete against each other. In April 2018 it was announced that the Regulator of Social Housing will adopt comparative metrics in assessing its value for money standard (Barnes, 2018). The metrics are based on information already collected through providers' existing annual accounts regulatory return, and

have been drawn from the pilot launched by the Housing Sector Scorecard working group. Although the metrics are intended to support continuous improvement across the housing sector as value for money transparency becomes more easily comparable, their very narrow financial and economic focus may not make it best suited to the complexities of extra care delivered by partner agencies.

8.5 IMPLEMENTING QUALITY MANAGEMENT IN EXTRA CARE HOUSING

This chapter has so far considered general approaches to total quality management, models to implement quality management activities, and frameworks to help assess and analyse performance management. It now turns to how they could be applied in the context of extra care.

8.5.1 The context for quality management within the extra care housing sector

Being clear about the purpose of a quality and operational excellence management system is important in all sectors, including the public sector and not-for-profit run extra care schemes. The plethora of quality and operational management systems can confuse managers and may seem overly onerous for sectors that are still in their infancy and characterised by scarce resources (Muras, et al., 2008; Moxham, 2010).

Commissioning for quality became prominent with the reform of public services and the introduction of social care markets in the 1990s (Knapp, et al., 2001). Commissioners began to encourage more creative activities by setting outcomes that would meet customer requirements, and outcome-based commissioning became the subject of both government policy and scrutiny in social care and housing sectors (Glendinning, et al., 2007; Macmillan, 2010; Lucas, 2012; Harlock, 2014; Slay & Penny, 2014). In March 2018 a renewed Memorandum of Understanding to improve the health and care of individuals through an appropriate home environment was made by government departments and

organisations from across the health, social care, and housing systems (GOV.UK, 2018). Twenty-five government bodies and organisations in the health, social care and housing sector made a shared commitment to joint action and identified what success might look like in terms of the impact, outputs and outcomes of a system improved through leadership, analysis of knowledge evidence, and implementation of solutions.

Extra care housing meets the outcomes of individuals through the provision of accommodation, and housing management, care and support services. The mix of housing accommodation and service delivery within extra care is often complex, involving a partnership of multiple providers (Twyford, 2016). There is still relatively little literature on how quality is managed in extra care housing, especially where there are different partnership models of extra care provision. At a minimum, quality is assured through external regulatory systems for extra care.

Quality assurance within the regulatory framework for extra care housing relies on two pieces of legislation; the Housing and Regeneration Act (2008) and the Health and Social Care Act (2008). Regulation is undertaken by two different bodies, the Homes England⁶⁷ and the Care Quality Commission (CQC). Each use separate standards, set out in Figure 8-5.

The regulation of housing is concerned primarily with sustainability and economic viability. The regulation of health and social services is concerned with ensuring people are fit to deliver services, that the services are person-centred and safe, and that services remain viable. Both Acts are concerned with ensuring residents are involved and empowered during the process of receiving services, which implies that residents should be a central focus of any service planning and quality assurance processes.

⁶⁷ At the time of the research regulation of housing was provided by the Homes and Communities Agency (HCA). The Homes and Communities Agency was replaced by Homes England in January 2018.

Housing with Care Regulation – Extra Care

Housing and Regeneration Act 2008

Objectives of the social housing regulator (Homes England):

- Protect social housing assets
- Ensure providers are financially viable and properly governed
- Maintain confidence of lenders to invest into the sector
- Encourage and support supply of social housing
- Ensure tenants are protected and have opportunities to be involved in the management of their housing
- Ensure value for money in service delivery

Regulatory Requirements

3 economic standards:

- The Governance and Financial Viability Standard
- The Value for Money Standard
- The Rent Standard

4 consumer standards:

- The Tenant Involvement and Empowerment Standard
- The Home Standard
- The Tenancy Standard
- The Neighbourhood and Community Standard

Code of Practice



Health and Social Care 2008 (Regulated Activities) Regulations 2014

Regulated personal care activities must be registered (CQC):

- Requirements relating to persons carrying on or managing a regulated activity
- Fundamental standards
 - General
 - Person centred care
 - Dignity and respect
 - Need for consent
 - Safe care and treatment
 - Safeguarding from abuse
 - Nutritional and hydration needs
 - Premises and equipment
 - Receiving and acting on complaints
 - Good governance
 - Staffing
 - Fit and proper persons employed
 - Duty of candour
 - Display of performance assessments
- CQC (Registration) Regulations 2009 including:
 - Statement of purpose
 - Financial position

Figure 8-5: Regulation of extra care housing

Finding out, understanding and using customer requirements to inform successful business process and performance management systems is key to business excellence (Garver, 2012; Camgoz-Akdag, et al., 2013; Kassela, Papalex and Bamford, 2017). Total Quality Management as an approach has been adapted by some organisations to enable the voice of the customer to be heard and their needs and expectations effectively responded to (Kassela, et al., 2017), but there has been little evidence that it has been applied within the housing sector.

8.5.2 Choosing a strategic approach to quality management

An organisation's approach to managing quality is influenced by whether performance measurement is to be focussed on the organisation, a department, or individual services. The approach will also be influenced by the organisation's

information management requirements, and how far it has centralised the function of performance management (Jaaskelainen & Laihonon, 2014). There are few centrally driven or externally mandated performance measures in extra care. Performance is frequently measured within single organisations rather than across partnerships, with little standardisation across schemes. The complexity of extra care arrangements is unlikely to lend itself to straightforward aggregation of measurement information, suggesting a decentralised approach, specific to each set of unique partnership arrangements.

Jaaskelainen's strategy framework (2014) is helpful in trying to understand some of the complexity of performance management in extra care. Jaaskelainen positions four strategic approaches to public performance measurement within the framework, using a quadrant set out in Figure 8-6. The framework uses horizontal or vertical service 'chains'⁶⁸ to represent how far the service is focussed around the customer. Customer focus should be better achieved where processes flow easily from one service component to another as part of service delivery. Figure 8-7 illustrates how an issue raised by participants in the focus groups, lack of joined up support for residents to take part in activities, could be delivered through a service process orientated approach. There is likely to be less customer focus where extra care partners operate their services in silos, with resulting vertical service chains as reflected in the contingency based approach.

⁶⁸ A chain represents a flow or sequence of processes required to deliver the service

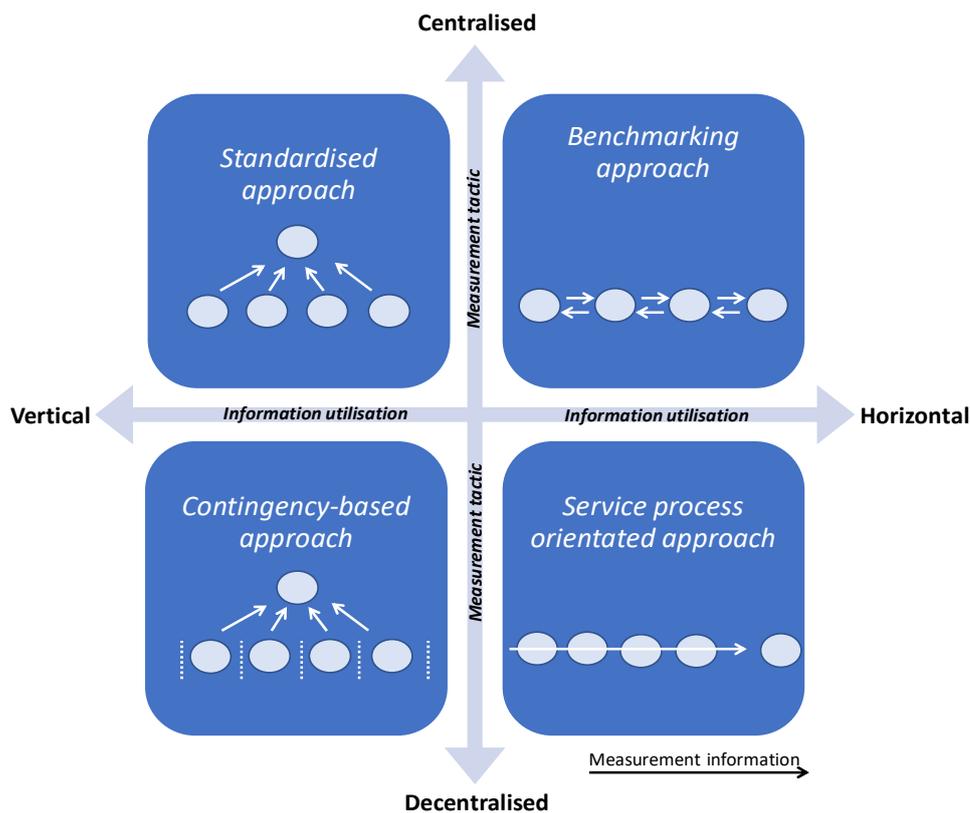


Figure 8-6: Strategy framework for public performance management

Source: Jaaskelainen and Laihonon (2014)

The service process-orientated approach outlined in Figure 8-7 will enable staff from different partner agencies to appropriately share information as part of the process flow. In contrast, a contingency-based approach might make it more difficult to share information as each staff group may be working in a person-centred way with the resident, but in silos as different organisations. A contingency-based approach might be appealing because it would allow housing and care service providers each to have their own measurement solutions; providing relevant information on the performance of individual teams, and in turn supporting learning and development for each individual service provider.

*Partners working together in a service process orientated approach:
Supporting a resident with dementia to take part in an extra care activity*



Phone resident to remind them there is an activity that day

Provides personal care assistance and support if the resident needs help to get to the extra care lounge for the activity

Ensures the resident has arrived, is with other people, and able to take part in the activity

Checks who is taking part in the activity; meets any specific dietary requirements and provides appropriate assistive eating and drinking implements

Monitors the group and is alert to any specific needs that individuals or the group may have

Checks when the resident leaves the activity, and unobtrusively monitors whether they have safely returned to their apartment

Shares any information that may help the organisation to better support the individual resident or the group next time

Figure 8-7: Example of a strategic service process orientated approach to service delivery in extra care

Having separate measurement systems is not unusual in many extra care schemes where each partner organisation is accountable to its parent organisation, and each provides information that is used in bottom-up performance measurement systems, used by multiple layers of their own organisation and by external regulatory bodies, as those shown in Figure 8-8. Separate performance systems may appeal because each can provide specific information for the different regulatory bodies, Homes England and the Care Quality Commission. The drawback of separate systems in the contingency-based approach is that it can lead to fragmentation, and it could be difficult to gain a whole service picture of performance (Jaaskelainen & Laihonon, 2014, p. 361). Where extra care providers break from the traditional hierarchies of their own organisation's structures they are more likely to minimise the performance gap and optimise service delivery to meet resident expectations through a service process-orientated approach.

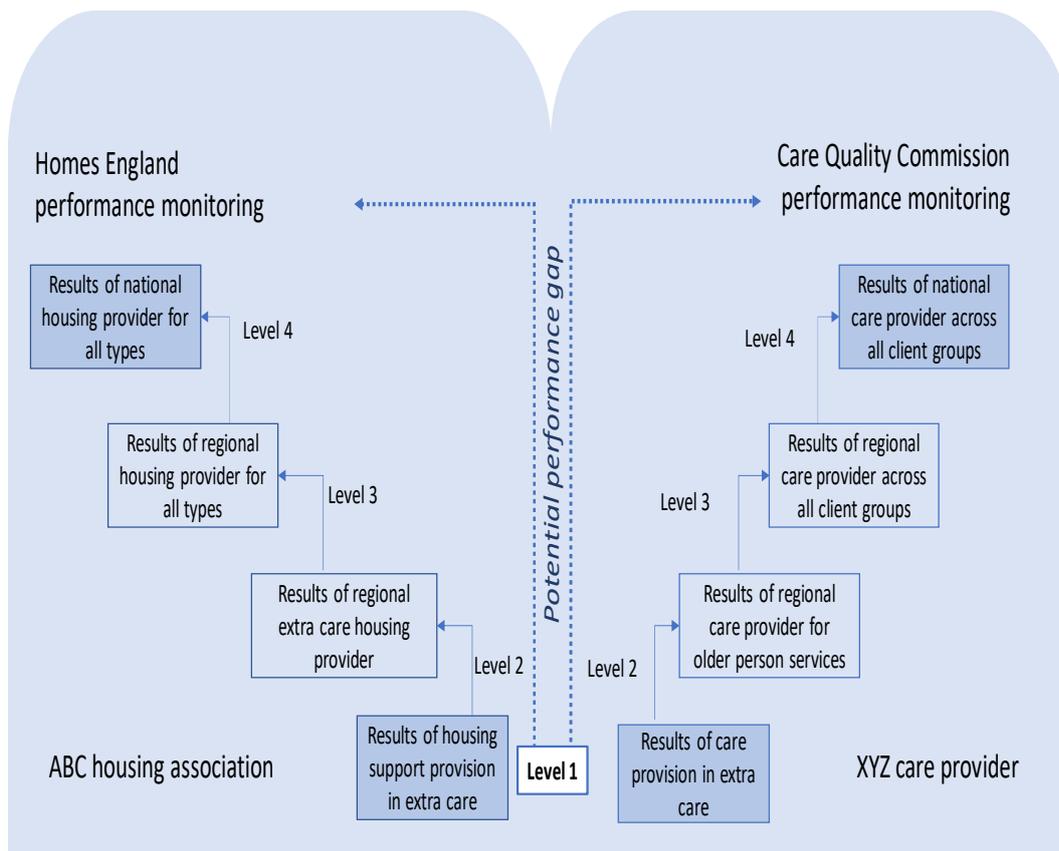


Figure 8-8: Example of a bottom up performance measurement approach in Extra Care schemes

Although resident participants in this extra care research did not express concern about who provided the service, they were very concerned when gaps or delays in service provision were caused by professional divisions, roles and responsibilities. With a service process-orientated approach to performance measurement, local managers at the extra care schemes would have the management information needed to monitor performance about how well (or not) an integrated service is delivered. Integral to performance measurement and management is having systems in place to enable the voice of the resident to be heard. It should also provide information to help partner organisations to learn and develop with each other as part of a shared continuous improvement process. It is possible that individual extra care schemes might aspire to have a service-process orientated approach but be limited by the constraints of operating within more rigid corporate organisational structures.

8.5.3 Implementing a model for quality management and operational excellence

The literature review suggests that TQM has a positive impact on performance (Aquilani, et al., 2017), and that the EFQM Excellence Model can be applied to improve the quality of the business and guide the systematic implementation of TQM (Bou-Llusar, et al., 2009). One of the fundamental elements of both TQM and EFQM is leadership, and that it starts within top management⁶⁹. Both the housing association and their local authority partners had reporting structures with at least three tiers of management. Top management support from the two partner organisations would be required to address gaps in joint quality management of extra care schemes at a local level.

Bou-Llusar et al say that a general commitment to and acceptance of the TQM principles is essential in order to benefit from the application of EFQM criteria (Bou-Llusar, et al., 2009, p. 17). The EFQM Excellence Model can be successfully joined up with the Balanced Scorecard to enable companies to prioritise strategic objectives and select the most efficient measures for each strategic objective (Vukomanovic & Radujkovic, 2013). In contrast, research on TQM, EFQM for Excellence and the Balanced Scorecard or Public Sector Scorecard revealed mixed views about their effectiveness or usefulness in some settings, set out in Appendix 18. A general view was that with some adaptation all three models can be appropriate for service organisation and can provide vehicles for top management to communicate the organisation's vision and goals across all stakeholders. Involving employees in developing the models can create 'buy in' and help organisations to control key success factors and provide evidence for organisational improvements.

⁶⁹ Businesses use a variety of terms for their executives or senior managers. The term top management is used here to describe the executive managers, directors and senior managers in each extra care partner organisation. They are the people that make decisions that affect everyone in the organisation and are held responsible for the success or failure of the organisation and the services it delivers.

Implementation of the models can focus resources on those aspects important to customers and help determine causal links between determinants and results of performance. Within the extra care sector those benefits should be weighed against possible disadvantages associated with the models. Implementation of the models are not a 'quick fix', rather it is a 'journey' which may be difficult for public and not-for-profit extra care organisations when there is short term insecurity of funding for services. Reconciling partner organisational visions and strategies into a single shared vision and strategy that can be used in the model may be challenging, and there may be internal resistance to creating joint performance indicators when there are separate regulatory bodies to satisfy. Deployment of the models would rely on leadership and top management support which is usually located outside the extra care schemes, and implementation may be resource intensive if not appropriately focussed.

The benefits of using a TQM approach appear to outweigh the disadvantages, with quality and operational excellence now embedded in many service organisations, including those in the public and not-for-profit sectors. It is mainly used in single organisations, even though those organisations may comprise many departments. It is possible that the main issues raised by participants in this extra care research, set out in Table 8-1 on page 261, could be improved if partners tried to tackle the issues together as part of a joint approach to quality management. A joint approach to developing a quality management strategy often starts with diagnosing the current position against where the organisation wants to be. Different approaches are used to support strategic planning, with many including a template set of questions to guide diagnosis and assessment. Two such approaches are the 4 or 5D approaches⁷⁰.

⁷⁰ There is not a clear literature setting out the development of 4 and 5D, but they have been subject to consolidation and adaptation, and are now used variously by a number of consultants including (Oakland Consulting 2013; Design Thinking Methodology, 2017; Equiniti Group, 2017; Lancera, 2017; Smith, 2017; and Trigent 2017).

The 5D approach set out in Figure 8-9 provides a template that could be used with senior management teams from extra care partners to identify the best organisational excellence approach to meet their requirements.

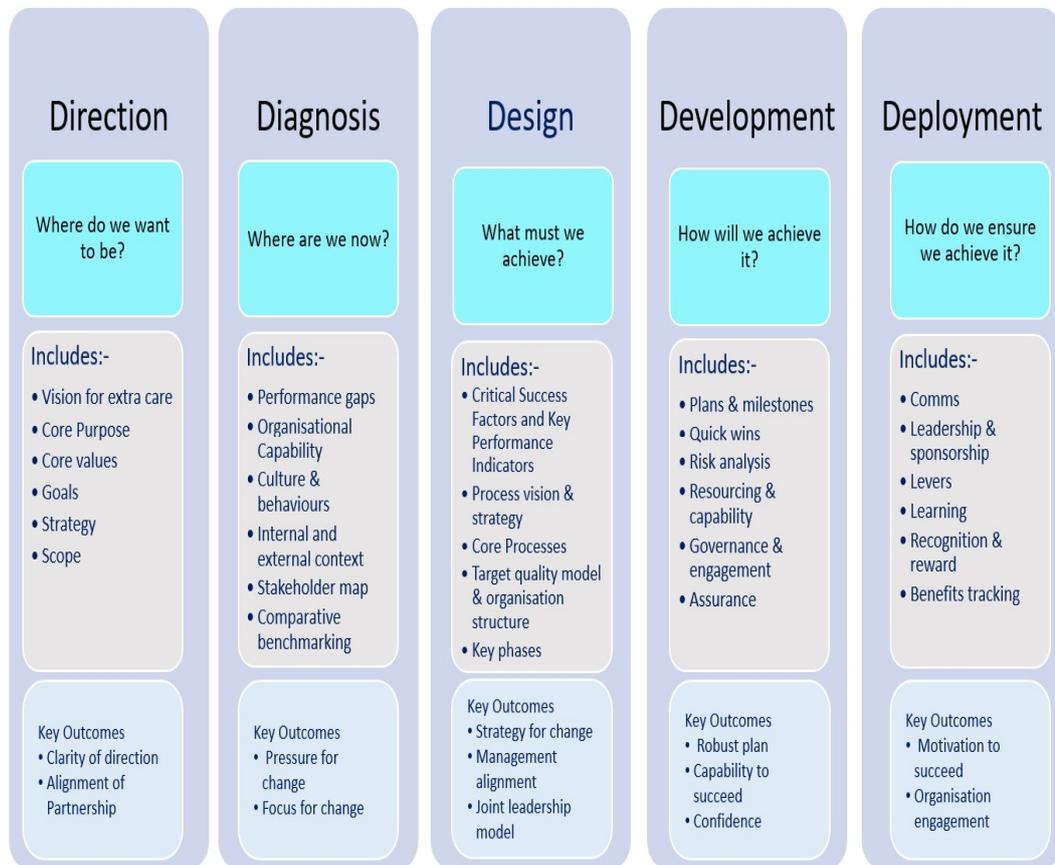


Figure 8-9: 5D Approach to operational excellence in extra care

Identifying the best approach would include selecting the most appropriate methodologies, tools and techniques to help the extra care partnership to achieve desired improvements in performance. An approach that included a cross-section of stakeholders within extra care would help create organisational engagement and improve the chance of realising necessary changes such as the issues outlined in Table 8-1 on page 261.

The principles behind the 5D approach are embedded in the EFQM Excellence Model (Oakland Consulting, 2013), enabling extra care partners to transfer the outputs into an EFQM model if it is adopted at a future stage. The 5D model asks five questions, each leading to one of the key areas within the model.

QUESTION**LEADING TO INFORMATION ABOUT**

Where does the extra care partnership want to be?		Direction
Where is the extra care partnership now?		Diagnosis
What must the partner organisations achieve?		Design
How will the partner organisations achieve it?		Development
How do the partner organisations ensure they achieve it?		Deployment

The issues raised by participants in the research have been mapped against the 5D questions in Table 8-3, illustrating how a structured approach could help resolve the issues, with key outcomes identified to help plan services and manage quality within an extra care scheme. Critical to using the 5D questions will be whether the partners agree to act together or as single organisations to establish the best way forward. Irrespective of whether they act jointly or separately, answering the five D questions should provide clarity of direction and executive alignment (or agreement of any areas of non-alignment) for both partners. It should also provide pressure and a focus for change leading to a strategy for change that can be agreed by both partners enabling local extra care scheme managers to align their actions. Finally, it should result in a robust plan with a commitment to provide the capability to succeed, which will engender confidence and a motivation to succeed based on engagement throughout the organisation.

The process of asking the 5D questions should provide an opportunity for the extra care partnership to reflect on the maturity of its service quality planning, and to agree any improvements that may be required to ensure that individuals live as well as possible in extra care, including those individuals living with dementia.

5 D question	Asking the 5D question should help resolve the following issue from the research	Key outcomes
Direction – Where do we want to be?	<ul style="list-style-type: none"> Partner agencies should work closely together to agree and communicate its strategic vision. 	<ul style="list-style-type: none"> Clarity of direction Alignment of partnership
Diagnosis – Where are we now?	<ul style="list-style-type: none"> A strategy should be in place to drive the development of skilled, competent and capable staff teams with clearly defined roles that can work together to support residents. Gaps in the process of service delivery should be identified and removed. 	<ul style="list-style-type: none"> Pressure for change Focus for change
Design – What must we achieve?	<ul style="list-style-type: none"> Financial and non-financial drivers should be aligned across partner organisations to make sure that all partners can meet their strategic priorities in delivering an extra care service to meet the needs of residents and family members. Clear leadership within and across partner organisations is critical to ensure there is a culture in which person-centred care can be delivered. Processes should be in place to value and develop the best possible service with contributions from volunteers, residents, and commercial suppliers. Processes should be in place to maintain residents’ rights and to manage risks. 	<ul style="list-style-type: none"> Strategy for change Management alignment Joint leadership model
Development – How will we achieve it?	<ul style="list-style-type: none"> Clear leadership within and across partner organisations is critical to ensure there is a culture in which person-centred care can be delivered. 	<ul style="list-style-type: none"> Robust plan Capability to succeed Confidence
Deployment – How do we ensure we achieve it?	<ul style="list-style-type: none"> Clear leadership within and across partner organisations is critical to ensure there is a culture in which person-centred care can be delivered. Partner organisations should have opportunities to learn together about why the service might fail to meet the needs of some residents, and see if there are any improvements that can be made. 	<ul style="list-style-type: none"> Motivation to succeed Organisation engagement

Table 8-3 : 5D approach questions mapped to issues from the research

8.6 CONCLUSION TO THE INSIGHTS TO EXTRA CARE AS A COMPLEX ORGANISATION

This chapter has considered Total Quality Management as an approach to ensure good quality and operational excellence within extra care. The European Foundation for Quality Management Excellence Model was reviewed to see if it could be used to implement quality management within a TQM approach. The need to establish how well the organisation is performing was explored, and different types of performance measurement frameworks were reviewed. They included a framework that was developed for the non-commercial sector, such as the Public Sector Scorecard. It was acknowledged that there is not yet a commonly accepted model of performance management or performance measurement in either the general service industry, or in extra care housing.

Given extra care's relative immaturity in the field of quality management, managers could be confused by the array of models and frameworks available and how best to use them. Any confusion could be compounded by the different discourses of 'customer' and 'resident' that are used sociology and management disciplines. The EFQM, Balanced Scorecards and Public Sector Scorecards can be tailored to make them more suited to individual organisations, and to be more easily understood by those using them; in effect each organisation constructing its own balanced scorecard. The EFQM Excellence Model and the Scorecards can be used together to complement each other if used judiciously.

The current model of Total Quality Management does not focus on the importance of place or the physical environment in the delivery of service, which is crucial to running an effective extra care scheme. The physical layout of an extra care scheme, or servicescape, can help or hinder someone with dementia to navigate their way around extra care and to remain as independent as possible. Servicescape and service culture were gaps in the TQM model that could be used to assess the effectiveness of extra care using the model proposed in this research. Notwithstanding the gap in the current model, TQM does

provide a holistic approach to empowering people within and across organisations to develop a shared understanding of and commitment to long term success through customer satisfaction.

It is unclear from this research whether the extra care partnerships are sufficiently mature or flexible to develop a shared approach to quality management. A 5D approach to organisational excellence was introduced to show how extra care partnerships could assess the gap between current quality management within extra care and where partner organisations would like to be. It was suggested that using a 5D approach to develop a quality management system to deliver organisational excellence could help extra care partners to focus on what they jointly want to achieve in delivering a service that best supports people with dementia to live well in extra care.

The research suggested that success would not be achieved overnight, but that implementing a total quality management approach to achieve operational excellence would take time. There was also a clear message that early wins could be gained, especially where an organisation involved its people in making the changes. Overwhelmingly, the research indicated that quality and performance management should be an integral part of the organisation's strategy and that there needs to be strong leadership if implementation is to be successful.

Leadership of people, commitment and culture underpin the effectiveness of a total quality management approach. The inter-relationship of these will be affected by the way in which extra care operates as a social world or series of social sub-worlds. Chapter 9 sets out a new understanding of the integration of quality and organisational excellence with social worlds theory, and how it underpins an extra care model that could help those who develop, deliver and operate extra care schemes to best support individuals living with dementia.

9. CHAPTER NINE: A FRAMEWORK FOR EXTRA CARE DEVELOPMENT

The research findings in Chapters 4 and 5, and discussion in Chapter 6 revealed that individuals with dementia can and do live well in extra care housing, but there may be some exceptions. It was agreed with participants that it is important that individuals with dementia should still be able to navigate their way around a new environment, establish new routines, and make relationships with other people when they first move into extra care, although they might need support to do that. It was reported that those already living in extra care whose dementia progressed might have to move out if an individual's rights, risks and safety could not be appropriately managed. Where a person with dementia lived as part of a couple, the carer appeared to be instrumental in enabling the person with dementia to remain more settled in extra care as their dementia progressed. Together the researchers and participants identified a model of extra care housing that would support individuals to live well, including those with dementia, shown in Figure 9-1.

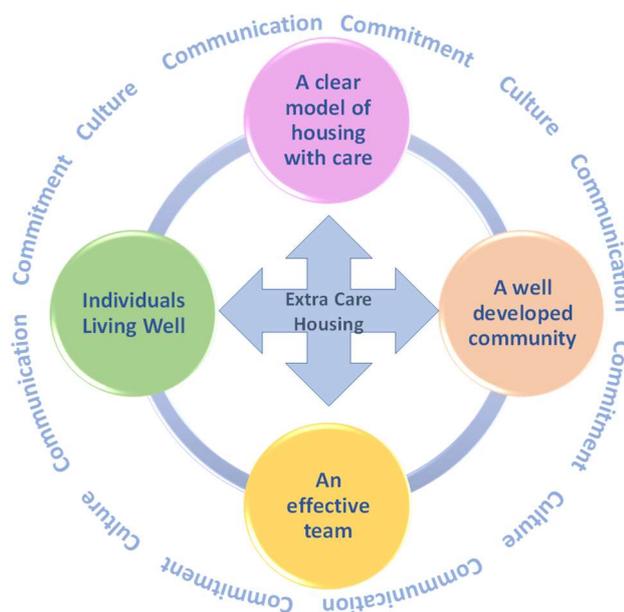


Figure 9-1: Model of extra care housing agreed with research participants

The model included elements that would help those who live and work in extra care to optimise the factors described as supportive to people living with

dementia. They included but were not limited to; having a clear vision for the service and what it could provide; having processes that support appropriate moves in and out of extra care; having a helpfully designed environment where people are able to easily move around the building; being supported to take part and to manage relationships and be part of the community; and having a positive approach to managing the rights, risk and safety of all those who live and work at extra care.

To gain new insights that could help further ground the extra care model, the participant findings were compared with literature about social worlds theory and quality and operational excellence theory. These insights were set out in Chapters 7 and 8. This chapter will consider how social worlds theory can enhance a framework for quality and operational excellence and will discuss how an extra care organisation can plan for and evaluate excellence in extra care provision so that individuals can live well. The chapter consolidates the extra care model developed with participants and puts forward new knowledge to support those who develop, deliver and operate extra care housing. 'People with dementia living well' is used as a central reference point for the quality and operational excellence framework described. The chapter will consider how far the theoretical model of extra care housing can be generalised to accommodation and care settings other than extra care.

The model of extra care identified with participants derived from the experiences of those living and working in extra care as well as from the experiences of those who contributed to commissioning, developing and running the extra care schemes. Having a common language that describes a model and strategy that is understood by all stakeholders is often a challenge. Choosing an appropriate language has also been a challenge for this chapter, where the focus has been on exploring managerial tools that can support quality and operational excellence in a way that embodies the important sociological context of extra care as a social world in which people operate within and between different social sub-worlds. Selected quotes from the research have been used to put

the voice of participants into the managerial discussions in Sections 9.2 and 9.3 and add meaning and relevance to the model and framework.

The review of social worlds theory in Chapter 7 showed that individuals and groups operate at many different levels, and that being able to join those groups can have an impact on the experience of people in extra care, especially those who may be living with dementia. Each extra care scheme was defined as a social world and the range of groups that emerged and disappeared within the extra care scheme over time were defined as social sub-worlds. An important aspect of extra care and social worlds theory is that there are boundaries between an individual's private space in their own home and the social world of the communal parts of the extra care. Although some people may choose to live in relative isolation in their own home, sufficient and appropriate groups, or social sub-worlds, existing in harmony with each other were considered by participants to be important to meet the needs of extra care residents and establish a well-developed community.

How well social sub-worlds operate in extra care appeared to be dependent on the culture and the availability of support and commitment from those living and working in extra care. That support and commitment was considered especially important in maintaining a person with dementia's sense of self, and in minimising the potential for people with dementia to be marginalised from the extra care community. Organisational support from extra care partners was dependent on their approach to service delivery and operational constraints. A shared approach to quality and operational excellence across partner organisations involved in developing and delivering the extra care was considered helpful in creating a well-developed community with individuals living well. Significantly, the findings of this research suggest that an extra care model that combines social worlds theory with a shared approach to quality and operational excellence could helpfully provide a tool to address some of the issues raised by participants, described earlier in this chapter.

Three key issues arose from the application of the social worlds theory and quality and operational excellence theory to extra care in Chapters 7 and 8. The first was to enable people living with dementia to have agency and be able to develop reciprocal relations with other residents and staff in extra care. It was recognised that a perceived lack of agency and the presence of negative reciprocity may cause individuals with dementia to be marginalised or excluded within the extra care community. It was suggested there is a role for staff to support new residents to settle into the extra care social world and that staff can help individuals join and be accepted in social sub-worlds and take part in community life at the extra care scheme. The economic climate, resource limitations, culture and leadership were identified as some of the factors that precluded the development of flexible staff roles within extra care, resulting in a service that did not always meet the needs of some people with dementia.

Second, it was recognised that good design affects how well people can find their way around and navigate between the private and semi-public areas within extra care. The interaction between organisational structure, social sub-worlds and the spatial design of the scheme was described as complex in Chapter 7. Chapter 8 considered the importance of organisational structure and the physical environment when adopting different approaches to quality and operational excellence. It was suggested that 'place', and how the physical environment is used, is an element missing from many approaches to operational excellence.

Third, the nature of the partnership arrangements and organisational structure for delivering extra care appeared to influence what sort of quality model and approach to operational excellence was adopted in the extra care schemes. It was not clear how stakeholders came together to review how well the extra care scheme was performing, or what vehicles and arenas there were for making improvements.

Given that extra care as a model of housing is still relatively young, managers could be confused by the array of quality models and frameworks available and

how best to use them. The managerial discourse used to describe the quality models and frameworks was considered a potential barrier to their adoption by managers who may be more familiar with a care and support discourse from their original professional disciplines. This chapter proposes a new approach to managing quality within extra care by using social worlds theory to understand how operational excellence can be achieved, with resident or customer satisfaction a fundamental concept in judging the results of operational excellence. Resident satisfaction depends on having the right extra care model with the right environment. Getting it right is an on-going process affected by how individuals and groups live and work together in social worlds. An open culture, where residents and staff are encouraged to communicate their ideas about what works and what does not work is required if residents are to be involved in shaping continuous improvements to an extra care scheme, and if commitment is to be gained from staff across partnerships to deliver an excellent service which achieves a good quality of life for residents including those living with dementia.

9.1 INTEGRATING SOCIAL WORLDS THEORY AND ORGANISATIONAL EXCELLENCE WITHIN THE EXTRA CARE MODEL

The model of extra care set out in Figure 9-1 was based on a thematic analysis of participant accounts of living and working in extra care. Approaches to service planning and quality management must reflect those lived experiences as well as being driven by industry specific or professional knowledge. The quality profession advocates that approaches to service planning and quality management should consider the impact of the external and internal service environment; develop a strategy to set out stakeholder requirements and to ensure all organisation requirements are reflected in operational frameworks and processes; embed a culture of assurance so that effectiveness of the service is evaluated and is consistent with stakeholder requirements; and facilitate a culture of learning and improvement (CQI, 2015; Turner, et al., 2016:17). Figure 9-2 maps the four drivers of the external and internal environment, strategic

drivers, operational delivery, and performance onto the four components of the extra care model derived from the lived experiences of participants, including those with dementia. Interpretation of the external and internal context may vary according to whether it is seen through the eyes of social worlds theory or quality and operational excellence theory.

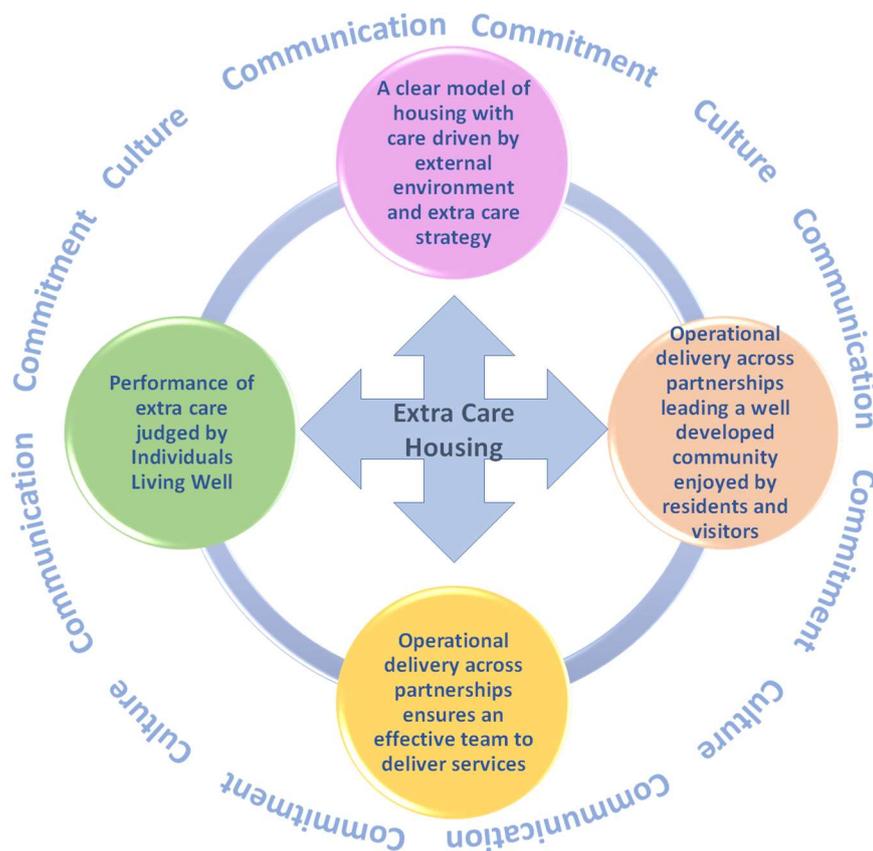


Figure 9-2: Model 1: Contextualising the model of extra care housing within an approach to quality and operational excellence

External environment

The external environment seen from a social worlds perspective would focus on how central and local government have engendered collective action using government policy, grants, research and best practice and examples of the lived experience as boundary objects⁷¹ to bring together extra care housing providers and other stakeholders to develop extra care. In contrast, viewed from the perspective of quality and operational excellence the external environment may

⁷¹ As set out in more detail in Chapter 5 a boundary object provides information that is common enough to link separate social worlds together around a common task or issue.

be driven by housing and social care sectors coming together to look at planning frameworks that affect purchase and use of land, by standards that allow partnerships to develop, and by procurement regulations that guide how extra care can be commissioned. From both perspectives the external environment will influence the strategy for commissioning, developing and delivering a model of extra care housing.

Internal extra care strategy

Developing a strategy for extra care housing from a social worlds viewpoint would involve using boundary objects such as procurement and contractual documents to negotiate and agree principles and standards for what the extra care housing is to deliver. Other boundary objects such as joint operating agreements and allocation protocols would be used as tools to formalise the extra care strategy. In shaping the policies and protocols partners would typically discuss and agree matters such as desired level of independence of residents, the balance of care needs across the resident group, what level of support would be provided to help people take part in activities, and the implications for staffing models. It is here that the notion of the floating support worker put forward by participants in this research could have been explored. A social worlds approach would bring key actors together to shape the strategy, policies and procedures; those key actors would include representatives of those living, or with the potential to live in extra care.

Implementation of an extra care strategy from a quality and operational excellence perspective is more likely to focus on what needs to be in place to ensure that all partners meet the regulatory standards and what processes should be in place to measure performance against those standards, including standards that measure customer or resident satisfaction. Bringing the two perspectives of social worlds and quality together should better ensure that there is a clear vision for each extra care housing scheme. A vision which is shared by all partners and stakeholders involved, and which is communicated to

residents and their families, to staff and other service providers within the extra care scheme, to other professionals, and to wider society.

Operational delivery

Delivery of services to both residents and the local community results in different groups and individuals having a stake in how the extra care scheme is operated. Understanding the diverse range of groups and how their social sub-worlds can work together more or less harmoniously will help achieve effective service delivery. Boundaries between the different groups are likely to be negotiated and understood by new members using tools such as the joint operating agreement, allocation panel meetings, resident meetings, and multi-disciplinary care planning meetings which may lead to the development of custom and practice. As described in Chapter 8, an approach to service delivery underpinned by social worlds theory would focus on staff teams being person-centred and flexible in responding to the planned and unplanned physical, emotional and social needs of residents to help them make the most of the extra care social world. That will impact on how effectively people are supported to manage risks and how well their own and others' wellbeing is safeguarded. It will influence how well people with dementia and their carers live in extra care and is strongly influenced by the culture and leadership within the extra care schemes.

In contrast, a quality and operational excellence view of operational delivery is more likely to focus upon whether the allocation policy is being adhered to; whether there are people processes in place to ensure that services can be delivered, whether catering contracts are being delivered and customers are satisfied, whether there are processes in place to enable people to comment or complain about services and action taken. Leadership and communication are key to making sure that the needs of residents are at the forefront, and that there is an appropriate culture and commitment to implement the operational processes in a person-centred way.

Taking account of both social worlds and quality and operational excellence viewpoints when planning how services are delivered should help to deliver a viable and affordable model of extra care, which meets the individual and collective needs of the residents resulting in people living well.

Performance

Developing a holistic view of people living well with dementia in extra care was discussed in Chapter 8, where a range of financial and non-financial indicators that can be used to measure extra care performance were considered. A social worlds perspective on performance is likely to focus more on the non-financial indicators, such as the extent to which individuals can settle into extra care and become members of the extra care social world; the level of harmony or friction between different social sub-worlds, leading to people with dementia being marginalised or embraced as part of the community; the level of satisfaction expressed by residents about living in the scheme; and whether or how residents choose to leave the social world of extra care, and if so for what reasons. From a quality and operational excellence perspective the performance of the scheme is more likely to be measured by tangible indicators including whether the scheme is financially viable, whether staffing levels are acceptable, whether the services are complying with regulatory requirements, how many residents are satisfied, and how many leave and for what reasons.

The two different approaches to developing and delivering extra care are not mutually exclusive. Figure 9-3 shows how the two perspectives of social worlds theory and operational excellence can each shape the development and delivery of extra care by their contribution to the external environment, strategic drivers, operational delivery, and performance.

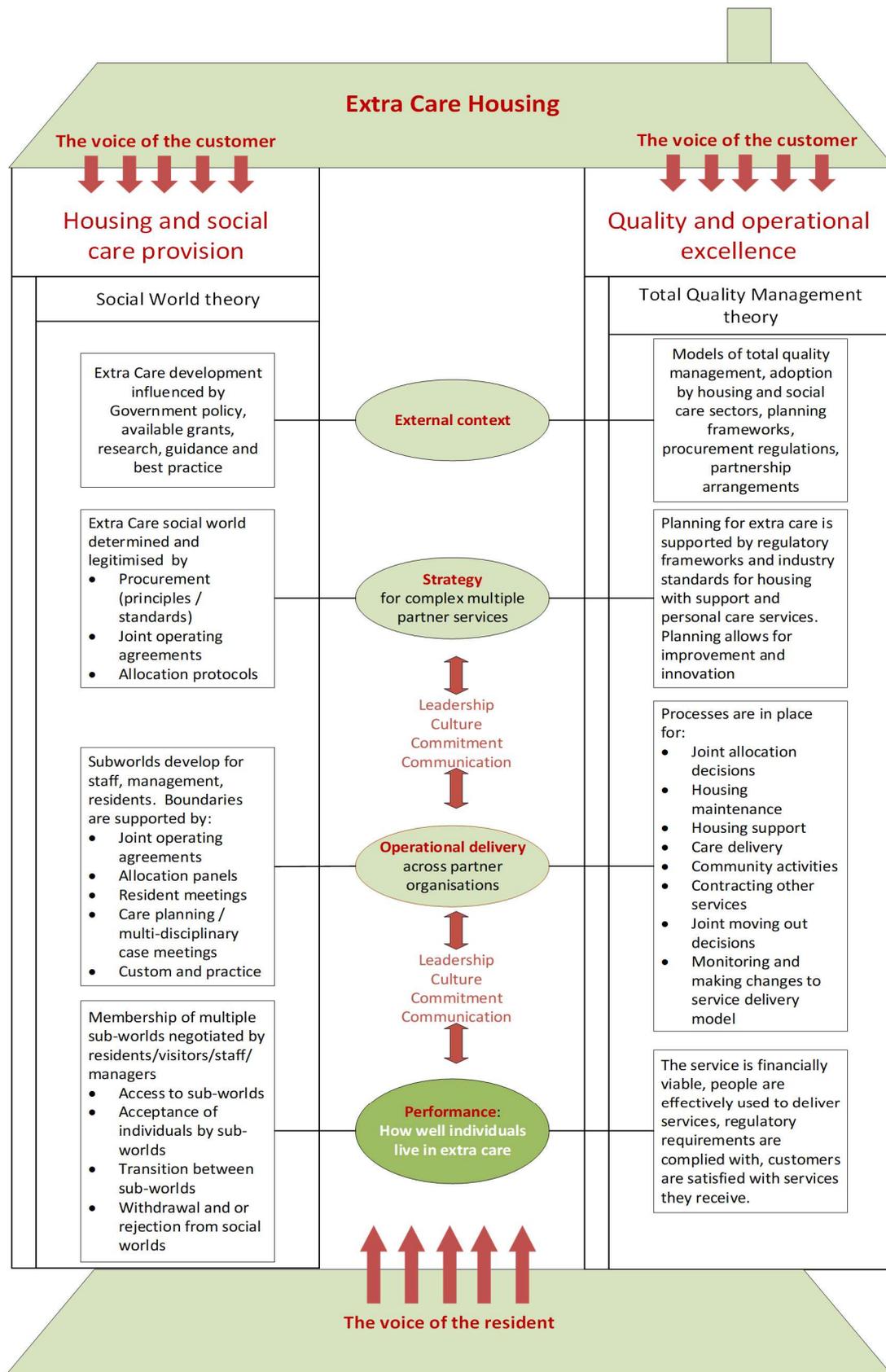


Figure 9-3: The development and delivery of extra care housing seen through the lenses of social worlds and quality management

The two perspectives can be caricatured; extra care delivery seen from a social worlds perspective focuses on working with the customer or resident to deliver a personalised and flexible service to ensure they are satisfied. Extra care delivery from a quality and operational excellence perspective focuses on consistent processes to ensure that customer needs are efficiently met, and customers are satisfied. A strategic approach for extra care partners to deliver quality and operational excellence in extra care will be reconsidered in the next section before returning to whether the two caricatures are diametrically opposed or whether they can converge in support of a holistic model of extra care.

9.2 DELIVERING EXCELLENCE WITHIN THE EXTRA CARE MODEL

The extra care model set out in Chapters 4 and 5 was developed with participants with many examples of what worked well and what could be improved. As discussed in Chapter 4, one of the biggest areas identified by participants was the need for a clear vision that described what extra care was; whether it was intended to support independent living or to provide more care and support than would be available in mainstream housing for older people such as sheltered housing. Staff and residents talked about variation in the way the service was delivered, depending principally on the leadership at the scheme but also influenced by which staff were supporting which residents, reflecting both the individual nature of people and the power dynamics within relationships. Staff and resident groups also expressed strong views about how the availability and nature of services provided by the commercial operators in the scheme, such as the caterers, affected their wellbeing.

There was appreciation that staff were often willing to go the extra mile to make sure residents received an excellent service, as well as discussion about the constraints imposed by financial resources available to support the service. The constraints described were at three different levels; at an external level due to allocation of public or organisational funds, at an operational level due to the viability of the different services within the scheme such as the catering and

wellbeing services; and at an individual level where personal budgets were sometimes deemed by social workers, staff and residents to be insufficient to support people to take part in activities within the extra care community. There was some understanding that constraints were driven by policy decisions underpinned by politics, local government funding, and by fair allocation of funding across different sectors. As one senior manager said:

We've got a huge big cloud hanging over the world of supported housing at the minute, it's around the future financial viability of having it [catering] in the service charge anyway. The whole service charge issue is under scrutiny, in what's the housing benefit/budget bill picking up and should catering be part of that? Is that not just a luxury that has gone too far that housing benefit pays for catering. Now that... if things go to Government's plan, will change around the whole issue of the future funding model for housing costs.

And as one social worker said:

I think the reality is ... particularly in terms of support... it's funding. It's funding. You know, that's what everybody says, well you know particularly in terms of services now, it's what it is being driven by, its funding. Certainly, the notion is now, we'll keep people at home as long as possible, you know, we'll try everything in our power to keep people at home, we exhaust all options around telecare. You know we'll put in equipment, we've put checking systems into people's homes, and only on that basis and it's all evidenced... until you've got that evidence we'll not admit to residential care. So, community is the only option until one's needs tip over that

Residents and their families, staff within the organisation, politicians, regulatory bodies and members of the local public all have an interest in extra care delivering financial and non-financial benefits that provide value for money. Non-financial outcomes may typically include having a good reputation, providing innovative services that meet local needs, and delivering clearly defined services in an ethical and transparent way that values both residents and staff.

Figure 9-4 provides an illustration of what excellence within an extra care service might look like for different stakeholder groups. The role of stakeholders is discussed further in the next section.

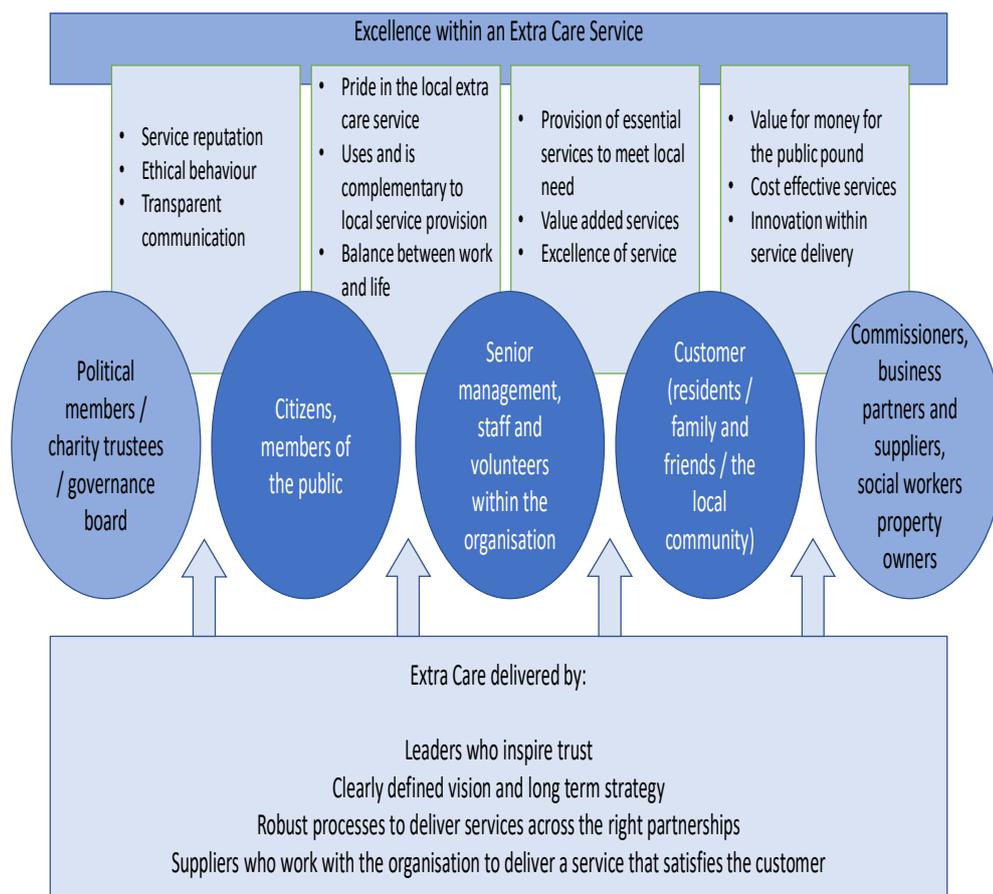


Figure 9-4: Providing an excellent extra care service to meet stakeholder expectations

Each extra care partnership should have its own blueprint of how to achieve their definition of excellence. It appeared from the research that there were no suitable arenas in which to discuss how excellence could be achieved. For example, one senior manager said:

What you are trying to vision and what is happening on the ground everywhere... is that the vision is either not understood or in reality there are restrictions and pressures on resources that mean that people can't do that. Or it doesn't even get understood, or the operational vision isn't joined up, and ... you lose it.

The 5D approach⁷² to organisational excellence set out in Chapter 8 could help managers to gain clarity of direction and join up their vision for extra care. Jointly agreeing where they want the extra service to be, where they currently

⁷² The 5D approach was described in Chapter 8 and sets out an approach to a quality management strategy using a set of questions that cover the direction, diagnosis, design, development and deployment of a quality strategy within an organisation.

are, what they need to achieve, how it can be achieved, and how they can ensure they have achieved it should give impetus for making the improvements suggested by participants in this research. Although they may not have used terminology including expressions such as 'vision' or 'direction', residents in the focus groups were well able to describe what they had believed to be the vision for extra care. One of the challenges for the organisation will be to introduce such an inclusive and empowering approach with tools which may appear very managerial. Its introduction is likely to be better realised if it is introduced in a way that makes explicit that the organisation wants to hear the resident voice and other stakeholders' voices as part of the process, equivalent to forming a social sub-world where key players are brought together with sufficient agency to identify and address common problems together. The original 5D approach has been adjusted in Figure 9-5 to include social worlds theory by asking at each stage who needs to be part of the social world group that comes together to make decisions and agree actions. In line with social worlds theory, each of the 5 questions will provide a focus for agreeing joint action for the group, and the support and tools required by the group the boundary objects that will help the individual group members negotiate agreed actions. For example, in the first question about 'direction' three factors would need to be considered to ensure the approach to operational excellence accounts for the social world of extra care. They are first, who needs to be part of the group to decide what the direction should be? Second, what support or tools (tangible boundary objects) need to be used to agree what the direction will be? The third factor is to decide what is the best way to bring the different members of the group together to make sure that they can all contribute effectively. The means of bringing the group together is a form of intangible boundary object used within social worlds to provide an arena for collective action.

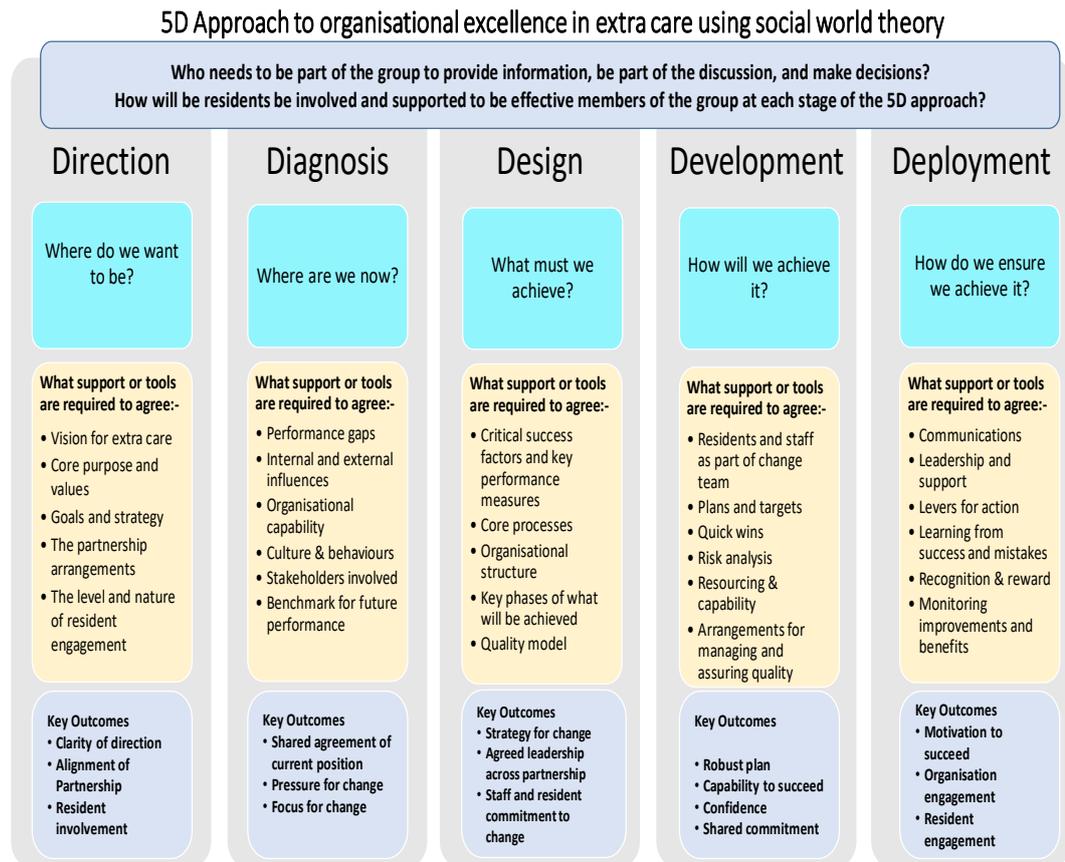


Figure 9-5: 5D Approach to operational excellence in extra care using social worlds theory
Adapted from Oakland Consulting (2017)

In looking at the direction of the extra care scheme, resident committee representatives might need to be included with the commissioning manager from the local authority, the senior manager from the housing provider, the senior manager from the care provider, and scheme managers. To help such a group agree a direction they may need to refer to or amend boundary objects including procurement / contractual documents, promotional literature, the allocation policy, the joint operating agreement and tenancy or lease agreements.

To ensure that members of the extra care social world are given a voice and agency in making decisions about the extra care scheme the membership of the group and the boundary objects used by the group may need to change over the course of exploring the 5Ds. For example, in the second and third questions about 'diagnosis' and 'design', there may be much greater emphasis on involving

more residents and staff members from the extra care social world and consideration of whether to use an external facilitator with sufficient expertise and independence to enable perspectives to be shared across boundaries.

Chapter 8 discussed how having a shared understanding and commitment to extra care is likely to be better achieved if the organisational structure avoids fragmentation and silos within service delivery by adopting processes that are orientated to the service rather than the organisation (Jaaskelainen & Laihonon, 2014). A shared service approach does not necessarily require a joint quality management system. If separate systems are used there would ideally be an alignment of organisations within the partnership and a shared understanding of how the different systems will be brought together to support residents. That will require a shared understanding of how to achieve the vision, ensure overall operational excellence and support continuous improvement within the extra care scheme for the benefit of residents who are living there.

9.3 A FRAMEWORK FOR ACTION

This section of the chapter sets out an argument for using a total quality management approach in extra care that includes the EFQM model and a performance scorecard. A TQM approach to operational excellence was described in Section 8.2. The EFQM model for excellence can provide the means to implement TQM and a balanced scorecard can evidence how critical measures of success are being achieved. Taken together, they can provide a comprehensive framework to support an organisation to achieve quality and operational excellence in service delivery and to meet the needs of customers. This section will reconsider each from a social worlds perspective, with an emphasis on maximising inclusion of people with dementia as an integral part of how the extra care model is implemented.

9.3.1 Total Quality Management

A critical review of TQM was undertaken in Section 8.2 which concluded that it is

an adaptable and relevant approach for not for profit and public sector sectors such as those providing the extra care housing in this research. Total quality management requires an organisation to be clear what it needs to do to achieve its mission or vision, to be clear what factors are critical to its success, and to integrate TQM activities into the business or organisation strategy (Yousof & Aspinwall, 2000; Wali, et al., 2003; Oakland, 2014). The 5D analysis described in Section 9.2 should have enabled extra care partners to agree on these. The benefit of using TQM at the design and development stages of the 5D analysis is that the core processes, resources and capability can be considered at a very early stage under the TQM constructs of planning, process, people and performance (the 4 Ps).

The participants' lived experiences described in this research highlighted the importance of the physical environment. The importance of space in supporting social interaction and group formation was a critical element uncovered by the application of social worlds theory to the findings. The complex interaction between organisational structure, social sub-worlds and the spatial design of the scheme indicates that any quality approach for extra care should include the design, the appropriation and the use of space. This leads to the proposal for a fifth 'P' to be included in the TQM model to accommodate 'place'.

Social worlds theory concentrates on individuals coming together as a group to take collective action, which resonates with a total quality management approach. Enabling the 'voice of the customer' to define and meet customer requirements is central to total quality management. It is helpful to consider Sampson and Spring's (2012b) broad approach to involving customers in service delivery organisations, and to explore how customer roles can move beyond having a voice. Two of the roles described by Sampson and Spring are especially pertinent to service quality planning; the customer as design engineer, where customers express views on how the service should be designed and delivered; and the customer as operations manager, where the customer directs the service provider as to how the process of service delivery should be conducted.

Sampson and Spring's roles may appear to be technical or business orientated because of the language used to describe them; the concept of customers as design engineers or operations managers may be alien to those working in housing and social care settings where concepts of service users, or residents, and co-production are more familiar. Seeing beyond the immediate language barrier, the extra care resident in the role of design engineer customer could be part of a social world focussed on co-producing the 'planning' and 'process' elements of TQM in extra care. In contrast the resident in the customer role of operations manager would be within the 'people' element of TQM, involved both in directing their own service provision and helping other residents as part of the peer support given to each other. The design engineer and operations manager roles rely on the resident being able to have reciprocal relationships within social worlds and social groups as described in detail in Chapter 7, with the associated challenges of those who are easily marginalised not being silent actors, but having a meaningful voice. Applying social worlds theory to a TQM approach shines a light on enabling residents to act together, and with other stakeholders, to co-design or co-produce the model of extra care.

Chapter 2 reported that although co-design and co-production are recognised ways of developing and delivering services increasingly being used in the UK and abroad, they can be challenging for those involved (Boyle, 2009; Pacey, 2010; Boviard & Loeffler, 2012; Scriven, 2012; Boviard, et al., 2015). The Care Act 2014 (Great Britain 2014) set out two influences in co-production which are relevant to the application of social worlds theory within TQM. The first is the influence of those individuals who use services, similar to Sampson and Spring's (2012b) role of the customers as operations manager. The second is the groups of people who get together to affect the development and delivery of services, like Sampson and Spring's role of customer as design engineer.

Given the significance of co-design and co-production within service quality planning this research proposes that the TQM model makes the voice of the resident (including residents living with dementia) an explicit rather than an

implicit element. A revised TQM model with both 'place' and 'resident voice' for use within an extra care setting is illustrated in Figure 9-6.

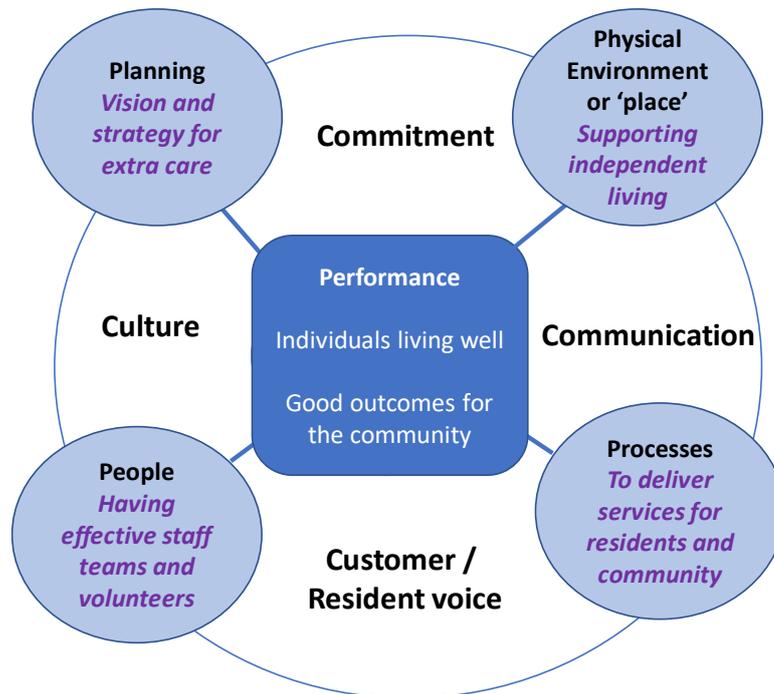


Figure 9-6: Total Quality Management for extra care housing

If an adapted TQM is to be used to overcome some of the issues identified in this research, including being clear about the vision for extra care, there should be a shared approach to TQM across the extra care partner organisations. Section 9.2 suggested that extra care partners do not necessarily require a shared quality management system so long as the partner organisations are aligned, with a shared understanding of how the different systems will be brought together in one approach to achieve the vision, ensure overall operational excellence, and support continuous improvement within the extra care scheme. That requires a shared culture that gives prominence to the customer voice. Using the 5D analysis to inform a TQM approach for extra care housing should help partner organisations to achieve that. Once a shared approach to TQM is achieved the next step is to develop and communicate a commitment to use either shared or separate quality framework to implement it. The EFQM Excellence Model will be considered as an implementation framework in the next section.

9.3.2 European Foundation for Quality Management Excellence Model

Section 8.3 provided a critical review of the EFQM as an implementation framework to manage quality. Section 8.3 reported that while there is limited take up of recognised quality performance frameworks in not for profit organisations (Moxham, 2010), research across a range of organisations varying in size, sector and location confirmed EFQM's generic applicability across a range of sectors (de Domartin, 2000), including where the criteria have been adapted to meet specific industry standards (George, et al., 2003; Vallejo, et al., 2006; Jacobs & Suckling, 2007; Bou-Llusar, et al., 2009; Lui & Ko, 2017). On that basis it was suggested by the researcher that it is an appropriate framework to consider for use by extra care housing.

EFQM is built around 9 criteria separated into 'enablers' that cover what an organisation does and how it does it, and 'results' which cover what an organisation achieves. Understanding the inter-relationship within and between the results and enablers within the EFQM is critical to being able to understand and improve performance (Rusjan, 2005). This research suggested that social worlds theory can be used to help better understand the inter-relationships between the enablers and results of performance and illustrates this with a suggested additional enabler of 'place'.

Section 9.1 put forward that managing strategy, operational delivery and performance could be viewed differently depending on whether they are seen from the perspective of social worlds theory or quality and operational excellence. It was suggested that the two views, person-centred and process-centred, might not be diametrically opposed, but that some convergence could be achieved. The style of leadership, which is the first enabler in the EFQM model, is likely to be a strong influence on how far partner organisations are person or process centric. The convergence of person and process-centred service delivery styles is illustrated in Figure 9-7 in which the voice of the resident is fundamental to achieve an efficient and effective service.



Figure 9-7: Convergence of service delivery styles within extra care

It is outside the scope of this research to provide a detailed analysis of leadership styles but it is important to note that in person-centred organisations there is a continual shift of focus from individual to team and back again. Team work, in which residents are included as part of the team, mattered a great deal to participants and has been the subject of substantial discussion. One resident reflected on being part of a team of people supporting his wife who had lived in extra care with advanced stages of dementia before dying:

George: And the care team met us here, including a lady who was her main social lady. They all met here, arranged everything, if you know what I mean, for four times daily. From that day the wife never went out... you know... leave the apartment

Staff member: She'd got her own little social circle, though hadn't she?

George: Oh yes, with the carers, yes.

People are encouraged to pool their strengths and to compensate for one another's weaknesses in person-centred organisations. George also said that he chose their apartment because it was located close to the staff room. He wanted

to be near to staff so that they could be company for him and could support him to care for his wife when he and his wife could no longer get outside because of his wife's increased frailty. He said:

I think I told you why I picked where I live... I picked it because it is directly over here, straight across the corridors was the carers ... that's the main reason I have it, plus the view.

In a person-centred organisation inter-departmental rivalry is forcefully discouraged, instead the organisation sees itself as a learning organisation where people believe that working effectively means knowing how to solve problems and where to go to find the information they need. In consequence people learn to take informed risks with senior leaders serving in a facilitative role, rather than a dictatorial role. It is reported that the adoption of these sort of person-centred strategies lead to a commitment to quality (Ishikawa, 1986: Plas & Lewis, 2001).

In a process-centred organisation processes exist across organisational boundaries, and require the use of teams, groups and individuals with various skills drawn from different function areas. To some extent, this is what participants were looking for when they described the constraints imposed by job role boundaries around which staff could support residents. As one participant Sarah said:

The thing is they make up silly rules as they go along... ask them to take you somewhere in the wheelchair and they're [the housing staff] not allowed to push wheelchairs, they haven't done the exam.

A process-centred team doesn't see the individual tasks in isolation but sees the entire collection of tasks that contribute to a desired outcome (Hammer, 1997). One of the staff members illustrated this when describing how they helped residents to attend activities.

They'd [care staff] remind them, we'd also remind them, because I do wellbeing checks in the morning, and I'd say, "don't forget there's this coming on". And even though I have given them that information I would also then ask the team or the whole team, if we are free and available to do so, obviously, tell the people that had forgotten that I had told them in the morning, to come to the event.

In this instance the task of telling someone about an event had been done, but the staff member recognised that that on its own was not enough to help someone with dementia to take part, the process of helping someone to take part needed repeating with varied attempts to encourage the person to attend.

Without convergence of person and process-centric service delivery styles the service may not deliver its aspiration to support individuals to live well. In focusing on personalised services, if the organisation becomes too person centric the required flexibility is likely to result in great variability of service provision leading to an inefficient and perhaps unaffordable or undeliverable service. If the focus is too process-centred it may lead to efficiencies, but in doing so may lose some effectiveness if the processes aren't flexible enough to meet the needs of different residents living in extra care. Participants in the research criticised the service for both these. In a reference to the lack of flexibility because staff are too driven by process and rules within their own organisation rather than working together across organisations, one manager commented:

The battle is, the workers who work here say 'I'm not available'. Which, you know, we know they are available, because they are sat there doing nothing. But they very often, just knock on the [care provider manager's] door and say, "can you send somebody up to get such and such a person, who's just rung to say they want to come down for lunch". And the [care provider] manager will say 'well why can't you assist? Because primarily it should be you who provide it and ring us if you can't'. So, there has been that bit of battle.....

On the other hand, when talking about the difficulties of achieving a flexible and person-centred service another manager said:

The flexibility around non-planned support, particularly in the day, is more difficult because we do have carers who are supporting throughout the day from 6 o'clock in the morning up to lunch time, 1, 2 o'clock. Then they have a bit of a respite time period, where there is not as many people needing support. And if we get an emergency during that period they need to respond. But to get the fluctuating "I might need you at this time... or I might need you at that..." during that period is very difficult, and very difficult to actually provide.

The adoption of process and person-centred service delivery styles is not static but can fluctuate depending on circumstances. Achieving a synergy between the

two styles would require the ‘leadership’ and ‘resources’ enablers within the EFQM model to be focussed on ensuring ‘processes’ deliver person-centred results to the ‘customer’ or ‘resident’.

Section 8.3 reported that the EFQM model is described as an effective self-assessment tool of the enablers and results, which can be used to identify the gap in required performance (George, et al., 2003; Li and Yang 2003; Rusjan 2005; Vallejo, et al 2006; Oakland 2014). The model is intended to remain fixed at its highest level of the 9 criteria as set out in Figure 9-8, but allows organisations to define criteria that are helpful to them at lower levels (Seghezzi, 2001). Others have disagreed with the fixed criterion approach saying that fixed nature of the criterion can make it challenging to apply the model in specific sectors, and some such as Vallejo et al (2006) have proposed adapted models. For the EFQM model to be relevant to participants in this extra care research it would be helpful for it to include and reflect some of the support and performance issues raised by participants in Chapters 4, 5 and 6 which reflected their experiences of living and working in extra care.

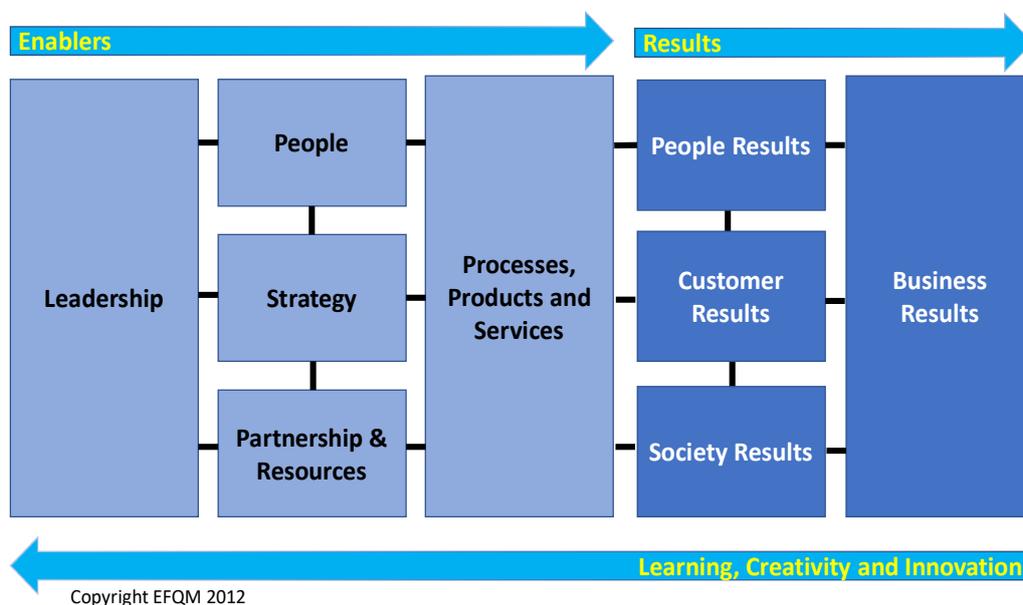


Figure 9-8: EFQM Excellence Model

Three adaptations for use of the EFQM model in extra care are proposed as a result of the findings in this research; first to include ‘place’ in the high level

enablers, second to re-order the high level enablers to give greater prominence to the role of planning a clear vision and strategy in driving the other enablers, and third to amend the terminology to make it more relevant to extra care housing. Amending the EFQM model should help to bring together the different discourses in extra care, providing a boundary tool to help negotiate and give agency to different members of the social worlds in extra care.

Proposal 1: Adapt the EFQM model to accommodate 'place' in the high level criterion

The EFQM model can be used to assess both person and process-centric approaches to service design and delivery. Application of social worlds theory to the EFQM model helps to see which perspectives are being favoured where. Bou-Llusar et al (2009) identified the 'process' and 'resource' enablers of EFQM as being the technical dimensions of TQM and the 'leadership' and 'people' enablers as the social dimensions of TQM, but application of social worlds theory suggests that the relationship may not be that straightforward. The more complex relationships can be illustrated by considering the importance of 'place', an element that was identified as missing from the current TQM approach.

The physical environment or 'place' within the EFQM model (2013) is located within the 'partnership and resources' enabler, whose subcriteria state that:

...buildings, equipment, materials and natural resources are managed in a sustainable way. (EFQM, 2013, p. 10)

This would normally be interpreted from a facilities or estates management perspective. It is unlikely that there would be an explicit focus on the importance of spatial design in enabling people to navigate easily around the building, or on using the spatial elements of the building to support social activities or social sub-worlds as described in Chapter 7 of this research thesis. Chapter 7 argued that within an extra care service model, 'place' or the physical environment was a complex interaction between organisational structure, social sub-worlds and spatial design.

One could also assess the management of the building in the EFQM model through its 'people' criterion, which has three relevant sub-criterion including;

- 'people's knowledge and abilities are developed
- people are aligned, involved and empowered
- people are rewarded, recognised and cared for' (EFQM, 2013, p. 10)

The 'people' enabler referred to in EFQM is usually the workforce within the organisational structure. Extra care residents could be viewed as the 'people' in the EFQM model as they support each other as volunteers to belong and take part in the extra care community, and they take part in directing their own person-centred service.

Taking that a step further, one of the desirable EFQM customer results could be achieving harmony within and between the extra care social worlds. To measure the level of harmony achieved the 'people' criterion may need to assess, for example, how far staff, volunteers and residents are empowered to have agency within the network of social sub-worlds; whether there are skilled people helping residents with less agency to join social groups; whether there are people skilled in managing conflict within and between social groups; and whether a resident is enabled to direct or co-ordinate their own person-centred services.

As the enablers are currently described in EFQM the 'partnership and resources' and 'people' enablers do not appear to fully address the complex interaction between organisational structure, resident focussed social subworlds, and spatial design. This research proposes that it would be better achieved if 'place' is included as a new explicit enabling criterion in an adapted EFQM model.

Proposal 2: Adaptation of the EFQM model's high level enablers

The EFQM model sets out the enablers so that 'strategy' is central to the operating model. Strategy is linked to people, to partnership and resources, and

to processes. If an additional enabling criterion is added to assess the contribution of place as suggested in proposal 1 above, then 'strategy' would be one of a list of four enablers, and no longer central to the illustrated conceptual model. Participants in this research repeatedly said that one of the most important issues was to have a clear vision for the extra care, which would then lead to a strategy. This research is not suggesting that the EFQM enablers are linear, but the addition of 'place' would be an opportunity to re-order the enablers so that planning a clear vision and strategy is at the top of the diagram to recognise its primacy in driving the other enablers of the business. An adapted extra care EFQM model, with a 'place' enabler and with 'vision and strategy' at the top, is illustrated in Figure 9-9.

In the adapted model the 'leadership' enabler has additional detail to make it explicit that part of the leadership role at the beginning of the TQM and EFQM process is to agree with partners their approach to quality, culture and strategy. The leadership approach will depend upon how far the partner organisations agree to have a joint service model as part of the service vision and strategy as described in more detail in Section 8.5.2.

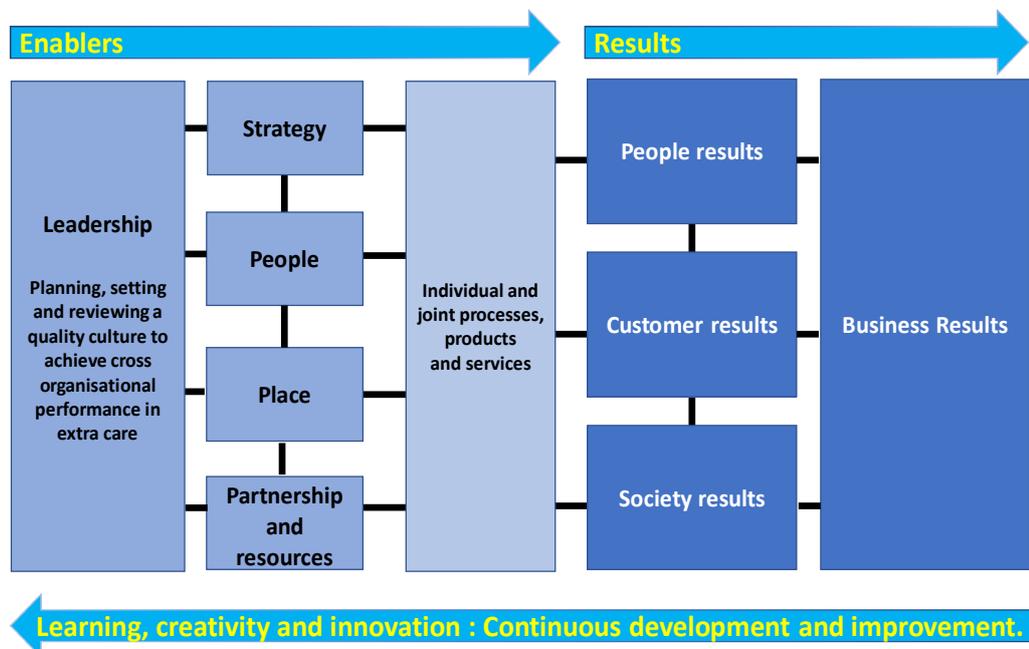


Figure 9-9: Extra care quality management model 1
(Adapted from EFQM 2012)

The 'processes, products and services' enabler has also been adapted to reflect that the processes and services may be either the responsibility of individual organisations or there may be joint responsibility through the partnership arrangements in place within the extra care scheme.

Proposal 3: Amend the terminology to make it more relevant to extra care housing

Chapter 8 suggested that quality management across extra care organisations is not yet fully mature, that there were few formal quality frameworks and tools used, and that there was not yet a clearly understood shared language to describe quality management. That suggests that if an EFQM model were to be successfully adopted within extra care it would be helpful to use terminology that is familiar to stakeholders likely to be involved in developing and using the model. Those stakeholders will include residents who are representing the customer voice within the quality approach. With that in mind the third proposed adaptation of the EFQM model for extra care is to use terminology that resonates more with the findings of this extra care research. Changes include rewording some of the enabler and result criterion.

As suggested earlier the 'strategy' enabler should make clear that it includes planning a clear vision as well as planning the strategy. It is suggested that the results enablers are also changed. The 'society' result could be changed to 'supplier results'. The change from 'society' to 'supplier' reflects the importance participants placed on suppliers such as the social workers, district nurses and caterers being an integral part of the processes supporting the wellbeing of residents and a sustainable extra care community. The business results have been separated into business and regulatory results to be explicit about the minimum CQC and HCA regulatory standards that must be complied with as well as the broader business results that the partnerships must deliver. The revised terminology is summarised below.

	<i>Becomes</i>	
Strategy	→	Planning: a clear vision and strategy
People results	→	Employee and volunteer results
Customer results	→	Resident and community results
Society results	→	Supplier results
Business results	→	Business and regulatory results

Figure 9-10 illustrates the proposed revisions within the EFQM model for extra care. The revised EFQM model may still be problematic for it to be used collaboratively with all stakeholders, including residents and staff because the terminology is still largely cast in business terms. Further changes could make it more relevant to the discourse of care and support relationships and outcomes but may then alienate those who are more familiar with the managerial discourse. For example, 'results' could be renamed 'outcomes' and 'business results' could be changed to 'service outcomes'. The extent to which the terminology of the two different discourses could be merged or switched within an EFQM model for extra care, and the impact that has on relationships of power within the social worlds of extra care, warrants further research.

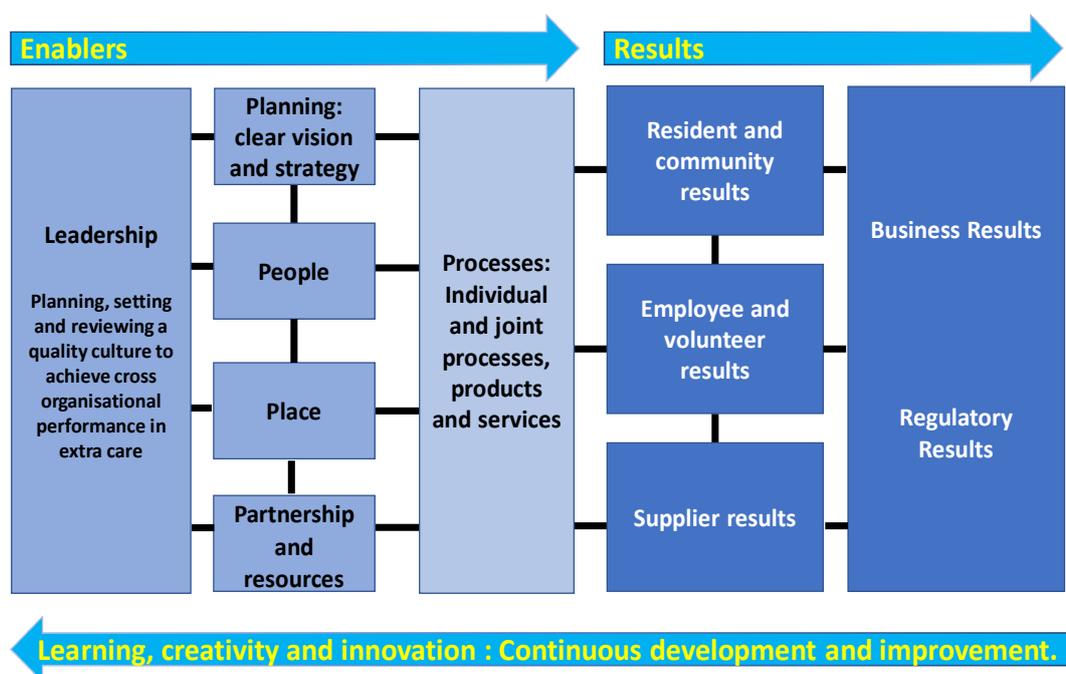


Figure 9-10: Extra care quality management model 2
(Adapted from EFQM 2012)

The four components in the extra care model were each made up of individual elements⁷³ described by research participants as important to enabling people with dementia to live well in extra care. It is therefore imperative that these individual elements are included in a suitable EFQM model for extra care. As reported at the beginning of this chapter, EFQM is an implementation framework for TQM with its four primary constructs of planning, people, processes, and performance supported by secondary constructs (Mosadeghrad, 2015). The supporting constructs in TQM are similar to the individual elements that support the 4 components in the extra care model. Supporting or secondary constructs are helpful in considering how the four components of the extra care model fit with the EFQM enablers and are mapped in Appendix 16.

In critically reviewing the mapped components in Appendix 16 to gauge whether EFQM is an appropriate tool for assessing the quality of extra care there are two items of note. The first was that some of the individual elements of the extra care model support more than one of the EFQM enablers. For example, having a positive approach to managing risk and safeguarding issues will influence the way that the processes are written; will influence the extent to which leaders are flexible in responding to situations involving risk; and will influence what should be included in the development of peoples' knowledge and skills. In the research, the response to residents who demonstrated behaviour that challenged either the organisation or other residents was affected by the policies of the extra care scheme, the leadership and guidance provided by manager, and the attitudes of staff and other residents. All three affected the wellbeing of the resident whose behaviour was challenging and led to the individual resident and other residents being more or less satisfied. Resident wellbeing and satisfaction would be measured within the results area of the EFQM model.

The second item of note was that all the extra care model elements could be mapped against at least one of the EFQM enablers. On that basis, the EFQM

⁷³ The individual elements within each component of the extra care model are described in detail in Chapters 4 and 5.

model should provide an appropriate tool for extra care providers to assess how well their service model supports their desired service model. The results section of EFQM will need to be equally able to evaluate how good performance is, identify where there are gaps between actual and desired outcomes or results, in turn leading to a review of what impact that is likely to have on people with dementia living well in extra care. The use of specific tools to measure performance is discussed further in the next section.

The EFQM model has a structured scoring system to support organisational self-assessment and benchmarking. The first step to validate the suggested amendments to the EFQM model for an extra care setting would be to use the revised model with each of the elements of the extra care model mapped against it. If the model is to be used to benchmark quality within and between extra care organisations the model should be tested and validated with revised scorings allocated to each of the high-level criterion within the model. This would need to include an allocated score to the proposed additional enabler of 'place'. Due to the time and resource constraints of this research it was not within its scope to validate the proposed revisions for an extra care EFQM model, but this could usefully be included in a future research study.

Although there is general recognition that EFQM is a helpful model researchers have also warned that it has some limitations, and that some organisations face difficulties when trying to move beyond assessing performance to identify strengths and prioritise improvements within action plans (Kanji, 2001; Li & Yang, 2003; Rusjan, 2005; Moxham, 2010). The 5D questions described as useful to developing an approach to TQM in the previous section, could be enhanced if used in conjunction with the EFQM model. The EFQM self-assessment results would inform the 'diagnosis' of where the extra care partnerships currently believe they are, both individually and as partner organisations. Diagnosis should be part of a continuous learning process for the extra care organisations leading to improvements. An improvement plan would be jointly 'designed' around what has to be achieved, how it will then be

‘developed’ through the enablers, and how they will ensure it is achieved through the ‘deployment’ of resources.

Research indicates that EFQM is enhanced when it is used with other tools, such as a balanced scorecard⁷⁴ (Jacobs & Suckling, 2007; Bon-Llusal, et al., 2009), which can help understand and evidence the inter-relationships between the enablers and the results. The EFQM self-assessment would provide an internal benchmark against which future performance could be compared.

9.3.3. Performance measurement through scorecards

Section 8.4 set out the importance of linking strategy to performance through a logical framework which enables an organisation to describe its strategy through focused, strategic objectives and measures across a range of perspectives (Cross & Lynch, 1988; Keegan, et al., 1989; Kaplan & Norton, 1992; Kloot & Martin, 2000; Ittner & Larcker, 2003; Moxham, 2010; and Oakland, 2014). A critical review of the development of performance measurement systems was provided in Section 8.4 (see also Appendix 15), leading to the suggestion by the researcher that two tools might be considered appropriate for extra care; the balanced scorecard (Kaplan & Norton, 1992) and the Public Sector Scorecard (Mouillin, 2017).

There are some significant similarities and differences between the Balanced Scorecard and the Public Sector Scorecard. Four perspectives are core to both tools, these being financial, customer or service user and stakeholder, internal or service delivery, and innovation and learning perspectives. The Public Sector Scorecard has an additional element for key performance outcomes at the head of the scorecard to ‘ensure that the main aims of public and third sector organisations – and the public and social value they create- are prominent’ (Mouillin, 2017, p. 444). Mouillon asserts that poor performance in the public sector is often the result of limited partnership working, poorly trained or

⁷⁴ A balanced scorecard sets out key performance results in four main areas; financial results, customer results, people results and society results.

motivated staff and inadequate resources or ineffective leadership rather than the result of processes within an organisation, thus justifying the addition of a capability perspective to the scorecard. One could argue that the Public Sector capability element is implicit within the ‘internal business perspective’ in the Balanced Scorecard, and that either scorecard can be amended to reflect priorities that are important to individual organisations adopted the scorecard as a tool. For ease of reference Figure 9-11 compares the seven perspectives from the Public Sector Scorecard (PSS) with the four in the Balanced Scorecard.

The Balanced Scorecard Perspectives

Customer perspective:
 How do residents and customers see us?
 Have we got the right balance between independent living and extra care?
 Do residents have a sense of belonging and wellbeing?

Financial perspective:
 How do we look to our trustees / political members / regulatory bodies?

Internal business perspective:
 What must we excel at to meet regulatory requirements?
 What must we excel at to deliver person-centred extra care services with social cohesion and a vibrant community life?

Innovation and learning perspective:
 Can we continue to improve and create value?

Source: Adapted from Kaplan and Norton (1992)

The Public Sector Scorecard Outcomes:

Strategic perspective:
 Key performance outcomes

Service user / stakeholder perspective:
 How do residents and customers see us?
 Have we got the right balance between independent living and extra care?
 Do residents have a sense of belonging and wellbeing?

Financial perspective:
 How do we look to our trustees / political members / regulatory bodies?

The Public Sector Scorecard Processes:

Service delivery perspective:
 What must we excel at to meet regulatory requirements?
 What must we excel at to deliver person-centred extra care services with social cohesion and a vibrant community life?

The Public Sector Scorecard Capabilities:

Innovation and learning perspective: Can we continue to improve and create value?	Leadership
	People, partnerships and resources

Source: Adapted from Mouillon(2017)

Figure 9-11: Similarities and differences between the Balanced Scorecard and the Public Sector Scorecard

One might argue that both scorecards provide a tool that will inform the EFQM assessment. Both ask questions about what will enable the required performance to be delivered, and in both scorecards the service user or

customer, financial, internal service or business perspectives provide evidence for the EFQM results section. The Public-Sector scorecard leans more towards the care and support discourse than the Balanced Scorecard, using the terms 'service' and 'outcomes' rather than 'business'. In both scorecards the innovation and learning perspective provides the feedback loop between results and enablers.

It is the measurement and evaluation of performance that underpins an effective framework for quality and operational excellence in extra care, providing evidence of whether critical measures of success are being achieved. Whichever performance scorecard tool is selected for extra care there will be a decision about whether a shared or separate scorecards are used by the partner organisations, depending on the partnership's strategic choice for joint or separate quality systems. A scorecard is not intended to include the wealth of analytical information needed to evidence the full range of regulatory and business results captured in the EFQM model. Rather it is intended to communicate strategic objectives throughout the organisation and measure the cause and effect of those strategies on results. If implemented appropriately the scorecard should generate only a small number of activities that need to be controlled (Vukomanovic & Radujkovic, 2013). It should capture the elements that are important to the range of stakeholders each with their own perspective and expectations for the extra care service, enabling the heartbeat of the organisation to be scrutinised. As set out at the beginning of this chapter there could be a tension between having a strategic management approach to implementing a quality framework and performance measurement system and having an approach that is meaningful to those who live and work in extra care. One way of making it meaningful for residents and staff is to jointly agree which perspectives and measures are most important to them, and which are most likely to reflect and influence how well they live and are supported in extra care.

It is important that organisations adopt a model that they are comfortable with. Mouillon (2017) and others such as Drevetton (2013) and Perramon et al (2016)

have reported that the process of developing the scorecard is as valuable as the evaluation of measures that results from it. Dreveton (2013) identified four steps to implement a balanced scorecard in public sectors. They include; getting an inventory of existing performance indicators; gathering data on what the scorecard needs to deliver based on the organisation's strategic vision and objectives; engaging and communicating with all staff; and then implementing the scorecard. Dreveton's four steps are in keeping with social worlds theory in which people come together in a common arena to focus on issues and actions. In Dreveton's research one of the participants commented:

At the beginning I was very surprised by the composition of the working group but, in the end, the presence of directors, managers and [other staff] was a positive element in the enrichment of our debates. (Dreveton, 2013, p. 134).

The model of stakeholder involvement used in this research, which included the different perspectives of residents, staff, managers, social workers, commissioners and senior managers, could helpfully be adopted as a foundation for a social sub-world who come together to develop a scorecard for extra care. The diverse range of stakeholders set out in Figure 9-4 extended beyond the participants of this research to include trustees, business partners, suppliers, and wider citizens or society. Social worlds theory suggests that as 'sub-world' members come together, in this case each with a vested interest in measuring and evaluating the effectiveness of the extra care service, a natural division of power and responsibility might occur. Group dynamics would need to be managed to enable the less powerful members of the group to have voice and agency within the process, which might be helped by boundary objects like a memorandum of understanding for the group. The establishment and development of such groups is in the spirit of the EFQM and other excellence models. Conti (2002) says that leadership and people management should be aimed at encouraging stakeholder contributions, helping people to grow and bring forward the results of their investment for the benefit of the stakeholder and the company.

Building on the critical analysis undertaken in Section 8.4 this section has considered two approaches to measuring and evaluating extra care performance through scorecards; the Balanced Scorecard and the Public Sector Scorecard. Both approaches give space for key stakeholders to collaborate and share information about performance which should lead to continuous learning and improvement. Cultural shifts and processes specific to each individual scheme may need to take place to enable residents, staff, and scheme managers to collaborate effectively. This research does not endorse one performance measurement approach over the other but suggests that using social worlds theory would add value to the process. Social world theory would help in considering who should be involved, what cultural changes may be required to ensure residents have agency within the group, and what boundary objects would help residents, staff and managers contribute effectively to decide which indicators should be measured. This subject could usefully be explored in future research.

9.4 FROM THE SPECIFIC TO THE GENERAL: A MODEL FOR OPERATIONAL EXCELLENCE WITHIN EXTRA CARE HOUSING

The research findings in Chapters 4 and 5, and discussion in Chapter 6 revealed that individuals with dementia can and do live well in extra care housing, but there may be some exceptions. The model of extra care became a core concept of this grounded theory about people with dementia living well. By discussing matters that were important to those living and working in extra care the researcher and participants agreed a model of extra care housing that should support individuals to live well, including those with dementia. Insights from social worlds theory helped further understand how people with dementia become members of the social worlds within extra care, and how that is influenced by the model in operation. Meeting resident requirements through a well operated and harmonious extra care model was fundamental to supporting individuals with dementia to live well. A total quality management approach was used to consider how extra care partners could together develop

operational excellence. Social worlds theory was applied to the framework for total quality management to explore how different stakeholders could be given agency and voice in determining how best extra care should operate. A small number of service managers and providers in the extra care community outside the immediate case study organisations were included in the research to provide insight to see whether the total quality management approach to implementing extra care could be generalised to other settings.

The substantive theory that has developed from this grounded research is that individuals with dementia can live well in extra care, helped by having a clear model run by partnership organisations who have a shared approach to managing quality and operational excellence from a social worlds perspective to achieve a well-developed community, with agreed processes in place to support effective teams to deliver person-centred care and support. Figure 9-12 sets out the model of extra care that emerged from the substantive theory.

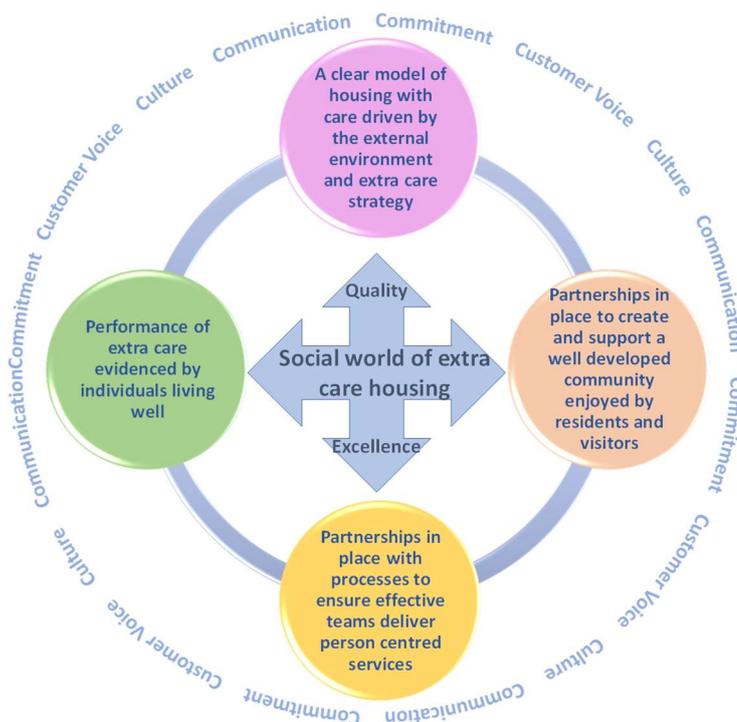


Figure 9-12: Model of extra care run by organisations who operate a total quality approach to excellence considered from a social worlds perspective

It has been outside the scope of this research to test how far the theory can be adopted within the extra care sector, or whether the theory can be applied in

generic settings other than extra care housing. That would involve four areas of testing:

First, whether having a clear model of service delivery run by extra care organisations who operate a shared total quality approach to operational excellence which encompasses a social worlds perspective can effectively support individuals with dementia.

Second, whether individuals with dementia can be effectively supported in other settings helped by having a clear model of service delivery run by organisations who operate a total quality approach to operational excellence which encompasses a social worlds perspective.

Third, whether the adapted EFQM model is valid in other settings, or whether new concepts emerge that are relevant when it is used in different settings or with client groups other than people with dementia.

Fourth, whether the process of developing a performance scorecard with key stakeholders helps communicate the strategic objectives of the service and translates those objectives into results required for each stakeholder group.

The four areas of testing outlined above could usefully form the basis of a future research project.

9.5 CONCLUSION TO A MODEL FOR EXTRA CARE DEVELOPMENT

This chapter reviewed the model of extra care that had been developed with participants in the extra care research. The chapter considered three issues in relation to how the model could be delivered. First, staff can help individuals living with dementia to be part of the extra care community and to live as independently as possible but there are barriers to staff support being put in place including the economic climate, resource constraints, style of leadership and culture. Second, effective use of space by individuals and groups both with and without dementia can be helped by having a well-designed environment and

by having staff support. However, the use of space is often missing from current approaches to service excellence. Third, the nature of partnerships affects how quality frameworks are adopted, which may impact on whether residents receive joined up services.

The chapter introduced a new approach to achieving excellence in extra care provision by integrating social worlds theory with a framework for quality management. Building on the critical review of Total Quality Management set out in Section 8.2, this chapter explored a TQM approach to extra care service delivery from a social worlds perspective and proposed that the approach could be enhanced by the inclusion of an additional construct. The four existing constructs are planning, people, processes and performance, the 4P's. This research proposes an additional 'P' to accommodate the dimension of space or 'place' which is instrumental to how individuals and groups function within extra care, and is central to creating or removing barriers to people living with dementia being able to live well. The TQM approach is underpinned by 3 'c's of communication, culture and commitment and a fourth 'c' of customer or resident voice was proposed to make explicit the central role of residents in both co-designing and co-producing the extra care service to meet their needs. The fourth 'c' for the resident or customer voice raises questions about issues of differential agency and power within the care and support and managerial discourses, and the cultural shifts that may need to take place to enable residents to co-design extra care.

People with dementia living well was used as a reference point for the quality and operational excellence framework, evidenced by resident outcomes. The EFQM model was recommended to implement a quality approach within extra care. Consideration was given to the extent to which extra care provision is person or process-centric. The research concluded that the two are not diametrically opposed and that some convergence could provide the optimal service that participants were seeking; a consistent but flexible service. The application of social worlds theory helped to identify and understand the

complex interactions between the different enablers in the EFQM model. For example, the 'partnerships and resources' and 'people' enablers are linked; reflected by the frustrations expressed by some participants that the lack of funding impacted on their ability to deliver a personalised service that met the social and emotional needs of residents with dementia.

Expanding on the critical review of the EFQM model in Section 8.3 this chapter proposed that three adaptations to EFQM are made; first, to include 'place' as an enabler of performance with a focus on the design, appropriation and use of space to support social interaction, group formation and provide a more enabling environment for people living with dementia. Second to revise the high-level enablers in the model to emphasise that the 'leadership' enabler has additional detail around partners agreeing their approach to quality, culture and strategy, and reflecting that processes may be either the responsibility of separate organisations or shared jointly across organisations. Consideration was given to how to enable the resident or customer to co-design or co-produce both the overall extra care model and their individual services within it. Lastly, it was proposed that the terminology used in the model be amended so that it is easily understood by the range of stakeholders who are likely to be involved in developing and using the EFQM model.

The critical review of performance measurement tools in Section 8.4 suggested that performance scorecards could be appropriate for extra care organisations. This chapter further compared two versions of a performance scorecard to consider how they might help measure and evaluate how far extra care meets the requirements of its stakeholders. The Public Sector Scorecard was designed for use in public and not-for-profit sectors such as extra care, and focused on the capability, processes and outcomes involved in meeting stakeholder requirements. The Balanced Scorecard focussed on the outcomes and has been evidenced to work well with the EFQM model, which covers capability and processes. It was suggested that the process of developing a performance scorecard within an organisation was advantageous and that organisations

should be comfortable with their choice of tool, using the implementation process to get the right people involved in shaping the service. Application of social worlds theory should help in considering who the right people to be included are, that they have a voice and can contribute their skill and expertise in agreeing what should be measured and for what purpose.

To summarise, this chapter has set out an approach to total quality management that uses EFQM as a framework to evaluate the inter-relationship between the enablers and results of performance, and then suggests using a performance scorecard to communicate the strategic objectives throughout the organisation and to analyse and evaluate how far it is achieving them. Given the relative youth of the extra care sector it was suggested that working through the 5D questions to agree where they want to be, where they are now, what they must achieve, how it will be achieved, and how they can ensure they achieve it would be helpful. In answering the questions it will be crucial to maintain a focus on how any proposed actions will help or hinder someone living with dementia to live as well as possible. The answers from the 5D questions will provide information needed for the EFQM and performance scorecards. Critical to the approach is to make sure that the experiences and views of those living and working in extra care shape how extra care is developed and delivered. That will be helped if the quality and operational excellence approach is seen through the lens of social worlds theory.

The chapter concluded by suggesting the findings of the research could be applied more generally in other settings, but it would require further testing, and could usefully form the basis of future research.

10. CHAPTER TEN: CONCLUSIONS

10.1 INTRODUCTION

In this thesis the researcher has used a grounded theory approach to explore the possibilities and practicalities of people with dementia living in extra care. The research has drawn on the experiences of those living and working in extra care to identify common issues, themes and areas for improvement. Most of the participants described how they enjoyed living and working in extra care, and there was much emphasis on the benefit of being a community and the value of extra care as an alternative to living alone in the community or living in residential care. Participants were realistic about the economic and political constraints that were in operation. Issues both big and small were identified by participants, who were insightful into why they had occurred or how potentially they could be prevented. A model of extra care which could support people living with dementia emerged from focus groups and interviews. The model addressed issues raised by participants including the importance of having a vision when planning and delivering the extra care service; managing an individual's rights, risks and safety through person-centred approaches to support; recognising and developing the extra care community; being an effective team with the right people; and supporting an effective team with the right guidance on ways of working and support.

Although extra care was described by participants as a valued and appropriate model of housing with care for people living both with and without dementia, some limitations to the model were noted. Participants said that it is important that individuals with dementia should still be able to navigate their way around a new environment, establish new routines, and make relationships with other people when they first move into extra care, although they might need support to do that. The complex inter-relationship between individuals and the use of space to support social interactions was dominant in conversations about the challenges and limitations of extra care for people with dementia. The role of

staff in supporting people with dementia was another critical factor in how well people could live in extra care. Participants also said that even when extra care offers a supportive social environment, the barriers of the built environment may be too difficult for that person to manage safely and with dignity. It was suggested by participants that if safety and dignity were compromised it may be appropriate for the person to move to a less disabling environment like a care home.

The research has demonstrated that the extra care model could be better interpreted by using social worlds theory to understand how someone with dementia can be either helped or hindered in living well in a community setting such as extra care. The dynamics resulting from the interaction of social worlds with each other, and from individuals who are welcomed into or excluded from social sub-worlds or social groups in extra care, can greatly affect the wellbeing of people living with dementia. The research has explored how taking an organisational approach that focuses on quality and operational excellence can help in planning the right model and setting out a clear vision for extra care, which in turn will help identify whether the best team of people are delivering individual and community care to the required standard of performance to meet the needs of residents in extra care.

Each extra care scheme is unique, and the research proposed that the way extra care partners approach planning, delivery and evaluation of extra care will need to be tailored to their own circumstances if it is to succeed. The process of tailoring the quality frameworks and using the suggested tools will, of itself, be of value to extra care organisations; helping them to set and communicate their extra care strategy throughout the organisation. The voice of the resident and their carers or family is crucial to ensure that a viable extra care scheme is designed, delivered and operated to meet their needs as well as the needs of other stakeholders. The model of extra care developed within this research emphasises the importance of understanding how social groups and social worlds operate and impact on the lives of individuals living and working in extra

care. Together with the suggested framework to implement it and assure its quality the model should provide tools that are relevant to residents and others and can be used to shape how extra care is taken forward.

The rest of this chapter will revisit the research question that was asked and will summarise the contribution this research has made to knowledge about extra care. It will go on to reflect on the strengths and limitations of the research, set out implications for policy and practice in the field of extra care, and highlight possible directions for future research.

10.2 RESEARCH QUESTION REVISITED

The research set out to explore the appropriateness of extra care housing provision for people with dementia including the opportunities it offers, the barriers it creates, and whether there is a model of extra care which can be inclusive of people with dementia. It focussed on three main lines of enquiry; what is extra care, and what did it mean to participants; whether the model of extra care in the case study sites was appropriate for people with dementia; and whether there were modifications to the extra care model participants could suggest that might make it more appropriate for individuals with dementia and their carers.

Using the grounded theory approach to ask questions about what extra care is, informed by those living and working in the extra care schemes, led to the development of an initial extra care model. The grounded theory approach moved beyond the initial responses from participants as the researcher sought further insights from the prevailing literature on social worlds theory and quality and operational excellence. The insights helped understand the issues raised by participants and enriched the emerging extra care model. These insights were fed back to those who lived and worked in extra care and the extra care model further refined. A new line of enquiry arose as part of the grounded theory approach which led to interviews with managers of extra care organisations about their approach to managing service delivery, quality and operational

excellence. At this stage the researcher became aware of a potential schism between the sociological approach and the managerial approach to the extra care model. Understanding and responding to that potential schism was fundamental to developing a model of extra care that contributed new knowledge to how extra care operates.

10.3 RESEARCH IMPLICATIONS AND CONTRIBUTION TO KNOWLEDGE

This thesis makes an original contribution to knowledge in the field of extra care housing provision which is outlined below.

What is extra care, and what does it mean to participants?

There was an implicit understanding that extra care was a model of accommodation that provided more care and support than was available for people in the wider community and where people lived more independently than in a residential care home. It was frequently described as a bridge between the two. Residents, staff and managers participating in the research said that they really valued extra care, and that it provided a great service. Beneath those accolades there were varying levels of agreement about its purpose and suitability for people with dementia. It is believed this research is the first contribution to literature where a model of extra care sets out an inter-relationship between its constituent components. The model will provide a basis for comparison in future research discussions.

The level of support available in extra care, the impact of support on a person's independence, and whether extra care could be a home for life were important to participants in the focus groups and interviews. The research described a tension between the rhetoric of being able to provide a personalised care package with full community support to enable someone to remain in extra care as their circumstances change, and the reality of having limited resources to support individuals appropriately. Staff particularly highlighted the constraints they experienced in being able to provide informal emotional or social support required by extra care residents in contrast to the planned physical support

scheduled through personal care plans. Supporting mental wellbeing appeared to be secondary to supporting physical wellbeing. The research contributed to the body of knowledge about balancing social and physical care needs in extra care through the application of social worlds theory, which brought new understanding to how extra care, and individuals within that extra care, function. The application of social worlds theory shed light on the importance of both formal and informal support to help people negotiate their role and desired level of participation in the extra care community. Having the right culture, being able to maintain and reflect the personal identity of residents, having person-centred teams, understanding dementia and having a positive approach to managing risk and safeguarding issues were critical to achieving harmony across groups within extra care. These were helped or hindered by leadership styles, policies and procedures, job roles and informal ways of working together, which could create or remove boundaries between different individuals and social groups.

Relationships between residents and between staff and residents impacted on how well people lived in extra care, especially people with dementia. Both resident and staff participants expressed strong views about the difficulty of managing negative group dynamics in communal settings, whilst at the same time valuing the community spirit and the level of friendships in place. The management focus on being person or process-centred in delivering extra care varied across time and between different leaders, not helped by having two separate lines of accountability for the housing and care providers. Theories of quality and operational excellence helped understand the complex nature of delivering extra care through partnership organisations. It suggested that person-centred and process-centred approaches were not diametrically opposed, but that a useful synergy between the two could be most effective in creating a flexible and viable service model. Social worlds theory helped explain why quality and operational excellence models may be challenging to apply in service industries, including the relatively young extra care housing sector. This research has made a new contribution to approaches to quality and operational excellence in extra care housing, providing a framework that can be used by

partner organisations to help develop and implement a model of extra care housing that seeks to meet the needs of all stakeholders and places residents at the heart of both shaping and delivering the extra care service.

Is the model of extra care in the case study sites appropriate for people with dementia, and are there modifications that could make it more appropriate for people with dementia and their carers?

Existing literature set out in Chapter 2 was not conclusive on whether extra care housing could effectively support people living with dementia, especially in the later stages of dementia. This research confirmed that people living with dementia can and do live well in extra care, but that it may not be appropriate for everyone. It also confirmed that people with dementia can live to the end of their lives in extra care, but the examples given involved the person with dementia being supported by a partner. The research has provided greater clarity around the circumstances in which extra care may not be appropriate for someone with dementia; when individuals cannot navigate their way around their new environment, cannot establish new routines and cannot develop new relationships at the point they move into extra care. Both resident and staff participants described having mixed feelings when they were concerned about the wellbeing of individuals who were in potentially risky situations or who could not manage. Their concern to help the individual was tempered by frustration that they could not provide adequate support or prevent the individual's behaviour from disturbing the harmony within the scheme.

The application of social worlds theory highlighted the importance of the spatial environment in supporting positive risk taking and minimising behaviour that can challenge others. The interaction between individuals, the environment and the support being offered can alter the perceived or actual risks and challenges both for people with dementia and those around them. From a sociological perspective, the spatial environment or place can be pivotal to someone being able to take part in the community, to have agency and to develop reciprocal relations, but was lacking from managerial models and tools to deliver service

quality and operational excellence. This research recommends that the addition of 'place' within a total quality management approach and within a quality implementation framework would put the provision and support of the spatial environment at the centre of the extra care model, helping organisations to identify and minimise barriers that make it more difficult for people with dementia to live in extra care. The provision of 'place' within the model provides a key element to ensure the extra care model can move beyond the generic to provide a specific focus for considering how best to support people living with dementia.

The research suggested that a perceived lack of agency and negative reciprocity may cause individuals with dementia to be excluded within an extra care community. Concepts of active third and frail fourth ages were explored in relation to the culture within an extra care scheme and the behaviour of dominant social groups such as the 'in-crowd' towards people in the fourth age, including those with dementia. This research has added to the knowledge about emotional and social support needed for those in extra care who are approaching or in their frail fourth age. Such support is part of the 'glue' that provides additional value to the extra care community but appears to be an under-recognised need, which is under-resourced within the current economic climate.

Delivering a model of extra care by adopting a shared approach to quality and organisational excellence

The value of extra care is judged differently by the range of people involved in commissioning, developing, operating, living in and working in extra care as well as by broader society. This research recognised the potential disparity that could arise if quality and operational excellence within extra care is measured only from either a sociological or managerial perspective. The nature of partnerships affects how quality frameworks are adopted, which may impact on whether residents receive joined up services to best meet their needs. This research suggested that a shared strategic approach to quality management could help

achieve a clear vision and deliver an agreed model of extra care across the partner organisations, but that it would be critical to ensure that the experiences and views of those living and working in extra care shaped how it was developed and delivered.

A new approach to achieving excellence in extra care provision was proposed by integrating social world theory with a framework for quality management, which would require strong leadership if implementation is to be successful. The proposed approach to Total Quality Management uses the European Foundation for Quality Management Excellence Model as a framework to evaluate the inter-relationship between the enablers and results of performance, and then suggests using a performance scorecard to communicate the strategic objectives throughout the organisation and to analyse and evaluate how far it is achieving them. This research suggests a new addition of 'place' to both the TQM approach and EFQM framework to make explicit the need to manage the spatial environment in extra care to give the added value of a cohesive community in which people living with dementia can be included. Developing a meaningful or shared terminology across the care and support and managerial discourses will be crucial if residents, staff and managers are to have agentic power to work collaboratively in setting both the approach and using the individual tools.

The research concluded that the process of establishing a quality and operational excellence approach helps communicate the strategic objectives of the service and translates those objectives into results required for each stakeholder group. It set out how social worlds theory could be used to determine how residents and staff are at the heart of the process.

10.4 REFLECTIONS ON STRENGTHS AND LIMITATIONS OF THE RESEARCH

An important part of the research process is to reflect on the challenges presented within a piece of research, and what has been achieved within the scale of work which constitutes a thesis. Holding a critical realist view, it has been especially important to consider the challenges of the research approach as

an integral part of the study. This section reviews the strengths and constraints of the research approach.

10.4.1 Strengths of the research

A major strength for this research was the overwhelming positive reaction to the research and a universal willingness to be involved. This was substantiated by the time and energy granted both by participants within the case study sites and by interviewees from housing and social care organisations.

The researcher's position as a previous 'insider' with commissioners and extra care managers in the proposed case study localities helped in identifying and approaching the key gatekeepers to gain access to participants. The researcher's positioning brought some privilege, or advantages, in terms of being able to forge relationships quickly with participants and to understand the issues they were describing. The researcher's independence from the organisations running the case study extra care schemes was helpful in reassuring participants that there was no bias or undue influence within the research.

The grounded theory approach used by the research was fundamental in enabling the research to be directed by the experiences and concerns of the participants rather than by any pre-determined concepts the researcher may have had. The support from the University of Sheffield Sociology Department was central to exploring the sociological aspects of the possibilities and practicalities of people with dementia living in extra care. This was enhanced by access to colleagues within the School of Health and Related Research and the School of Architecture which enabled a broader dialogue around the nature of the interactional environment and how it impacts on the lives of those living and working in extra care. These combined in a unique way to contribute to a new perspective on how extra care can best support people living with dementia. The resulting approach to quality within extra care puts the resident centre stage. It uses social worlds theory to better understand the inter-relationship between planning a model of extra care that creates the right physical

environment to support people, with having appropriate processes in place to ensure that resident needs are met by excellent operational performance.

An enduring strength of the findings is that they should resonate with those who plan, commission, develop and deliver extra care housing because the grounded theory approach was able to use their own experiences to develop a model of extra care that can be adapted to individual local circumstances. Of equal, if not greater importance is that because the model was developed through the voices of residents and staff members it should provide a tool for them to continue to be involved in further developing extra care as part of a continuous learning process.

10.4.2 Constraints of the research

The research was constrained by the characteristics of the participants and the extra care schemes themselves, as well as by the research process that was followed. Each of these will be addressed in this section.

The nature of participation

The findings of this research must be taken in the context of there being limited voices of people with advancing dementia within the research due to the ethical limitations set out in Chapter 3. Notwithstanding those limitations, the research directly involved some residents living with dementia, as well as current and previous carers of people with dementia. They were primarily people with early dementia who had mental capacity to be involved in the research, and couples where one partner had dementia. There were two carers each of whom had recently cared for a partner with dementia in extra care before that partner died.

A challenge for the researcher was to ensure that there was a balance to the findings, and to bring proportion and sense to what was being portrayed by participants. At times that was difficult, such as in the continued debate about whether extra care was intended for people to live independently or with high

levels of support and care needs. It was important to acknowledge this as a dominant issue, but still explore underneath that to see what the implications were for people living with dementia. A further challenge arose in achieving an approach that balanced the views and needs of resident and front-line staff with those in managerial positions. That was particularly challenging for the researcher who was striving to ensure the voice of the resident was at the forefront when writing about findings with managerial implications and set across the two disciplines of sociology and management.

Innate characteristics of the extra care schemes

The initial pilot questionnaire described in Chapters 1 and 3 was helpful in confirming that the two proposed case study sites were not atypical of other extra care schemes in England. The research deliberately excluded the large extra care retirement villages, and so the findings may be limited in their application to such settings. The research also deliberately included only not for profit extra care schemes rather than those that were privately or commercially run. The schemes included resident participants who were both tenants and leaseholders, reflecting the mix of public (through housing benefit) and privately funded apartments. There are likely to be different operating models between the not-for-profit and commercial extra care schemes, which may limit the application of the findings of this research. A comparison with commercial schemes could usefully form the subject of a future research project.

The external context

The research was undertaken at a time of uncertainty and change within the extra care housing sector as described in Section 0. The changes over the last three to five years have affected the perceived level of care needs in many extra care schemes, and this was undoubtedly the source of some of the comments made by participants about the lack of clarity in what extra care is. During the time of the study was an increasing focus on the role of housing within the health and social care provision, particularly in providing intermediate care and

or in supporting effective hospital discharge (Chartered Institute for Housing & Skills for Care, 2017). This thesis has not included health provision as there was no co-location of health at either of the case study sites. The future balance of care needs and how that might impact on the model of extra care that is adopted in future schemes remains uncertain and may be worthy of a future longitudinal research study.

Extra care within the local community

The primary focus for this research was on the possibilities and practicalities of people with dementia living in extra care. Issues of community involvement were raised and were considered as part of the discussion of findings and the model of extra care. The research did not include users of the community facilities who were not resident in the scheme. Future research could seek insights into the intersection between social worlds internal and external to the extra care schemes, and whether they can help people with dementia make a transition from community to extra care.

Limitations to the grounded theory approach

A grounded theory approach to research should provide a method for generating theory from data (Gibson & Hartman, 2014). The method seeks to produce theory that is practical and useful, and closely related to the field in which the theory has been developed; in this instance extra care housing. The aim of this research was to 'ground' a model of extra care in the perspectives of the people living and working in extra care and to try and work with others in the extra care arena to resolve any problems identified. This research was constrained by the boundaries set by a PhD study; namely to achieve the outcome of a thesis within three years. In this study the researcher was acting alone, not part of a research group, which limited the capacity and resources available to the study. Within those constraints the grounded theory approach followed the research methodology set out in Chapter 3 which included collecting data, exploring concepts within the extra care community, identifying

a theoretical model of extra care to support people with dementia and scoping out a framework to help deliver the model. The model has been shared with residents, staff and managers at the case study extra care schemes, and with professionals within the wider extra care community with positive feedback providing some level of validation. However, the research does not claim to have tested out or evaluated the framework to help deliver the extra care model in practice, which could form the basis of follow-on research.

10.5 IMPLICATIONS FOR POLICY AND PRACTICE

The original impetus for this research came from intellectual curiosity about the experience of living and working in extra care, together with a passionate belief that commissioners of services for people with dementia should not be setting up people to fail by placing them in extra care if it is not appropriate for them. As the thesis developed, aspects of extra care practice emerged which could be influential in how people with dementia experience life in extra care, and in how the attitudes of other people could change towards them. These are set out in tables below for the attention of commissioners, designers and developers of extra care; commissioners, contractors and allocation panels; and operational provider managers. Figure 10-1 first draws on issues highlighted in the research discussion and findings to summarise a set of central principles to help ensure older people are at the heart of the extra care service model, and then Figure 10-2 - Figure 10-4 set out the policy and practice implications of the research for groups at different stages of the process of developing, contracting for, and operating extra care. The policy and practice implications are not intended to be exhaustive, rather they are intended to stimulate high level discussion to reflect the findings of this research.

DEVELOPING THE EXTRA CARE SERVICE TO SUPPORT INDIVIDUALS WITH DEMENTIA TO LIVE AS WELL AS POSSIBLE

Putting older people at the heart of the extra care service model

Involve older people both individually and collectively in developing a shared vision of the extra care model. Involve older people in local groups that influence the future development of housing and personal care services for older people. Consider how 'hard to reach' groups such as those living with dementia can be targeted on a systematic rather than adhoc basis.

Seek individual and collective representation of older people. Involvement of a community member in co-designing services for a collective group will be different from individual residents co-producing their own individually tailored services.

Consider how older people can be empowered to take part. Consider how social groups form and operate and what will help older people be included and have agency within the group. Make sure that any professional or managerial tools can be understood and used by all members of the group.

Create a balance between person and process centred approaches. Adopt an approach that allows both flexibility and consistent service development to meet the needs of the whole extra care community and specific individuals within it. Ensure partners focus on how any separate processes across organisations jointly deliver outcomes for residents.

Tailor the group to the circumstances and the decisions and actions that need to be agreed. Concentrate involvement on what outcomes need to be achieved rather than on the process of involvement itself.

Value everyone's contribution and negotiate the best outcome for everyone.

Be systematic! Ensuring older people are at the heart of an extra care service will not happen by chance. Plan how to involve older people in developing the extra care model; get on and do it; review how effective it was; analyse whether and how it can be improved.

Figure 10-1: Putting older people at the heart of the extra care service model

DEVELOPING THE EXTRA CARE SERVICE TO SUPPORT INDIVIDUALS WITH DEMENTIA TO LIVE AS WELL AS POSSIBLE

For commissioners, designers and developers:

Develop a shared vision of the extra care model with older people, partners and contractors.

- Keep going back to the shared vision and consider how the quality of the service will be managed across all providers to deliver an excellent service
- For new schemes consider where it will be located and how the scheme will become part of the local community.
- Consider how the design and use of the spatial environment in the scheme will make it easy or more difficult for social groups to develop and for people with dementia to be included
- Build and design an easy to navigate scheme from the beginning - be bold! It helps everyone.

Figure 10-2: Implications of the research for commissioners, designers and developers of extra care

DEVELOPING THE EXTRA CARE SERVICE TO SUPPORT INDIVIDUALS WITH DEMENTIA TO LIVE AS WELL AS POSSIBLE

For commissioners / contractors and allocation panels:

Support the shared vision of the extra care model

- Be clear what the core services of the extra care model will be, and the support available for unplanned or flexible care to meet the emotional and social needs of extra care residents.
- Continue to seek a balanced allocation and consider how best to prioritise allocations to individuals living with the early stages of dementia
- Adopt best practice for assessing individuals before the allocation panel; home visits and meeting the person are strongly recommended; review the added value of a link worker; make plans for individuals to be supported in their transition to their new home.
- Be clear what performance measures will be important in determining how effective the scheme is in meeting the needs of all its stakeholders including residents and regulatory bodies
- Optimise the system of learning through operational management groups, and work together to promote innovation and resident focussed service changes.

Figure 10-3: Implications of the research for commissioners, contractors and allocation panels

DEVELOPING THE EXTRA CARE SERVICE TO SUPPORT INDIVIDUALS WITH DEMENTIA TO LIVE AS WELL AS POSSIBLE

For operational provider services:

Implement the shared vision of extra care

- Continue with person centred approaches; work with social work staff to plan for emotional / wellbeing support as well as physical care needs; consider different job roles
- Provide strong leadership, develop joint teams as far as possible by reducing boundaries between staff groups and maximise opportunities for shared development e.g. joint training etc
- Work as a team to create a culture where relationships, social groups and individuals can thrive
- Consider how to maximise the spatial environment to support social interaction between extra care community members, to manage risks and to minimising behaviours that challenge
- Develop a shared quality and operational excellence model that includes residents, partners and other service providers

Figure 10-4: Implications of the research for operational providers of extra care

Integration of different perspectives has been a central theme of this research. The development of an extra care model that integrates a quality and operational excellence framework with a social world approach contributes to a conceptual debate about bringing together the care and support discourse with the managerial discourse. Bringing the two together may help managers from different care and support backgrounds to more fully understand, and therefore adopt, the quality and operational tools available to them to deliver a consistent person-centred extra care service to support those living both with and without dementia. Using the findings of this research to bring the two together through policy and practice should contribute to a debate on how best a quality framework can provide the infrastructure to work collaboratively to develop an extra care service with residents at the heart. That debate should include how far people with dementia are active or implicated actors within the social worlds that provide the 'universe of discourse' (Strauss, 1978a) within extra care schemes.

10.6 DIRECTIONS FOR FUTURE RESEARCH

This research was an exploratory piece of work that set out to question the possibilities and practicalities of people with dementia living in extra care housing. It has generated new insights and contributed to the body of knowledge about models of extra care, the usefulness of applying social worlds theory in an extra care context, and the appropriateness of an approach to quality and operational excellence in developing a model of extra care in which people with dementia can live well. There are opportunities for how the findings of this research might be taken forward in future studies and for gaps in knowledge to be subject to future research.

First, there was insufficient evidence to suggest residents have become more, or less, empowered and involved in the everyday running and functioning of extra care schemes because of the reported swing from independent living to a more heavily dependent extra care model. The relationship between levels of

independence and engagement in shaping extra care delivery would merit further examination, with a specific focus on enabling the voice of people with different stages of dementia to be heard.

Second, the viability of non-commercial communal space in semi-public areas of extra care was reported in Section 7.4.1 as having been the subject of debate in extra care procurements, which may impact on the quality of spatial environments in future schemes. The viability and provision of the spatial environment in extra care could merit further research using social worlds theory to consider its impact on the development of social groups, levels of social interaction, and the wellbeing of potentially marginalised individuals.

Third, a notion was introduced that a social sub-world might be possible for groups of individuals who are marginalised by the in-crowd of an extra care scheme. Although there was some evidence of staff helping people come together to make friendships, further research built on the work of Star and Griesemer (1989) would be required to establish whether a framework could be developed in which people with vulnerabilities, including those associated with dementia, could have sufficient agency to develop or use the necessary boundary objects to address issues of mutual concern.

Fourth, the extent to which the care and support and managerial discourses could be merged or switched within an EFQM model for extra care, and the impact that has on relationships of power within the social worlds of extra care might warrant further research.

Fifth, due to the time and resource constraints in this research it was not within its scope to validate the proposed revisions to integrate social worlds theory within a Total Quality Management Approach and a European Foundation Quality Model for excellence in extra care, as set out in Chapter 9. An opportunity to test this could be considered by the case study or other similar extra care schemes.

Sixth, the ability of the EFQM self-assessment to provide an internal benchmark against which future extra care performance could be compared was considered. The research recommended developing performance scorecards to give space for key stakeholders to collaborate and share information about performance that could lead to continuous learning and improvement. This research did not endorse any specific approach, rather it suggested future research could helpfully explore using social worlds theory to consider who should be involved, and what boundary objects would help them to contribute effectively to decide which indicators should be measured and would add value to the process.

Last, there was little available in the body of literature on how full participation and collaboration of the different stakeholders could be effectively achieved either within grounded theory research or within models of quality and operational excellence. This subject could form the basis for some of the research suggested within extra care.

10.7 CONCLUDING REMARKS

To conclude, this thesis has explored the possibilities and practicalities of people living with dementia in extra care. It has argued that people can and do live well with dementia in extra care, but that it is not appropriate for everyone. What has been important has been not losing sight of the individual person when planning a model of extra care that meets the needs of all stakeholders. What matters to residents, staff and managers is being clear about what extra care is and having the right processes and people in place to support people to live as independently as possible and to take part in a well-developed and well supported extra care community. The complex interaction between organisational structure, social worlds and the spatial design of the scheme was critical to how extra care communities, including individuals living with dementia, function. The research argued that extra care organisations made up of complex partnership arrangements would be well served by adopting a shared approach to quality and operational excellence that keeps older people and

residents at the heart of the extra care model. The research suggested that realising such a model would be achieved by the integration of social worlds and managerial perspectives and proposed that future research could provide further evidence to validate the new approach.

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Key: The bibliography uses standard abbreviations for no place of publication [s.l.] and no named publisher [s.n.]

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APPENDICES

APPENDIX 1: PICOT

Table 1: Formulation of issues for literature search

Population / subject of interest	Issue of interest	Comparisons of interest	Outcome of interest	Timeframe
Research methods	Qualitative methods, mixed methods,	Social research methods, engagement, ethics, experience of using different methods, positioning the researcher,	Methods that can be used with individuals with dementia and their carers, techniques for involving participants in co-development or engagement	Last 50 years
Housing for older people	Historical development	Mainly UK but other countries if appropriate	What have been the main political economic, social and legal factors influencing development of housing	Last 5 centuries
Specialist housing for older people	What factors define different models of extra care	Mainly UK but other countries if appropriate	Range of models in operation, key factors, and how successfully they support older people	Since 1980s
Supply of specialist housing	Sufficiency of supply to meet the demand for older people Factors influencing supply of	Non-specialist housing for older people, residential care for older people	Whether supply can meet demand now and in the next twenty years	Last 10 years

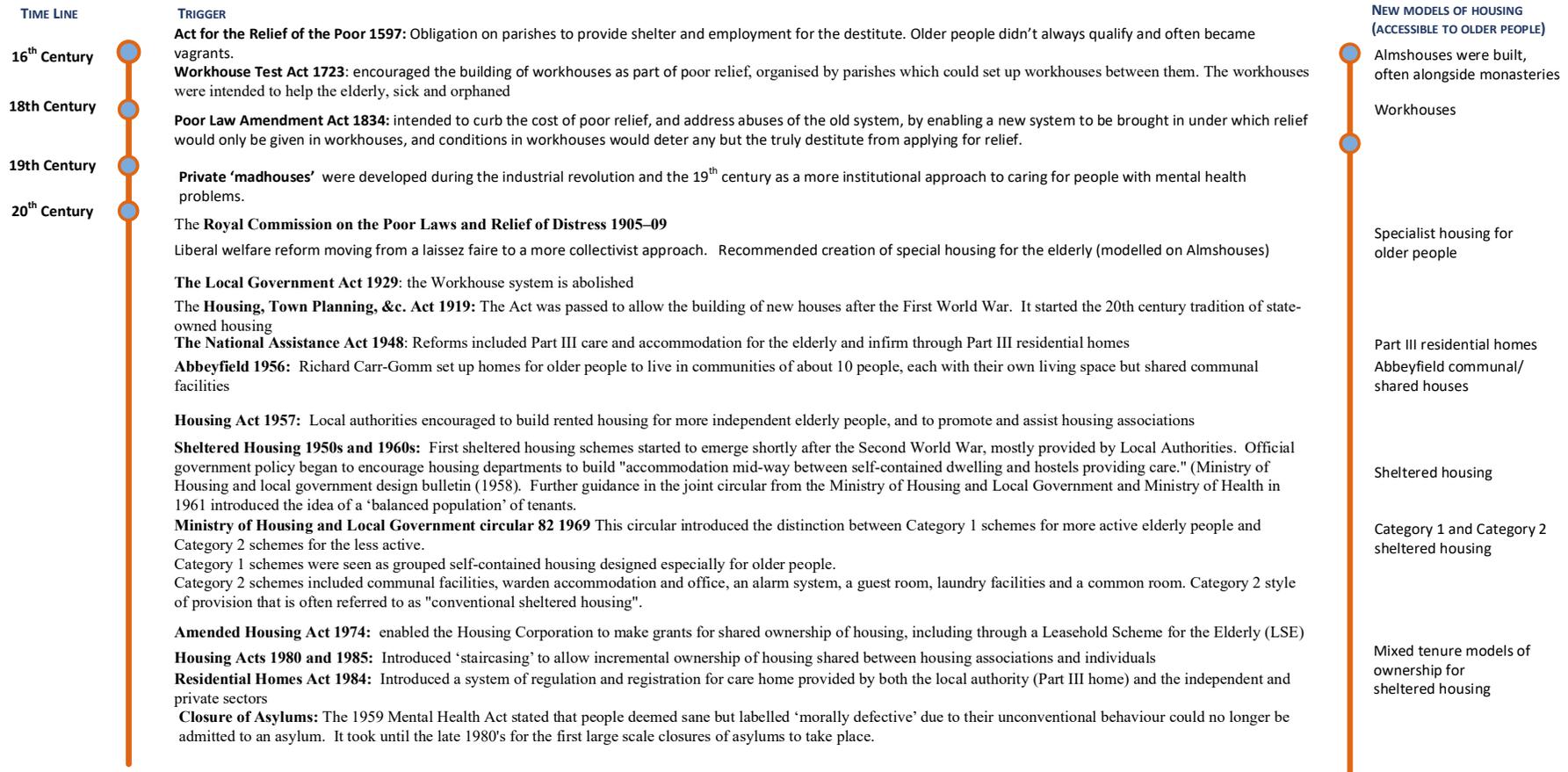
Population / subject of interest	Issue of interest	Comparisons of interest	Outcome of interest	Timeframe
	extra care housing			
Older people	Triggers for moving to a new house after the age of 55 / retirement	What types of new accommodation are considered and why	What factors are important in achieving a successful move to specialist housing such as extra care	Not time limited
People with dementia	What helps an individual to live well with dementia	Within existing home, within a change of accommodation and support		Since 1980s
Maintaining identity through person-centred support	What can help or hinder a person to keep their identity and sense of personhood	In own home, in new communities. Impact of dementia.	What the known barriers and enablers are to a person maintaining their sense of personhood and relationships with others. How far person-centred support can enable a person to continue to live in extra care as their dementia progresses	Since 1980s

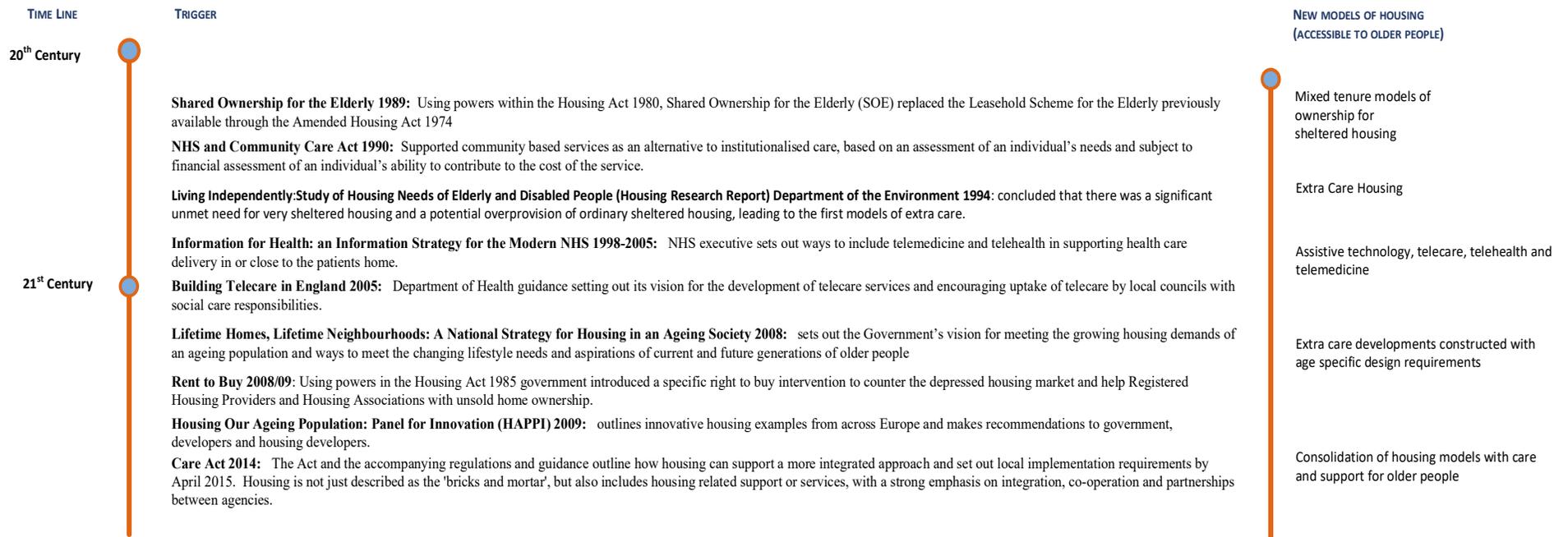
Table 2: Search Criterion

Question	Include (and alternative terms) in search strategy	Exclude	Key contributors (not in any specific order)
What have been the political, economic, social and legal drivers to the development of housing for older people in the last two centuries and how are they relevant today?	Undertaken using an inductive approach and based on previous knowledge and reviews.		A Walker, G Boyer, D Cowan, T Maltby, P Ring, D Sinclair, A Nanda, A Netten, R Darton, T Baumker, G Parker, A Sixsmith & J Sixsmith, M Abramsson and E Andersson, J Vincent, E Tulle and E Mooney, C Cantley, A Innes, J Manthorpe , A Cameron
What is extra care and is there one or multiple models?	Extra care or specialist housing or assisted housing and older people	Learning disability, children	Robin Darton , Ann Netten, Alan Lewis, Kevin McKee, Theresia Baumker, J Hanson, Rachel Dutton, J Barrett, M Riseborough, P Fletcher, D Gillie, M Valins, D Robson, Elderly Accommodation Council,
Is there enough extra care to meet demand from older people in the UK?	Accommodation or housing and old and move	Medicine categories, documents from non UK countries. Agricultural and biological sciences, biochemistry, genetics and molecular biology, chemical engineering,	T Baumker, R Darton, A Netten, E Thomson, R Dutton, K Croucher, N Gallent, M Ball and A Nanda, S Sodha, B Beach, F Wellings, Elderly Accommodation Council, Housing Learning and Improvement Network, Laing&Buisson,

Question	Include (and alternative terms) in search strategy	Exclude	Key contributors (not in any specific order)
		earth and planetary sciences	
What causes older people to move house?	Older people and move or transition, quality		E Lee, E Litwak and C Longino, MM Ball and Nanda, A Ballantyne, T Baumker, M Aaltonen, J Attfield, S Austen, S Vallelly, A Park and I Zeigler, A Sixsmith & J Sixsmith, K Croucher, I Hardill, R Darton, L Callaghan, A Netten
What factors are important to enable an individual with dementia to successfully move and live well in extra care, and are they in place?	Community Social connection Ageing in place Dementia, outcomes, quality of life, well-being, design, independence, characteristics, extra care housing, decision, cost, technology, adaptations		L Callaghan, F Oswald, S Aarts, CL Graham, B Bartlam and EA Greenfield, D Kneale and L Smith, J Porteous, J Torrington. Stirling University Dementia Services Development Centre, Kings Fund, Levitt Bernstein, G Jones, W Van Der Eerden
How does a sense of identity and personhood impact on a person with dementia continuing to live well in extra care, and is living well achievable?	Identity, personhood, dementia, agency		T Kitwood, L Pattoni, D O'Connor, C Hughes, J Hughes, H Chaudhury, K Zeiler, A Innes, S Behuniak, J McKeown, L Kellaher, S Peace,

APPENDIX 2: THE HISTORY OF ACCOMMODATION AND CARE IN ENGLAND

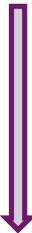




The term 'the elderly' is used in the timeline where it was current terminology at the time of the historic event. Today the term 'the elderly' is often seen as pejorative, bringing with it connotations of lack of individualism and potential ageism⁷⁵. Forty years after Robert Butler introduced the term 'ageism' he provided the preface to a guidance document for journalists on overcoming ageist language and beliefs (Dahmen & Cozma, 2009). After the guidance was published in 2009 the preferred term started to change from 'the elderly' to 'older people' amongst other more acceptable terms (Dahmen & Cozma, 2009).

⁷⁵ Stereotyping and discriminating against individuals or groups on the basis of their age.

APPENDIX 3: LEVELS OF HOUSING WITH CARE IN 2017

Category	Description	General Examples	Bespoke
Level 1 	Non-specialised and non-adapted housing	'Staying put' in own home	Adaptations and telecare in own home
	Independent dwellings which have been purpose built or adapted for fit and active older people who may need some support but can generally look after themselves	Almshouses Retirement bungalows General needs sheltered housing	Tailored adaptations and telecare in homes
Level 2 	Purpose built, self-contained dwellings in groups; with warden assistance and minimal communal facilities	Category 1 sheltered housing	Tailored adaptations and telecare in sheltered housing
Level 3 	Purpose built, self-contained dwellings (to HCA standards and more latterly Lifetime Home standards); with warden assistance and access to communal facilities aimed at physically frail older people	Category II sheltered housing Supported living Extra care light	Tailored adaptations and telecare in sheltered housing
	Comprise self-contained homes with design features and support services available to enable self-care and independent living, usually with on-site 24/7 assistance for housing and personal care (subject to assessed need), option to take meals	Extra care housing Very sheltered housing Housing with care Retirement villages	Extra care housing schemes and hybrid extra care housing and residential schemes
Level 4 	Residential care homes for older people who need personal care Specialist residential care centres Nursing homes for older people who need nursing care	Registered Care Home Registered Care Home ⁷⁶	Local authority and independent sector residential care homes Independent sector registered care homes
Level 4+	Acute and community hospitals	General acute / mental health / local hospital wards	Note ⁷⁷

Source: adapted from Robson 1997, pp 8 – 15.

⁷⁶ Registration requirements cover both residential and nursing home care, but each home should be regulated for the activities it provides as listed in Schedule 1 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.

⁷⁷ Hospitals can become a de facto accommodation option for people with dementia if they are unable to return safely to their own home, and if there are no residential or nursing home beds available.

APPENDIX 4: PILOT QUESTIONNAIRE

The pilot questionnaire was developed with input from a critical friend in the Housing Learning and Innovation Network (LIN). It was developed using Sheffield University Google Forms, hosted on an external website to provide access to people outside the university. The research study and the questionnaire were promoted via the Housing Learning and Innovation Network's (LIN) newsletter (Housing LIN, 2016), which was disseminated on 20 April 2016. The newsletter was sent to Housing LIN members providing extra care, asking them to contribute to the study. A close date of 17 June 2016 was set, providing an 8-week period for completion. The Housing and Dementia Research Centre (HDRC) copied the link to their members to encourage completion of the questionnaire by their members. Six further responses were received after the close date, which were incorporated into the analysis. The questionnaire is set out below.

Extra Care Housing and its appropriateness for people with dementia

You have been sent this questionnaire as a HOUSING LIN member who is registered as providing extra care.

The questionnaire is the first part of a research programme within the University of Sheffield on extra care for people with dementia. Its aim is to gather a national picture of how organisations support people with dementia to move into or to stay within an extra care scheme.

Please give some time to complete the questionnaire: it should take no more than 20 minutes and will help to build a full and up-to-date picture of UK extra care for people with dementia.

All information will be anonymised as part of the data analysis. All information will be kept confidential and stored securely. The findings will be used to inform the next stage of the research programme which will explore a limited number of extra care schemes in detail.



Section 1 of 3 Use of data

I understand that all data I provide will be kept confidential and stored securely in line with data protection requirements. Only the research team will have access to it.

Yes

No

I understand that all data will be anonymised. The results of this study will be disseminated through academic events and/or published articles. This may include any quotes provided in the comments boxes. However, I understand that I will not be identifiable from these comments.

Yes

No

Background information

This first section is intended to find out the range of housing providers and partners currently providing extra care housing schemes

What is the name of your scheme?

Short-answer text

Where is it located? Please provide the postcode

Short-answer text

Which county is it located in?

Short-answer text

How old is the scheme?

1. Less than a year old
2. 1 - 3 years old
3. 4 - 5 years old
4. 6 - 10 years old
5. 10 - 15 years old
6. More than 15 years old
7. Add option

Please say who the housing provider is

Short-answer text

Who is the onsite 24/7 care provider?

Short-answer text

Please detail below if there are different arrangements in place to an on-site 24/7 care provider

[For example, if there is an off-site 24/7 care provider or if all tenants have individual arrangements to purchase their own care]

Long-answer text

Please list below any local authorities who are partners in the scheme

Long-answer text

Was the scheme purpose built or remodeled from an existing building?

1. Completely purpose built
2. Completely remodelled from an existing building
3. Partly remodelled and part purpose built

Please make any comments as appropriate:

Long-answer text

How many apartments are there are in your scheme?

1. Less than 40
2. 40 - 50
3. 51 - 100
4. 101 - 150
5. 150 - 300
6. More than 300

How many rented apartments do you have in your scheme?

[If you are unsure please give a rough approximate e.g. more than a third, half, two thirds etc.]

Short-answer text

How many shared ownership apartments do you have in your scheme?

[If you are unsure please give a rough approximate]

Short-answer text

How many outright purchase apartments do you have in your scheme?

[If you are unsure please give a rough approximate]

Short-answer text

Please add any comments if appropriate

Long-answer text

Please indicate the approximate ratio of one to two bedded apartments

[This question intends to find out how many couples could be accommodated. A rough indication only is required. If you have 'one and a half' or 'one-plus' bedrooms, please class them as one-bedroom.]

1. 100% one bedded
2. 90% one bedded 10% two bedded
3. 80% one bedded 20% two bedded
4. 70% one bedded 30% two bedded
5. 60% one bedded 40% two bedded
6. 50% of both one bedded and two bedded
7. 40% of one bedded 60% of two bedded
8. 30% of one bedded 70% of two bedded
9. 20% of one bedded 80% of two bedded
10. 10% of one bedded 90% of two bedded
11. 100% two bedded

If your scheme contains 'one and a half' or 'one plus' bedded apartments, how many do you have?

Short-answer text

Do you have any apartments with more than two bedrooms?

1. No - all apartments have either one or two bedrooms
2. Yes - we have apartments with three or more bedrooms

If you have apartments with more than 2 bedrooms, please provide further detail below.

[for example, how many do you have, do they have more than two people living in the apartments?]

Long-answer text

Please indicate whether the scheme was developed with grant funding or a subsidy

[This may be central grant funding from the extra care capital funding rounds, or a local subsidy for example in the form of land contribution etc.]

Long-answer text

Please indicate if there are any local authority controls or rights in place with the scheme

[For example, fixed eligibility criteria, nomination rights, allocation rights, use of affordable rents and service charges etc.]

Long-answer text

Section 2 of 3 Models of extra care

This section describes common models of extra care which support people with dementia. It aims to find out the extent to which common models of extra care are being used, or if there are any new models emerging.

Please indicate which model best describes your scheme

1. Mainstream extra care which does not have people with dementia
2. Extra care which integrates people with dementia throughout the scheme
3. Extra care with a separate wing for people with dementia
4. Specialist extra care scheme only for people with dementia
5. Extra care combined with a registered residential home
6. Other, please describe below:

If your scheme does not fit one of the models listed, please describe below

Long-answer text

Please add any other comments that you would like to make about your particular model

Long-answer text

Does your scheme have eligibility criteria which specify whether the scheme is suitable for individuals with dementia?

1. No - there are no specific eligibility criteria for people with dementia
2. Yes - there are criteria which specify it IS appropriate for people with dementia
3. Yes - there are criteria which specify it is NOT appropriate for people with dementia

If there are specific criteria, please describe any limits to entry and how they are defined [If there are no limits please indicate n/a]

Long-answer text

Do you have formalised exit criteria?

1. Yes - there is a formal exit policy with criteria to help guide individual decisions
2. No - we judge each case as it arises

What are the main reasons (other than death) for tenancies coming to an end?

Please tick the main reasons that apply

- Move to be nearer family or friends
- Difficulty providing the necessary level and flexibility of care in response to increasing needs
- Targets for balance of dependency levels across the scheme
- Inappropriate behaviours
- Lack of community health support
- Availability of resources / changes to benefits
- Lack of ethnic diversity or ability of the scheme to meet different cultural needs
- Other...

Please provide any additional comments relating to the circumstances in which tenancies have ended

Long-answer text

Section 3 or 3 Design features of your scheme

There is a growing body of guidance on design features for extra care housing, including specific guidance to help support people with dementia.

This section explores how widely some of the most common design features have been included in schemes. It is expected there will be a large variation, especially with some of the older schemes.

This section asks you to rank how far you think each of the following design features have been taken into account in the communal and public areas of your scheme.

There is space to add any additional comments if you feel it is appropriate.

Meaningful spaces and building layout help people with dementia to recognise where they are and why

Spaces are used for small activity corners, there are no dead end corridors, rooms contain objects that illustrate what the room is to be used for, glazed windows show what is inside to help orientation eg glazed walls, glazed cupboards

	1	2	3	4	5	6	
There are no meaningful spaces or indicators and people sometimes get lost or don't know why they are there	<input type="radio"/>	The scheme has lots of meaningful spaces and indicators which help people recognise where they are and gives them something positive to do					

Please explain the reason for your ranking

Long-answer text
.....

Thoughtful layout of rooms within the building guide people to where they are and what the rooms are used for

Rooms for use by different groups such as the public or tenants are positioned so that they are easily accessible with appropriate links between them e.g. the cafe is available in a public space, there is a secure door to the tenant areas including communal lounge and apartments, circulation corridors are not too long and reduce unnecessary doors etc

	1	2	3	4	5	6	
Not at all	<input type="radio"/>	Fully taken in to account					

Please explain the reason for your ranking

Long-answer text

Simple spaces are created by decluttering the environment

For example: surfaces are plain and worktops only have meaningful objects on them; there is sufficient storage and no surplus equipment lying around; signs, notices and notice boards are meaningful and kept to a minimum

	1	2	3	4	5	6	
Most spaces appear cluttered and confusing	<input type="radio"/>	Spaces are clear and all items are meaningfully placed					

Please explain the reason for your ranking

Long-answer text

Lighting is sufficient and appropriate to the activity in the room

For example: natural daylight is optimised through glazing, roof lights etc; curtains can be drawn back as far as possible to let daylight in; darkness is encouraged during night-time hours to reduce nocturnal restlessness; lighting is used to highlight interesting features

	1	2	3	4	5	6	
Lighting is poor, may not help someone know what time of day it is, and can cause confusion	<input type="radio"/>	Lighting and darkness are optimised and appropriately used to help people with activities					

Please explain the reason for your ranking

Long-answer text

Colour and patterns are used appropriately

For example: use of contrasting tones differentiate between foreground and background objects; contrasting feature walls emphasise space and activity areas; minimal use of patterns avoids distorting what a persons sees; if not essential, reflective materials such as mirrors and shiny stainless steel doors are not used or can be covered

	1	2	3	4	5	6	
Colours, patterns and reflections cause sensory overload and confusion	<input type="radio"/>	Appropriate use of colours, patterns and materials provide an understandable and calm environment					

Please explain the reason for your ranking

Long-answer text

Artwork is meaningful

For example: tenants and families are involved in choosing artwork; artwork is used to break up monotonous spaces or provide a talking point; artwork that disturbs or disorients people is not displayed

	1	2	3	4	5	6	
Artwork choice is adhoc or chosen by a designer who is not familiar with dementia care	<input type="radio"/>	Artwork is chosen and positioned carefully taking into consideration its impact on tenants and the public					

Please explain the reason for your ranking

Long-answer text

Environmental features help individuals find their way effortlessly around the building

For example: routes through the building are as short as possible; the way to and back from parts of the building are signposted and landmarked; signs are repeated if necessary and appropriate; signs are easily understood (eg they employ symbols as well as words) and are at a height where they can be seen; doors are coloured to attract people into them or camouflaged to discourage people from using them

	1	2	3	4	5	6	
The building is a maze to find your way around, people get lost and frequently have to ask directions	<input type="radio"/>	The building is very easy to navigate without having to ask directions					

Please explain the reason for your ranking

Long-answer text

Assistive technology (telecare) is available and widely used to complement support from carers and families as part of a care plan

For example, core technology such as call alarms are supplemented by other peripheral devices such as automated prompts and reminders, communication aids, locator devices etc

	1	2	3	4	5	6	
Only call system in place	<input type="radio"/>	Fully interactive system in place with individual devices installed as part of care plans					

Please explain the reason for your ranking

Long-answer text

That's it! Thank you!

Thank you for your time and support in completing this questionnaire which will provide an invaluable insight into the range of extra care models across the country and the different approaches to supporting people with dementia.

The information you have provided will be anonymised when it is analysed. Any findings will be generic, and comments will not be attributed to individual schemes.

For further queries about this research please contact:

Katey Twyford
Doctoral Researcher, Sheffield University Sociology Department
Topic: Extra care housing and the opportunities and challenges for individuals with dementia
Email: krtywford1@sheffield.ac.uk
Website: <http://www.sheffield.ac.uk/socstudies/postgraduate-research-students/katey-twyford>.

If you have any complaints about this research questionnaire, please contact the research supervisor:

Dr Lorna Warren, Director of Post Graduate Affairs - Research
Email: l.warren@sheffield.ac.uk

If you are happy to be contacted again for more information, please leave your contact details below.

Please provide your name, position, and email address.

Short-answer text
.....

APPENDIX 5: ACTIVITIES IN PHASES 1 AND 2 OF THE EXTRA CARE RESEARCH PROGRAMME

Table 1: Phase 1 focus group / interview and other activity within the two extra care schemes

Type of meeting	Participant Group	Case Study Site		External to Case Study
		Scheme 1	Scheme 2	
Environment Assessment Environmental Assessments	Researcher only	30/09/17	29/09/16	
	County research officer	01/11/17	25/10/16	
	Resident and researcher		01/12/16	
Allocation Panel	Managers and allocation panel	28/10/17	01/11/16	
Focus Group	Managers and allocation panel	08/11/16	29/11/16	
	Residents (mini group)	08/11/16		
	Care and housing support staff	15/11/16	17/11/16	
	Residents	22/11/16	29/11/16	
	Social workers	30/11/16		
Interview	Resident		01/12/16	
	Regional/national housing manager	31/01/17 07/02/17	17/02/17	27/01/16
	Local Authority safeguarding manager			01/02/17
	Local authority commissioning and contracting managers			09/02/17
	Local Authority Assistant Director			14/02/17
Visit	Comparative housing manager			02/12/16

Table 2: Phase 2 range of focus group / interviews and other activity within the two extra care schemes

Type of meeting	Participant Group	Case Study Site		External to Case Study
		Scheme 1	Scheme 2	
Focus Groups	Residents	07/03/17	08/03/17	
	Resident (informal meeting)	21/03/17		
	Managers and allocation panel	14/03/17	Aborted	
	Staff	21/03/17	23/03/17	
	Local authority managers and social workers	10/04/17		
	Local authority domiciliary service managers	03/05/17		
	Field work and domiciliary care provider			09/05/17
Interview	Resident (by telephone)	03/04/17		
	Housing managers		26/4/17	
Individual Specialist Interviews	Quality and assurance manager of national housing association			10/07/17
	Housing and dementia project lead			11/07/17
	Regional director			03/07/17
	Regional operational manager			21/07/17
	Research associates			20/09/17

APPENDIX 6: PRACTICAL ISSUES EXPERIENCED DURING RESEARCH FIELD WORK

Prior assessment of practical issue	Experience within the research
Resident participants including those who are living with dementia or their carer	
Building trust and rapport with the person with dementia or their carer before undertaking research activities	Meeting with all potential participants individually to explain the study and what would be involved helped build relationships and trust.
Appropriate timing of interview	Advice from managers was taken initially, but the timing of meetings varied e.g. a resident meeting was brought earlier to avoid a clash with a film club.
Privacy	All meetings took place in private meeting rooms. One meeting room suffered from interruptions as staff members came through the meeting room to gain access to their preferred toilets. Other toilets were available, but the specific ones attached to the meeting room had been informally adopted as staff toilets.
Participation and inclusion of people with dementia, carers or community reference groups	Two out of 11 participants were living with dementia, and 7 out of 11 participants were current or previous carers of people with dementia.
Matters of mental capacity	These did not arise.
Potential fatigue of residents	One resident appeared tired but continued to be engaged and wished to continue.
Consideration of whether there should be continuity of focus group membership or whether new membership	There was continuity of membership between the two phases of focus group and interviews. There did not appear to be substantial benefits in drawing new resident participants into the research for

Prior assessment of practical issue	Experience within the research
should be sought for phase 2.	phase 2 as it built on the knowledge shared and produced in phase 1.
Practical access to venues	Not an issue, all meetings took place in the extra care schemes.
Expenses e.g. travel	Not an issue, all meetings took place in the extra care schemes.
Confidentiality and sensitivity for other members in the group	All participants agreed to the confidentiality requirement for the research. Group members were very supportive of each other. One group member made comments that could have been upsetting for other members of the group living, or caring for a partner, with dementia. The researcher steered the discussion and checked individual participant wellbeing before they left the meeting.
For organisational representatives (managers, social workers, and staff):	
Potential lack of response	<p>At one scheme staff initially were reluctant to attend the focus group. Their manager was not on site to offer support, but another manager encouraged attendance. Afterwards they said how much they had enjoyed it.</p> <p>At one scheme one of the managers did not take part in the focus groups. It is unclear whether this was by design or due to other commitments.</p>
Limited time availability to participate / time pressures on the day	The management participants struggled to find time to attend the focus groups, and sometimes did not notify the researcher in

Prior assessment of practical issue	Experience within the research
	advance. The researcher split focus groups or rescheduled them to accommodate organisational requirements.
Privacy	Not an issue as all meetings took place in private meeting rooms.
Potential focus group fatigue.	Not experienced. Participants were only required to attend two focus groups each.
For the researcher	
Balancing sufficiency of interviews and focus groups with time taken to transcribe /analyse the data	There was a tight schedule in the first phase, but it was achieved. Changes to second phase focus group meetings resulted in a more prolonged schedule of meetings and eased the pressure of transcription deadlines.
Recording / interpreting non-verbal communication of group members	The use of audio recording enabled the researcher to focus on non-verbal communication. At the end of each focus group a 'research note' was written by the researcher which captured any issues observed. Quality assurance was provided by Local Authority Stakeholder Engagement and Consultation Team who attended the focus groups. The researcher and SECT member shared views at the end of each meeting.
Ensuring individuals have sufficient time to contribute when mental capacity may fluctuate	Issue did not arise.
Venue and payment for refreshments	Small grant received from University of Sheffield for fieldwork expenses.
Ability to 'fund' any field project work	Small grant received from University of Sheffield for fieldwork expenses

Prior assessment of practical issue	Experience within the research
Design method and accessibility / ease of understanding by participants	Supporting materials had been developed in case needed to help stimulate discussion within the focus groups. The issue did not arise. All participants understood the process and actively engaged in discussions without additional materials.
Feasibility of drawing together more focus groups within timeframe of the research study	Achieved with the support of senior managers.
Scheduling the last set of specialist individual interviews within the field work time table	Potentially problematic as the researcher needed to analyse focus group data and confirm the draft theories back with participants before agreeing the lines of enquiry and best participants for the individual interviews. This was achieved by bringing forward other research tasks within the research programme; the overall timetable was achieved.

APPENDIX 7: CASE STUDY SITES

Case study 1 in the East Midlands

Market Position Statement for older people key points within district/borough

Town A has a population of just over 104,000 people (the third highest number in County in which it is situated). With a comparatively small geographic area town has by far the highest population density in the county. According to Indices of Multiple of Deprivation (IMD) scores, town A is the second most deprived part of the county.

Of town A's population, 20% are aged 65 and over, which is about average for the county. It should be noted that higher levels of deprivation are correlated with certain lifestyle issues that impact on health and wellbeing, notably poor diet, smoking, a higher level of alcohol consumption and a lack of exercise. Town A also has a relatively high proportion of people providing unpaid care.

Key points for Town A:

- 3,358 people provide 50 hours or more informal care each week;
- 9,510 people are aged 65 and over and have social care needs (4,800 'high' and 'very high');
- 1,350 people over the age of 65 live with dementia;
- 14% of households (6% of the population) are people aged 65 and live alone;
- 887 residential and nursing care beds are currently available in 25 settings;
- 55 local authority commissioned Extra Care apartments are available at Potters Place;
- 220 day care places are available across ten locations;
- There is a mixed market of domiciliary care available.

Source: *Strategic Direction for XX County Council Older Person's Residential Care Services 2015-2020* Appendix 1

Case study 2 in the East Midlands

Market Position Statement for older people key points within district / borough 2

The district / borough has a population of 113,170 and covers a relatively small area bordering two cities to the east and west. The second case study site is in town B, one of two main towns in the east of the district / borough. The geography may lead to some variability in where people want to go for service provision.

Town B has the third highest level of deprivation in the county and so there may be concerns around lifestyle issues. The district / borough has the second highest number of carers in the county.

Key points for town B:

- 2,917 people provide 50 hours or more informal care each week;
- 8,480 people aged 65 and over have social care needs (3,830 'high' and 'very high');
- 1,500 people over the age of 65 live with dementia;
- 12% of households (5% of the population) are people aged 65 and over and live alone;
- 1,058 residential and nursing care beds are currently available in 32 settings
- 200 day care places are available over a week;
- 61 local authority commissioned extra care apartments are available
- There is a mixed market of domiciliary care available.

Source: *Strategic Direction for xx County Council Direct Care Older Person's Residential Care Services 2015-2020 Appendix 1*

There are an estimated 913,600 people over the age of 65 in the East Midlands in 2017 (Institute of Public Care, 2018). Using the Elderly Accommodation Counsel statistics, together with the County Council's Market Position Statement information, and Public Health England dementia profile (Public Health England,

2016) a picture for towns A and B emerged⁷⁸, which is set out in the Table 1 below:

Indicator	Town A	Town B
People over the age of 75 (with all levels of need including those with no needs)	8,530	8,260
People with 'high' and 'very high' social care needs over the age of 65	4,800	3,839
People aged 65 and over predicted to have dementia (these are not necessarily mutually exclusive of those with high and very high social care needs) * see Note 1	1,491	1,560
Approximate number of specialist older person housing units for rent or sale (based on latest EAC information in 2013).	176	179
Number of designated extra care scheme supported by the Council	1 * Note 2	1 * Note 3
Number of residential care beds	To be confirmed	To be confirmed * Note 4

Table 1: Pen picture of Town A and B older person population

Note 1: The level of dementia prevalence has traditionally been under-reported, but the impact of the enhanced service specification for facilitating timely diagnosis and support for people with dementia (NHS Commissioning Body, 2013) (NHS England, 2015) may have resulted in a swing towards more accurate reporting since 2014⁷⁹

Note 2: There is only one designated extra care scheme in district / borough - town A, which opened in 2014 providing an additional 55 extra care units.

⁷⁸ Figures taken in 2015-16 at the time of scoping the case study sites for the research.

⁷⁹ An enhanced service specification is a requirement placed on General Medical Services through their contractual arrangements with NHS England commissioning body.

Note 3: There is only one designated extra care scheme supported by the Council in district / borough – town B, which opened in 2015 providing an additional 61 extra care units.

Note 4: Case study 2 site provides 16 dedicated residential care beds to support for individuals with dementia.

Distinctive features of the two case studies:

Three distinctive features in each case study in this research are set out in Table 2 below including reliance on public subsidy, entry criteria, and size of the schemes.

Distinctive factor	Cast study site 1, Town A	Case study site 2, Town B
Reliance on public subsidy	No public subsidy was required to develop the scheme. The scheme was developed and designed to be 'affordable' or below local market rent, and there are a proportion of residents who will be reliant on housing benefit.	No public subsidy was required to develop the scheme. The scheme was developed and designed to be 'affordable' or below local market rent, and there are a proportion of residents who will be reliant on housing benefit.
'Selection' or 'entry' criteria adopted by managing organisations	Allocation for extra care managed by panel including local authority adult care social work, the Registered Housing Provider, the District / Borough Council housing officer, and the domiciliary care provider. Where there is no consensus the deciding vote lies with the Registered Housing Provider.	Allocation for extra care managed by panel including local authority adult care social work, the Registered Housing Provider, the District / Borough Council housing officer, and the domiciliary care provider. Where there is no consensus the deciding vote lies with the Registered Housing Provider. Allocation to the residential dementia beds is through the local authority with final decision made by Registered Manager ⁸⁰ .
The size of the schemes	55 two-bedded extra care apartments	61 two bedded extra care apartments 16 specialist dementia care residential unit Day service

Table 2: Distinctive features in the two case studies

⁸⁰ In line with the responsibilities of a Registered Manager under Care Quality Commission requirements

**APPENDIX 8: CRITERION FOR SELECTING PARTICIPANTS FOR INDIVIDUAL INTERVIEWS
WITHIN THE EXTRA CARE RESEARCH**

Inclusion criteria	Exclusion criteria
<p>(1) Interviewees will be sought who, between them, represent the following organisations:</p> <ul style="list-style-type: none"> • National • Regional • Not for profit 	<p>(1) Interviewees will be excluded from private sector commercial organisations.</p>
<p>(2) Interviewees will be sought who have a role in quality management, performance management or service development in extra care</p>	<p>(2) Individuals who are not able to speak English to the standard required for day-to-day business transactions and interview purposes.</p>
<p>(3) Interviewees will be included, if possible, who are both new and experienced in quality management, performance management or service development</p>	
<p>(4) Potential interviewees will not be excluded on the basis of their race, ethnicity, gender, age, religion, or disability. If possible there will be positive selection to ensure that both males and females are represented.</p>	

APPENDIX 9: REVIEW OF LEVEL OF PARTICIPANT INVOLVEMENT AND COLLABORATION ACHIEVED IN THE EXTRA CARE RESEARCH

The scale used by the researcher to depicts the degree of participant involvement and collaboration was scored from 1 – 4:

Level 1: No influence

Level 2: Opinions actively sought by the researcher

Level 3: Active involvement and participation

Level 4: Full partners and use research finding for own purposes

Plan, Act, Check, Review Model	Description of involvement and collaboration achieved	Researcher view: level of involvement and collaboration achieved
Plan: negotiate each stage of the grounded theory research process		
Design and practicalities	<ul style="list-style-type: none"> • Initial discussion took place with key players within the field of extra care and dementia about the intended outcomes of the research • Initial discussion was held with key organisational representatives about the research model and how it can achieve the intended outcomes, and whether it can be supported by their organisations. • An exploratory meeting with managers at both proposed case study sites took place to discuss the research, the intended outcomes, and to gain feedback and ideas on how best the case study phase could be conducted • An early meeting was held with residents at the schemes to discuss with them the best method of involving them to achieve the desired outcomes 	Level 2
Potential lines of enquiry	<ul style="list-style-type: none"> • The questionnaire was influenced and reviewed by key players in the field of extra care and dementia to ensure it is fit for purpose (Housing LIN) • The Local Authority Stakeholder and Engagement Team reviewed the questions 	Level 2

Plan, Act, Check, Review Model	Description of involvement and collaboration achieved	Researcher view: level of involvement and collaboration achieved
	and provided feedback on their ease of understanding by potential participants	
Analysis and development of theories	<ul style="list-style-type: none"> Participants not involved in planning for the analysis 	Level 1
Validation	<ul style="list-style-type: none"> Participants not involved in planning for the analysis 	Level 1
Dissemination of results	<ul style="list-style-type: none"> Discussion held with senior managers in each case study organisation about possible feedback mechanisms including newsletters and presentations to key staff groups 	Level 2
Act:		
Collect the data	<ul style="list-style-type: none"> Participants willing to share experiences through group discussion and enable it to be recorded. Two participants completed environmental assessments / audits⁸¹ to collect the data as a benchmark to the researcher's data 	Level 2 Level 3
Compare experiences, code, and develop categories from the data	<ul style="list-style-type: none"> Researcher undertook initial comparisons and coding but validated the outcome of the coding through focus groups to ensure that participants agreed with the interpretation of data and analysis. 	Level 2
Identify concepts and move towards a nascent theory	<ul style="list-style-type: none"> Researcher undertook initial identification but validated the emerging concepts and nascent theory through focus groups and interviews. 	Level 1/2

⁸¹ An environmental assessment of the community area in each extra care scheme was undertaken by a member of County Council staff using the Enhancing the Healing Environment assessment tool (The King's Fund, 2014). In one scheme a resident was supported to use the tool to assess how dementia friendly his apartment was.

Plan, Act, Check, Review Model	Description of involvement and collaboration achieved	Researcher view: level of involvement and collaboration achieved
Check:		
Test the relevance of concepts	<ul style="list-style-type: none"> Validated the relevance of the concepts though focus groups and interviews 	Level 2
Identify new information to further develop the theory	<ul style="list-style-type: none"> Participants suggested other extra care sites to use as comparisons 	Level 2
Review:		
Test whether saturation point has been reached with additional information adding little to the theory	<ul style="list-style-type: none"> Participants only involved at the close of each individual focus group or interview 	Level 1
Agree how best to present the findings to different target audiences	<ul style="list-style-type: none"> Discussion was held with the group of case study participants on whether they would like to be involved in the wider dissemination of findings to other professionals outside the case study sites 	Level 2
Evaluate participant involvement in the research process and whether lessons can be identified	<ul style="list-style-type: none"> Informal discussion at the feedback session with participants at the end of the fieldwork phase. 	Level 2

APPENDIX 10: EXTRA CARE HOUSING RESEARCH: ETHICAL ISSUES COVERED BY THE NATIONAL SOCIAL CARE RESEARCH ETHICS COMMITTEE

1. Design of the project and the extent of participant involvement

A mixed-method qualitative approach to the design of the project was proposed to explore whether individuals with dementia can live well in extra care housing. It was important that elements of the project were developed jointly with participants as far as possible. A phased approach was considered most appropriate to support participants to contribute; with focus groups and interviews as the primary methods used to develop a theoretical model.

The study aimed to involve residents, carers, front line staff, managers, policy makers, commissioners and developers in exploring whether or how best extra care can support individuals with dementia to live well. Separate focus groups and interviews for residents, staff and managers were used to explore different participant group perspectives. The focus groups and interviews covered three areas that were thought to impact on individuals with dementia in maintaining their personhood, independence and wellbeing. The three areas were determined from a limited initial literature review, researcher a priori experience, and a pilot questionnaire. They included the culture within the scheme, the possible opportunities afforded, or constraints imposed by organisational structures, and the built environment.

The contribution of people living with dementia was considered essential, but careful consideration was given to whether the research could be undertaken without involving people who lacked mental capacity. The lived experience of those with dementia was needed to gain a nuanced understanding of the opportunities and barriers that they face, and so it was proposed that the research include individuals with dementia whose mental capacity may be borderline or may fluctuate. As part of the ethics approval process it was

determined that the research would not include participants who lacked capacity to take part (NRESC, 2016).

The researcher consulted the South Yorkshire Dementia Research Advisory Group on the possible qualitative methods that could be used most effectively with residents living with dementia. It was suggested that focus groups and interviews would be appropriate, but that other supplementary activities could also be beneficial, such as spending time in the schemes with residents and walking around the building whilst observing and interviewing residents. The use of such supplementary activities was agreed with scheme managers and participating residents at the beginning of the fieldwork phase of the research study.

2. Eligibility to take part in the research

Site 1 and Site 3 were approved as case study schemes by the two Registered Housing Providers. Permission was given for managers and front-line staff to be involved in the research.

All people living within the extra care scheme were eligible to volunteer to participate in the study, which sought to gain the views of those both with and without dementia living in the schemes. Family members and friends were also eligible, as they could contribute different perspectives. Opportunities for residents and family members to be involved both together and separately were to be offered so that their different perspectives could be heard. At Case study scheme 1 one daughter came to the initial briefing to hear about the research, but then did not take part. The daughter of a different resident at case study 1 site was interested in taking part but did not have enough spare time to meet the researcher.

Consideration was given to achieving a representative balance of participants from the extra care population in terms of age, gender, ethnicity, disability, level of need, and type of tenancy agreement. All available types of tenancy agreements were represented at both schemes. The profile of residents is

outlined in detail in Section 3.3.1. Information on level of need and disability was not explicitly gathered. From meeting residents, the researcher was able to ascertain that those who participated had various levels of both physical and mental disability, and a range of different levels of need.

The resident target group included residents without dementia, residents with early stages of dementia who retain mental capacity to decide to be involved in the research, and residents who have supported people living with dementia. Residents with fluctuating mental capacity were to be included if appropriate, but this situation did not arise. Staff from the scheme were available to support any individual if it was not appropriate for them to continue taking part during any specific activities, but they were not required.

3. Recruitment of participants

Participant involvement was through self-selection. Initially the researcher contacted potential participants by writing to all residents, staff and managers inviting them to open meetings to discuss the research. The scheme managers also advised residents and family that the researcher would be available to discuss the research informally in the café or communal areas of the schemes. The researcher worked with the scheme manager to encourage staff, residents and family members to find out about the project. Where individual residents expressed interest in taking part a personal visit by the researcher was arranged to clarify the expectations and obtain consent.

4. Consent of participants to be involved in the research

Participant information sheets were provided to each participant detailing what would be involved. Information sheets were tailored for each target group. A written consent form was sought from each participant, with a separate consent form for the researcher to take audio recordings and photographs. Both the participant information sheet and photo/audio consent forms were produced in 'easy read' versions to help explain what was required. As the research may have included individuals whose mental capacity fluctuates the researcher

adapted the information to enable a mental capacity decision to be made on an individual basis, in line with the Mental Capacity Act. The person would have been given personalised information and then asked whether he or she wished to take part in the project. Any expressed choices would have been recorded and reviewed each time the person participated in a project activity. In line with the Mental Capacity Act, if the individual was unable to fully express their decision, others that know them would have been asked for a view on whether it was in their best interests to participate. In line with the ethics determination, if the person did not have capacity to decide they would not be involved, but sensitively redirected towards other meaningful activity.

5. Potential risks, burdens and benefits to participants

The research aimed to be inclusive and involve participants in developing the study, with participants valued for their contribution to defining best practice in supporting individuals to live well with dementia. The involvement of participants was not intended to be intrusive, imposing or cause distress. Steps were taken to ensure that individuals were comfortable in participating, and that the environment was familiar by running activities and focus groups within the extra care scheme. A facilitative approach was used in focus groups to enable each participant to contribute. The researcher monitored the group for signs of withdrawal, fatigue or anxiety. Staff from the scheme were on hand to support the researcher if any individual participant needed to move away from specific activities. This assistance was not required.

Where participants raised issues that caused concern for themselves or others the researcher limited inappropriate disclosure, and discussed the matter separately with them, including any course of action that could have been taken. This occurred once. The researcher considered that there could have been a potential risk of harm to the participant and the matter was raised with the County's Safeguarding service. No further action was required. A detailed list of potential risks and burdens for research participants is outlined in Appendix 11, together with steps that would be taken to minimise them.

6. Confidentiality and privacy

Use of personal contact data was restricted to use of personal addresses, phone numbers and emails to support participation in the project. Profiles of participant personal details were gathered from the consent forms (socio-demographic such as age, gender) and recorded centrally using pseudonyms.

The data generated by the research activities, including transcripts, photos, audio recordings, were anonymised as far as possible. Care was taken when reporting findings to remove any identifying characteristics.

All data were stored securely, and data processing was done in accordance with the Data Protection Act 1998. The Chief Investigator acted as custodian for the data generated by the project, which were restricted to the research team. The University of Sheffield was the Data Controller for all information stored on the University's secure computer drive, accessible only by the research team. The researcher's laptop was used to capture temporary data whilst at the extra care scheme. The laptop was encrypted, and information was transferred to the University shared drive on return to a network connection. Any data was deleted from the laptop once transfer was complete. Personal data will be kept securely in line with the Data Protection Act for three years after the end of the research study, allowing time for any issues of validity to be pursued. Any personal data will then be destroyed.

APPENDIX 11: ETHICAL ISSUES, POTENTIAL RISKS AND BURDENS FOR RESEARCH PARTICIPANTS

Ethical issues surrounding personhood, dementia and maximising the inclusion of people with dementia in research underpinned this study (O'Connor & Purves, 2009; Murphy et al, 2015) which set out to:

- I. Provide a comfortable setting, which would encourage individuals to participate and prevent distress to participants.
- II. Ensure the researcher was responsive, flexible and adaptive to participant needs and that the design was adjusted appropriately to reflect insights provided through ongoing contact with participants, data collection and analysis.
- III. Make sure that any participation and contribution was through informed consent, and that confidentiality and privacy were maintained, unless there was any serious threat of harm to others.
- IV. Be undertaken transparently and honestly, both intellectually and in demonstrable behaviour. Interviews or observations were stopped when saturation point was reached.

The potential risks or burdens that could occur arising for any participant from their involvement in the research are described below, together with what steps would be taken to minimise the risks and burdens as far as possible.

(1) Risk of distress:

Participants may be anxious about discussing the subject of dementia. Support and living arrangements can be an emotive subject for some individuals.

Steps to be taken: The researcher will attempt to put individuals and groups at their ease in an accessible and comfortable setting to encourage participation. Activities will take place within the extra care scheme, where participants are at home and are easily able to return to their own private space (their apartment) if they wish to do so. The researcher will have already started to establish a

rapport with participants through introductory meetings, and additional visits can be arranged to overcome any specific anxieties.

(2) Risk of breach of confidentiality, including through use of audio recordings:

Steps to be taken: In seeking consent for an individual to take part in the study the researcher will share with the individual the steps that will be taken to ensure there are no breaches of confidentiality (see also the Participant Information Sheets). Consent to take part in the research will be covered when participants agree to join the research. At the beginning of each activity the researcher will remind participants that an audio recording may be made to support data analysis and will reassure participants that confidentiality will be maintained unless there is a serious threat of harm to a participant or someone else.

If participants object to audio recording this will be negotiated with them. There may be occasions when it is agreed that a recording will not be taken, in which case the researcher will take confidential notes. Care will be taken to avoid accidental breach of confidentiality, in both verbal communications and written analyses and reports.

(3) Risk of participants' situation changing which could affect the nature of their involvement:

Steps to be taken: Settling in time will be provided before each research activity so that any change in circumstances can be acknowledged and accommodated. During the research activities the researcher will be responsive, flexible and adaptive to participant needs and will adjust appropriately to reflect insights provided through ongoing contact with participants, data collection and analysis.

(4) Risk that research discussions are intrusive or cause tensions within a group

Steps to be taken: Participants may be unwilling to discuss some items whilst there are other people in the focus groups, in which case the researcher will

move on to the next topic for discussion. If the research discussion causes tensions within the group of participants, the researcher will acknowledge the differences and validate the contributions of all participants to the research. There is a risk that discussion in focus groups or other activities might give rise to complaints by participants about the extra care service they receive. If that happens the participant will be advised to follow the appropriate complaints route or advised to contact the local authority for advice and support.

(5) Risk that the research activity is not appropriate to the target group - people whose mental capacity may fluctuate

Steps to be taken: Any additional activities other than focus groups and interviews will be negotiated with participants at a specific meeting in November. Care will be taken that any activities, such as observation, do not impinge on participants' private lives. Research activities will not involve personal care to avoid any inappropriate intrusion. Any focus groups, interviews, observations or other activities will be stopped when saturation point has been reached. A member of the extra care staff team will be identified who may be called during a research activity should additional support be required if someone becomes distressed, needs personal care support or shows fatigue.

If any anxiety or distress is experienced which is likely to last beyond the immediate research activity a discussion will be held with the individual about what the best source of support for them might be. If such a discussion is not possible due to fluctuating mental capacity of a participant, action to support the best interests of the participant will be discussed with those in a position to advise in line with the Mental Capacity Act. Where appropriate, and with the individual's consent, members of the extra care staff team will be advised of the incident.

(6) Potential for the research activity to cause a burden for the participant

Steps to be taken: Research activities will take place at the extra care schemes to minimise disruption to daily living or working routines for those involved. For those who do not work or live at the extra care schemes consideration will be given to minimising travel arrangements as far as possible. Where it is necessary to travel, and participants do not belong to an employing agency that will pay travel costs, then costs will be offered to participants (e.g. resident family members). Care will need to be taken to ensure that any payment does not negatively impact on benefits that a participant may be receiving. If appropriate the travel costs may be substituted for a gift voucher at a nominal figure of £10 per focus group attendance. Individuals will be advised to seek advice if they are unsure of the impact on their own financial situation. The cost of personal care required specifically to enable a resident to participate in the research will be paid using the standard hourly rate for a service that can be negotiated by the Local Authority's contracting service.

(7) Potential disclosure of abuse or harm

Steps to be taken: There is potential that involvement in the research may empower a participant to highlight that one or more participants or other residents in the extra care scheme are experiencing abuse. If this is suspected the researcher will discuss it initially with the individual(s), if that is practicable, and will make a referral to the Local Authority's Safeguarding Vulnerable Adults service.

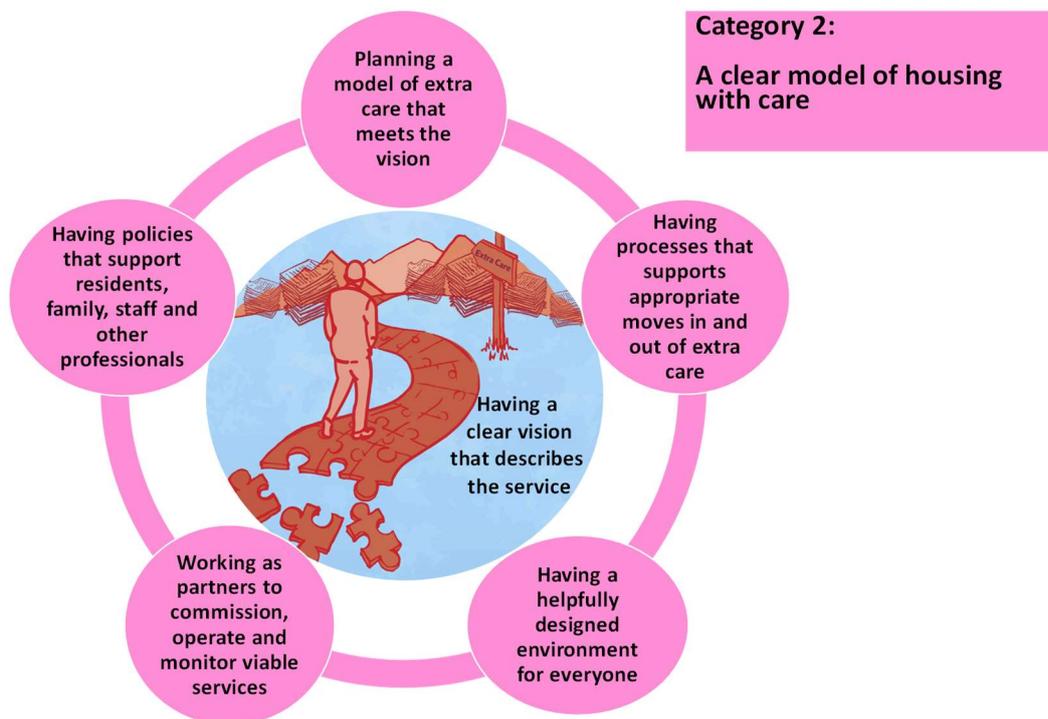
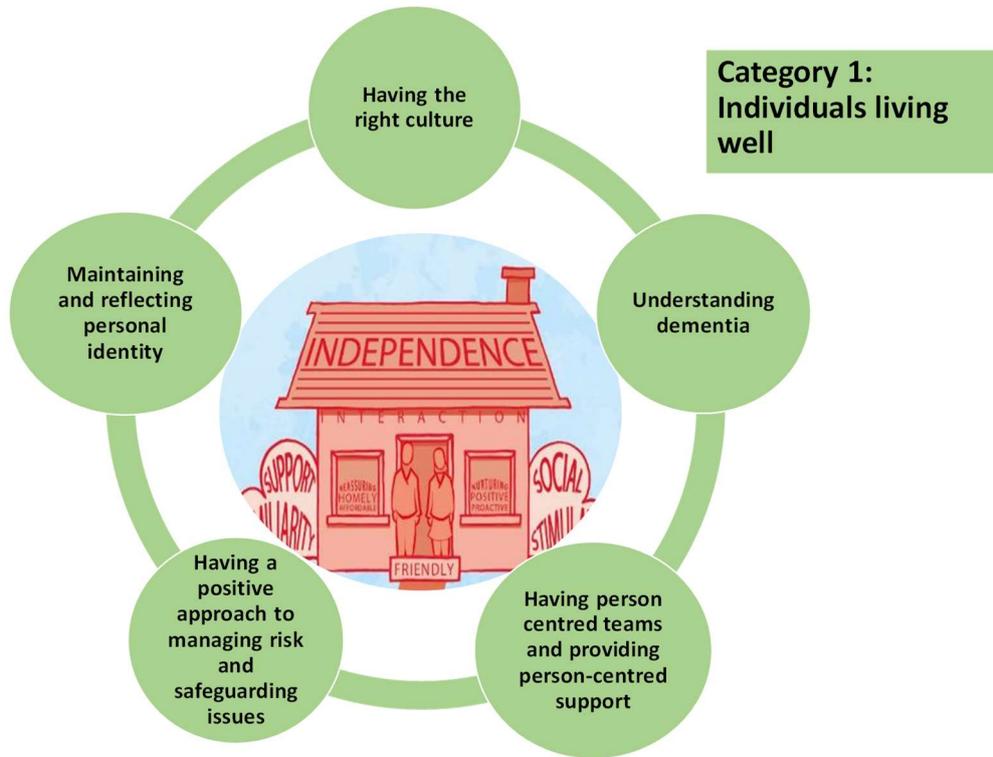
APPENDIX 12: MATCHING GROUNDED THEORY TO THE CORE ASPECTS OF CRITICAL REALISM

Requirement of Critical Realism	Core aspects of grounded theory
<p>The methodology should be capable of operating across the epistemological paradigms.</p> <p>Critical realism accepts attempts to uncover power-knowledge and socio-political agendas. (Fleetwood, 2013)</p>	<p>Grounded theory was intended to be useful to a range of different perspectives (Glaser & Strauss, 1967)</p>
<p>Critical realism lends voice to those who are relatively powerless. Ontology does not refer just to material issues. Anything is real if it has a causal effect (Fleetwood, 2013)</p>	<p>Grounded theory provides an open approach; the researcher shouldn't impose preconceived ideas (Gibson & Hartman, 2014)</p>
<p>Knowledge derives from uncovering causal mechanisms. Critical realism uses methodologies that are causal – explanatory. That is:</p> <ul style="list-style-type: none"> • 'Explanatory' because its objective is to explain • 'Causal' because it explains in terms of providing a causal account (Fleetwood, 2013) 	<p>Theories generated should work, and should explain how the concerns of those in the area are resolved (Gibson & Hartman, 2014)</p>
<p>Critical realism suggests all knowledge be seen as tentative and fallible. Good practice requires the humility to listen to other perspectives and to abandon our own in the face of countervailing evidence. (Fleetwood, 2013)</p>	<p>Theories should be generated from data rather than verified against preconceived ideas (Gibson & Hartman, 2014)</p>
<p>Critical realism has stratified, emergent and transformational, entities, relations & processes (Fleetwood, 2013)</p>	<p>Theories generated should have a specific structure, for example a proposition about the relatedness of different categories to each other (Gibson & Hartman, 2014)</p>
<p>Critical realists seek vertical explanations which link events and experiences to their underlying generative mechanism. (Oliver, 2012)</p>	<p>The research process becomes more and more theoretically controlled by ideas that have developed in the research (or truth-tracking) (Gibson & Hartman, 2014)</p>

APPENDIX 13: DEMENTIA DECLARATION OUTCOMES MATCHED TO CONCEPTS FROM EXTRA CARE RESEARCH THEMATIC ANALYSIS

	Dementia Declaration - outcomes for people living with dementia and their carers				
Concept	We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it	We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.	We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.	We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future	We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part
Developing skills and competence			Yes		
Having a clear vision that describes the service	Yes				
Having a helpfully designed environment for everyone		Yes			
Having a positive approach to managing risk and safeguarding issues	Yes				
Having a process to support appropriate moves in and out of EC	Yes	Yes			
Having person-centred teams and providing person-centred support				Yes	
Having policies that support residents, family, staff and other professionals			Yes		
Having the right culture	Yes	Yes	Yes	Yes	
Having the right facilities for the location		Yes			
Helping people to take part		Yes	Yes	Yes	
Maintaining and reflecting personal identity	Yes	Yes	Yes	Yes	
Managing capacity and resources			Yes		
Managing relationships	Yes	Yes			
New staff roles			Yes		
Promoting wellbeing and access to nature		Yes			
Providing strong leadership	Yes	Yes	Yes	Yes	Yes
Research					Yes
Respecting privacy/reducing unwanted isolation	Yes	Yes			
Support from informal carer / partner				Yes	
Understanding dementia			Yes		
Working as partners to commission, operate and monitor viable quality services			Yes		

APPENDIX 14: CONCEPTS WITHIN EACH OF THE CATEGORIES IDENTIFIED IN THE EXTRA CARE RESEARCH





APPENDIX 15: THE DEVELOPMENT OF THE QUALITY MOVEMENT

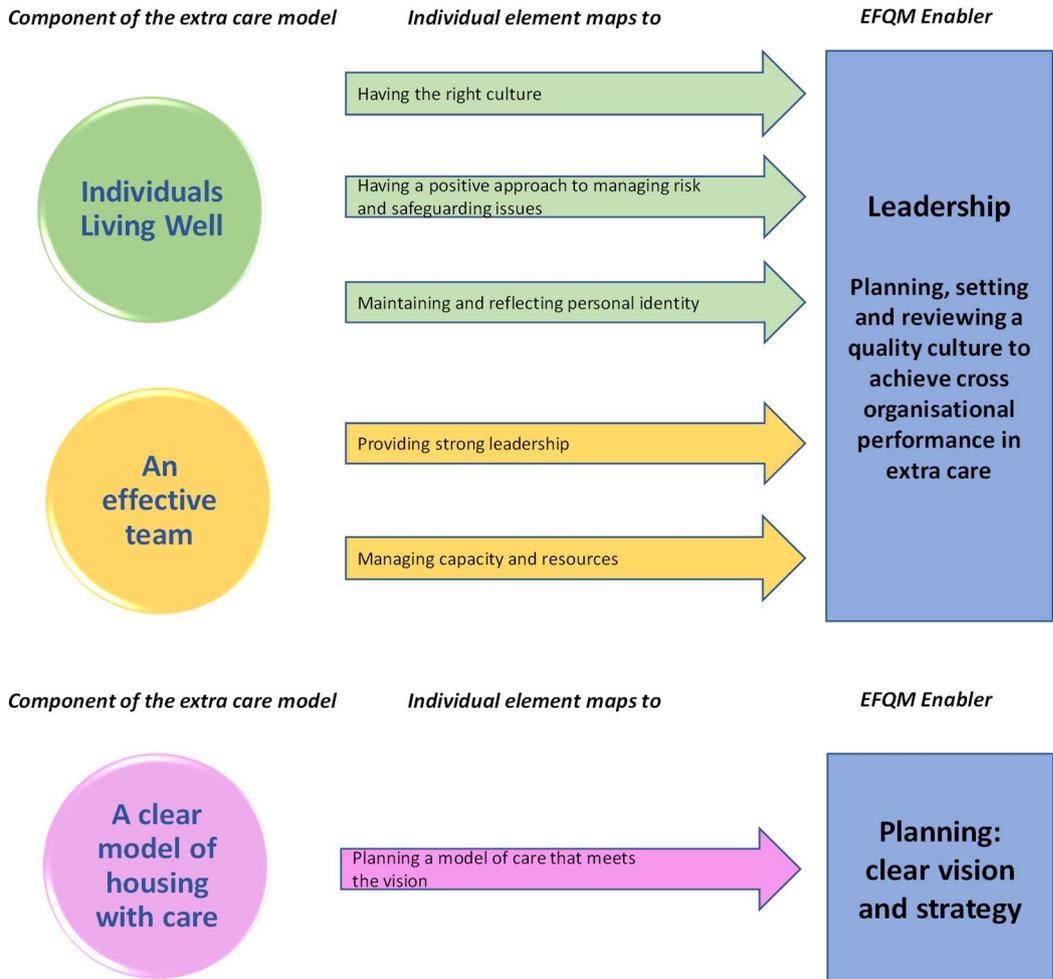
Timeframe	Quality leaders	Comment	Associated Frameworks
<p>1920s: Key work on quality control and statistical theory. Very early introduction of statistical process control.</p>	<p>Walter Shewhart</p>	<p>Developed an iterative four-step management method used in business for the control and continual improvement of processes and products.</p>	<p>Plan-Do-Check-Act cycle (PDCA).</p>
<p>1940s: Japanese industrial leaders invited Deming, Juran and Feigenbaum to advise on production of innovative high-quality products.</p> <p>1950s: Juran, Deming and Feigenbaum helped consolidate quality control and management in Japan</p> <p>1950s – 60s: Deming and Ishikawa popularised Quality Circles as a way of getting employees to help solve problems.</p> <p>Late 1960s: Total quality term first used by Feigenbaum, and Ishikawa</p>	<p>W Edwards Deming</p>	<p>Developed a philosophy of management including Deming's '14 points'. Popularised the PDCA cycle, which later became known as the Deming Cycle.</p>	<p>Deming Cycle PDCA.</p>
	<p>Joseph Juran</p>	<p>Pioneered quality and quality management. Developed an improvement cycle to reduce the cost of poor quality by planning quality into the product/process.</p>	<p>Juran Trilogy: quality planning, quality improvement and quality control.</p>
	<p>Armand Feigenbaum</p>	<p>Developed total quality control based on three steps to quality which included having quality leadership, modern quality technology, and organisational commitment to quality</p>	<p>PAF model used to make decisions about quality based on costs associated with Prevention, Appraisal and Failure.</p>

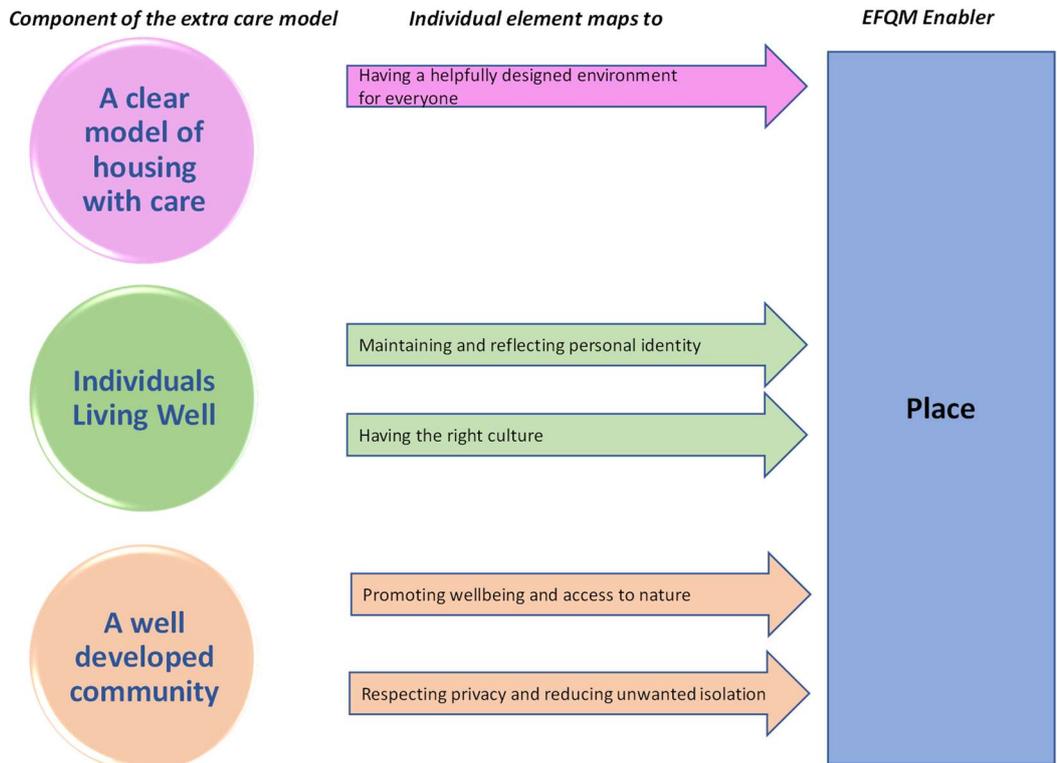
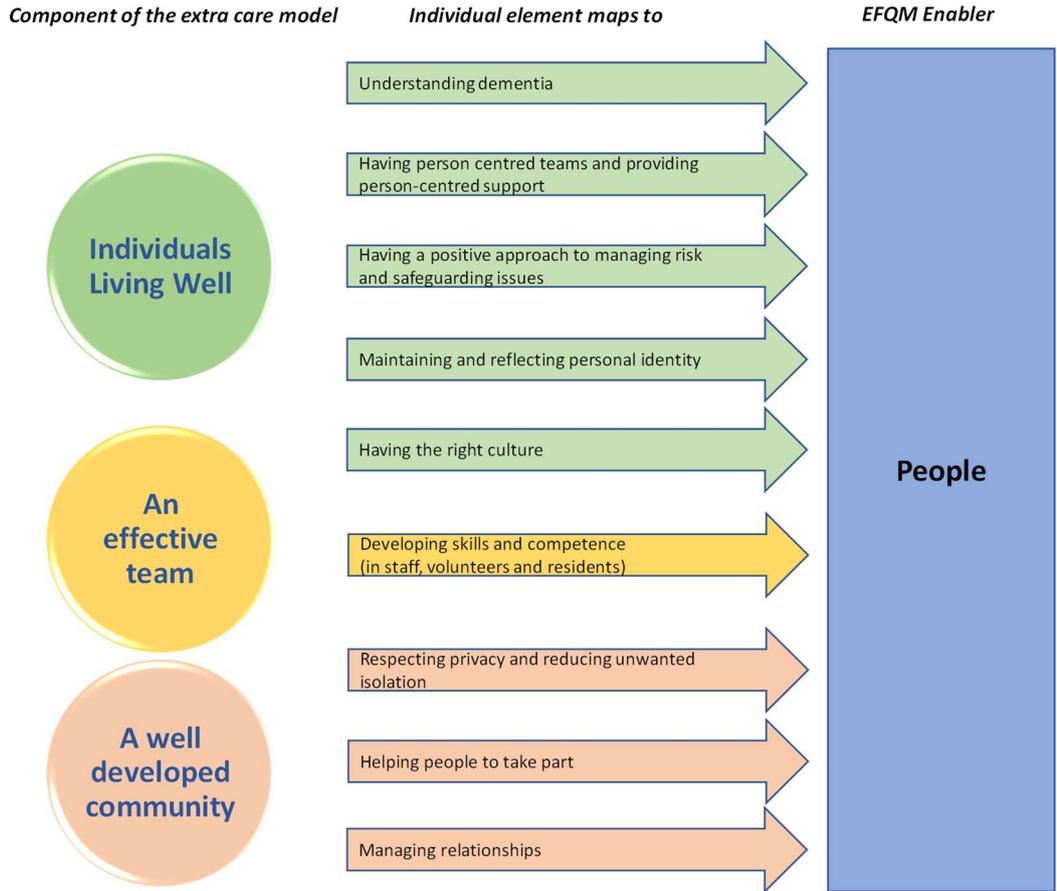
Timeframe	Quality leaders	Comment	Associated Frameworks
introduced Total Quality Control.	Kaoru Ishikawa	Known for popularising basic tools of quality and the philosophy of total quality.	Ishikawa Diagram used to consider cause and effect.
1980s: Lean production was introduced in Japan by Shigeo Shingo and developed to include concepts such as zero defects by Philip Crosby	Genichi Taguchi	Developed the idea of 'designing in quality' so that the design process was less sensitive to variation	The Taguchi methodology for robust design.
	Shigeo Shingo	Developed concepts of lean production which were widely used in the manufacturing industry. More recently they have been adapted by others to the service industries.	Poka-Yoke (mistake proofing) Just in Time (JIT) Lean manufacturing based on Toyota Production System.
	Philip Crosby	Developed the idea that quality improvement pays for itself through savings, increased revenue from more satisfied customers, and competitive advantage.	Zero defects: sets the goal of a quality programme to eliminate all defects, not just to reduce them to an acceptable level.
	A range of western companies introduced their own quality initiatives under the umbrella term of TQM.	A new phase of quality control and management developed in the west. Total Quality Management (TQM) covered a broad spectrum of quality-focused strategies and techniques within the western quality	TQM model, which brought together existing quality tools such as quality circles, problem solving, and statistical process control.
1980s – 1990s The term Total Quality Management developed from Ishikawa's earlier			

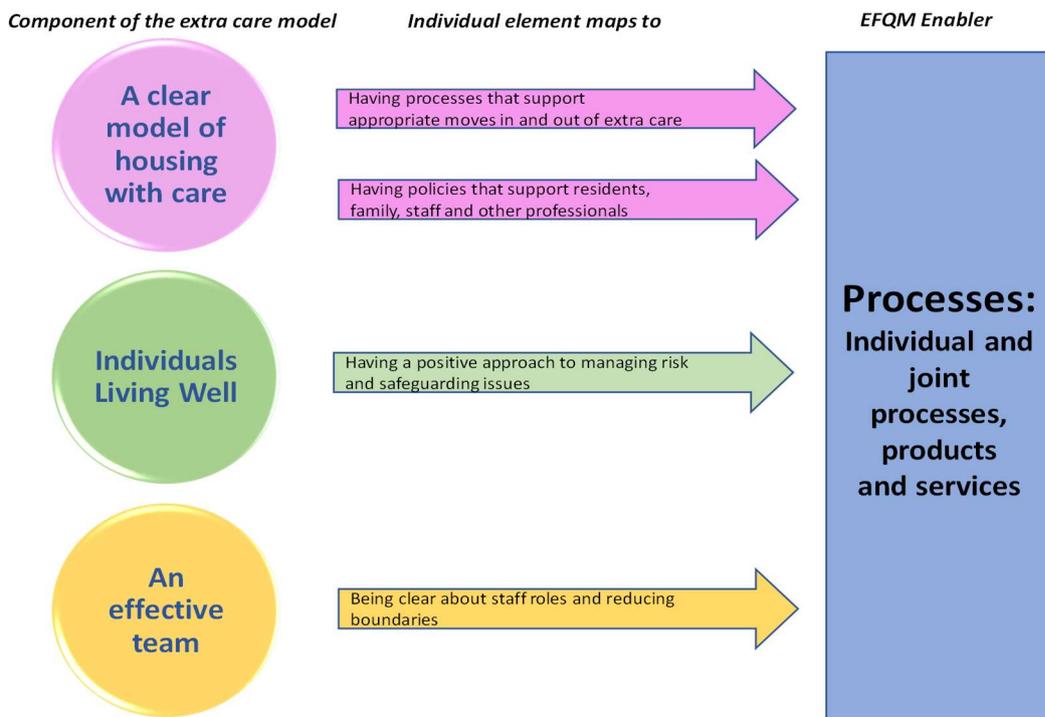
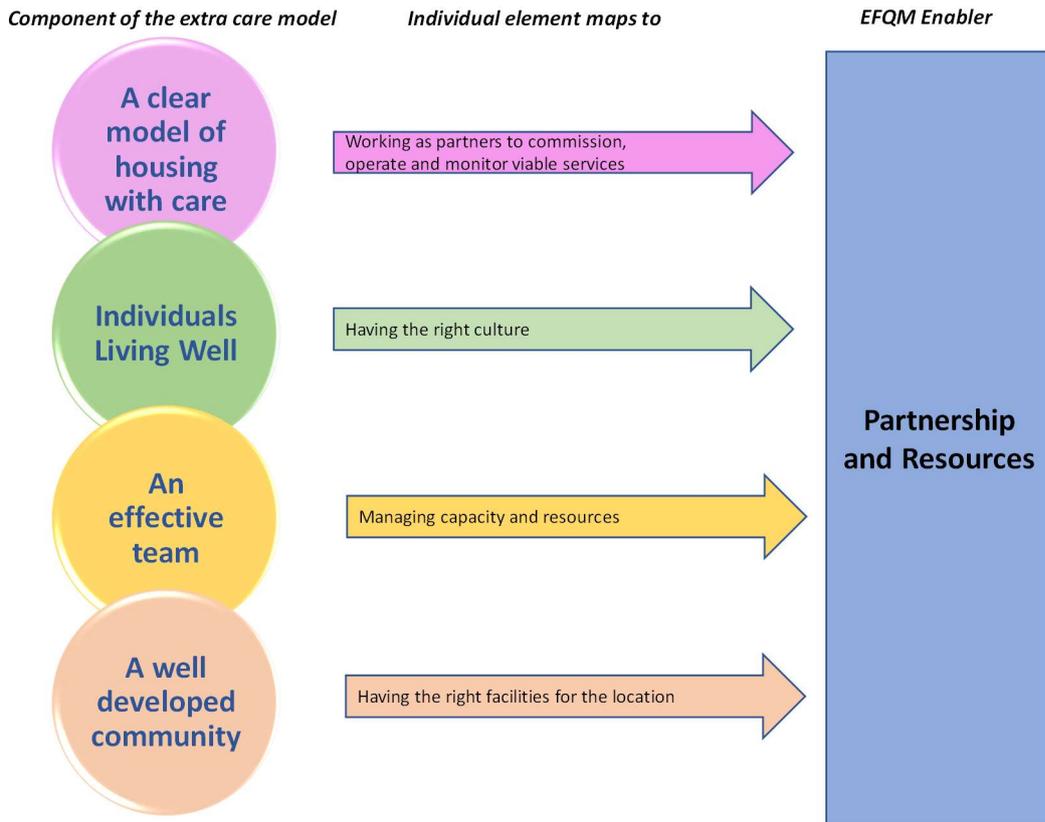
Timeframe	Quality leaders	Comment	Associated Frameworks
Total Quality Control.		movement. A TQM model was developed as the basis for US quality award the Malcolm Baldrige Award.	
Total Quality Management became the basis or promoting quality through awards.	On 15th September 1988, 14 European Business Leaders met with Jacques Delors and signed a "Letter of Intent" to form a European Foundation dedicated to increasing the competitiveness of European businesses.	European Foundation for Quality Management developed a European version of TQM for a European Quality Award.	The European Foundation for Quality Management (EFQM) Excellence Model
Business Excellence or Operational Excellence developed as a clearly defined approach to Total Quality Management.	John Oakland	TQM or Business Excellence provides a way of managing organisations to improve every aspect of performance, both internally and externally.	Oakland model for TQM
Systems for measuring and balancing customer satisfaction in relation to quality and profitability	Robert Kaplan and David Norton	Developed benchmarking tools and balanced scorecards to measure quality	Balanced Scorecards
	Various	The theory, practice and applicability of	

Timeframe	Quality leaders	Comment	Associated Frameworks
start to be developed.		the TQM movement in relation to public sector and academic environments is supported and challenged in USA and UK.	
<p>21st Century:</p> <p>Performance management frameworks are consolidated in local authorities.</p>	Various	Performance management became increasingly target driven in public sector services. There is greater focus on outcomes as well as financial measures. There is greater emphasis on service improvement and capability.	The Government consolidates National Service Frameworks, National Indicators and National Performance Frameworks to maintain quality of service in NHS and local authorities. Public sector scorecard is introduced.
Lean introduced into public sector services in UK and US		Lean methodologies introduced. Focused on developing behaviours throughout the organisation that continuously improve value, flow and performance by using a range of Lean tools.	Kaisen workshops, also known as Rapid Improvement workshops, process mapping, '5S', value stream mapping and, visual management

APPENDIX 16: EXTRA CARE HOUSING MODEL COMPONENTS MAPPED TO EFQM ENABLERS







APPENDIX 17: CRITICISMS OF THE BALANCED SCORECARD

Source: Vukomanovic & Radujkovic (2013)

Criticism of Balanced Scorecard	Author(s)	Year
The balanced scorecard doesn't align strategy with the competitive environment	Sinclair D, Zairi M	1995
The model is over simple	Kagioglou, M, Cooper R, and Aouad, G.	2001
The model doesn't cover all aspects of performance		
The four perspectives are not universal and not sufficient	Bontis, N; Dragonetti, N; Jacobsen, K; Roos, G	1999
The balanced scorecard is only designed for specific industries	Papalexandris, A; Ioannou, G; Prastacos, G; Eric Soderquist, K	2005
Too little significance is given to critical success factors (strategic objectives)		
The model lacks basic guidelines for selecting indicators of key performance	Dror, S	2008
There is a presumption that some things cannot be measured and that there is conflict of different functional managers within functional lines	Letza, S	1996
There are potential risks when implementing the balanced scorecard including measuring the wrong things in the right way		
The model has complex feedback from the financial perspective to other perspectives	Dror, S	2008
The causal relationship between indicators is questionable	Norreklit, H	2000
The scorecard doesn't allow benchmarking to be conducted	French, S	2009

APPENDIX 18: POTENTIAL BENEFITS AND DISADVANTAGES OF TQM, EFQM AND BALANCED SCORECARDS WITHIN EXTRA CARE HOUSING SCHEMES

Potential benefits	Potential disadvantages
All three models are appropriate for service organisations (with some adaptations for servicescape and service culture),	Within charitable and public sectors, it is less easy to plan for long term due to insecurity of funding or organisational structures which may make it more difficult to implement the models in the first instance.
Vision and strategy serves as the input to the models and can be clarified through the implementation process if necessary.	Extra care partner organisations may find it difficult to reconcile their different visions and strategies into a single shared vision and strategy that can be used in the models.
Deployment of the models provides top management with a vehicle to communicate the vision and goals of the scheme across all stakeholders	Deployment of the models relies upon leadership and top management support, which is located outside the local extra care schemes.
Involving employees in developing and implementing a new model generates 'buy in', can empower people, and help create a culture change.	Implementation of any of the models is not a 'quick fix', it is a 'journey'.
EFQM and balanced scorecard facilitate control of key success factors in an organisation and provides evidence on which to base decisions to improve organisational activities.	EFQM may not lead to benchmarking with other organisations.
TQM and EFQM focuses limited resources on those aspects that are important to customers and will improve the service.	May be resource intensive to implement.
The use of the balanced scorecard and EFQM allows for causal links to be made between determinants and results of performance.	There may be internal resistance to measuring, creating a barrier for implementation of a balanced scorecard.

Potential benefits	Potential disadvantages
All three models allow for adaptation and tailoring to the organisation.	One integrated balanced scorecard for extra care may not be achievable as extra care partners need to report separate measurements to different regulatory bodies.
TQM and Public Sector Scorecards leads to systematic and routine deployment of improvement or innovation across the scheme.	EFQM and Balanced Scorecard do not offer specific guidelines on problem identification and offer no structured approach to exploiting strengths or classifying and prioritising areas for improvement.

Sources: (George, et al., 2003; Rusjan, 2005; Bou-Llusar, et al., 2009; Moxham, 2010; Dreveton, 2013; Vukomanovic & Radujkovic, 2013; Perramon, et al., 2016; Moullin, 2017)