

Home or care? Capacity or incapacity? An ethnographic study of how capacity and best interests are decided for people with dementia on discharge from hospital

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Thesis submitted for the degree of Doctor of Philosophy in
the Faculty of Medical Sciences at Newcastle University

December 2017

Abstract

Whether people with dementia can make their own decisions regarding where they live on discharge from hospital is a complex but frequent and routine decision faced by multi-disciplinary teams working in general hospitals. The decision has potential to impact significantly on the lives of people with dementia and their relatives. In England and Wales, decisions must be made within the legal framework of the Mental Capacity Act (2005) and are based on judgements as to whether the person with dementia has capacity to make this decision, or whether they lack capacity and a best-interest decision must be made for them. There is little empirical evidence available about how these decisions are made in practice.

The aim of this thesis is to explore and understand the interpretive work in which practitioners engage, to make sense of, and enact the MCA when making judgements on the capacity of people with dementia to make decisions about place of residence on discharge from hospital.

Ethnographic methods were used to conduct this exploratory research in three hospital wards. The perspectives of people with dementia, their relatives and health and social care professionals were captured through observations, interviews and analysis of medical records. The data from 29 patient cases were analysed using constant comparative methods and grounded theory and interpreted using social science theory.

The findings illustrate four aspects of the enactment of the MCA: interpretation of the Act and how this impacts on capacity assessment; key narratives influencing capacity judgements; complexities of managing binary notions of capacity; and the involvement of people with dementia in decision making in the context of best interests. Issues with the enactment of the MCA within the medical context are then reflected upon.

The conclusions highlight the relevance and unique contribution of this work. Implications for practice are suggested, which may improve the outcomes of capacity assessment, best-interest decisions and hospital discharge for people with dementia, their relatives and practitioners.

Contents

Abstract.....	i
Contents.....	iii
List of figures and tables.....	ix
Acknowledgements.....	xi
Chapter 1. Introduction	1
1.1 The issue	1
1.2 Addressing the research gap	3
1.3 Research aim and objectives	5
1.4 Thesis overview.....	6
1.5 Personal motivations	7
Chapter 2. Background	11
2.1 Introduction	11
2.2 A brief overview of the impact of dementia.....	11
2.3 Dementia and medical influences	12
2.3.1 The medicalisation of dementia.....	14
2.3.2 Dementia and hospitalisation	15
2.3.3 Medicalisation of decisions about place of residence	16
2.4 Dementia and decision making.....	17
2.4.1 Dementia and communication.....	19
2.4.2 Dementia and risk	20
2.5 Dementia, citizenship and agency	22
2.5.1 The social movement of people living with dementia.....	22
2.5.2 Human rights approach to care for people living with dementia.....	24
2.6 The legal context and the MCA.....	24

2.7 Defining and determining mental capacity	28
2.8 Judgements on mental capacity	29
2.9 Determining best interests	31
2.10 Summary	36
Chapter 3. Theoretical and methodological approach	37
3.1 Introduction	37
3.2 Social gerontology.....	37
3.3 Social constructionist theory	39
3.3.1 Social constructionism and dementia	40
3.3.2 Cultural sociology	44
3.4 Medical ethics	46
3.5 Methodology.....	46
3.5.1 Hospital ethnographies	46
3.5.2 Challenges of conducting observations in the acute hospital environment	48
3.5.3 Methodological challenges of including people with dementia in research.....	50
Chapter 4. Methods.....	55
4.1 Ethnographic methods.....	56
4.2 Research approvals	56
4.3 Consenting participants	57
4.4 Sampling strategy.....	59
4.5 Fieldwork.....	62
4.5.1 Observations	62
4.5.2 Reflective notes.....	64
4.5.3 Interviews.....	65
4.5.4 Review of patient medical records	66
4.6 Data Analysis.....	67
4.6.1 Analytical framework	67

4.6.2 Coding.....	67
4.6.3 Memos.....	68
4.6.4 Case histories	69
Chapter 5. Interpretive work and assessment of mental capacity.....	71
5.1 Introduction	71
5.1.1 Defining informal and formal approaches to assessment	72
5.2 Informal and formal approaches to mental capacity assessment	73
5.2.1 Getting to know the patient.....	75
5.2.2 Formalising the informal	80
5.2.3 Documenting assessments.....	85
5.2.4 Formal or finite?.....	88
5.3 Insight, awareness and the decision-specific nature of capacity assessment	88
5.3.1 Judgements on insight and awareness	89
5.3.2 Fluctuating insight and awareness – Mr Miner’s questionable insight?	93
5.3.3 Insight or agreement with the MDT?.....	96
5.3.4 Lacking insight? Mr Miner talks “gibberish”	97
5.3.5 Unwise decisions	99
5.4 Chapter summary	103
Chapter 6. Invisible and visible work - capacity narratives, and specialist assessment....	107
6.1 Introduction	107
6.1.1 Defining objective and subjective approaches to capacity judgement	108
6.2. Doubling the patient account.....	109
6.2.1 Collateral history – the narratives of family and others	113
6.2.2 Pre-admission narratives – Mrs Carter at home	114
6.3 Practitioner narratives	117
6.3.1 Ward round narratives	117
6.3.2 The MDT meeting and Mrs Friar’s “madhouse”	119

6.3.3 Written narratives – medical records	123
6.3.4 Back to the future	126
6.4 Specialist assessment.....	127
6.4.1 Defining specialist assessment.....	127
6.4.2 Accounts versus assessments	128
6.4.3 Cognitive tests and assessment	130
6.4.4 Old Age Psychiatry assessment.....	134
6.4.5 Home visit assessment.....	137
6.5 Chapter summary	146
Chapter 7. Complex cases and enacting binary notions of mental capacity	149
7.1 Introduction	149
7.1.1 Defining borderline mental capacity.....	149
7.2. From borderline to binary outcomes.....	152
7.2.1 Medical discourses influencing mental capacity judgements	153
7.2.2 Behavioural discourses influencing mental capacity judgements.....	156
7.2.3 Cognitive discourses influencing mental capacity judgements	160
7.3 Who makes capacity decisions?	164
7.3.1 Senior medics and decision making	164
7.3.2 Other practitioners and decision making.....	166
7.4 Chapter summary	168
Chapter 8. The involvement of patients and their relatives in decision making and discharge outcomes.	171
8.1 Introduction	171
8.1.1 Tensions between autonomy and beneficence in best interests.....	171
8.2 Patient involvement.....	173
8.2.1 Challenges of exploring patients’ wishes and preferences.....	181
8.3 Family involvement.....	183

8.3.1 Judgements on relatives as advocates.....	184
8.3.2 Planning meetings and family involvement.....	185
8.3.3 Conflicting concerns.....	187
8.3.4 Challenging the MDT.....	189
8.3.5 Countering challenges and clinical risk.....	192
8.4 Risk management and achieving the ‘appropriate’ discharge outcome.....	194
8.4.1 Reducing risks.....	195
8.4.2 The appropriate place?.....	200
8.5 Chapter summary.....	207
Chapter 9. Discussion.....	209
9.1 Implementation of the Mental Capacity Act in other contexts.....	210
9.2 Residence decisions and mental capacity – a social decision in a medical context.....	211
9.2.1 Clinicians as decision makers for a non-clinical decision?.....	214
9.3 Binary notions of mental capacity and patient involvement in decision making.....	218
9.4 Social Science in interdisciplinary research.....	224
9.4.1 Reflections on my theoretical and methodological position as observer.....	224
9.5 Strengths and limitations.....	231
9.6 Summary.....	233
Chapter 10. Conclusions.....	235
10.1 The unique contribution of this thesis.....	236
10.2 Current relevance to practice.....	237
10.3 Reviewing the legal framework in practice.....	239
10.4 Recommendations for good practice.....	240
10.5 Concluding comments.....	242
Appendix A. Statement of contribution.....	i
Appendix B. Participant information.....	1
Appendix C. Consent forms.....	i

Appendix D. Interview schedules	i
Appendix E. Glossary	i
References	1

List of figures and tables

Figure 1. Five statutory principles of the MCA.....	26
Figure 2. The legal test of mental capacity.....	29
Figure 3. Best interests checklist	33
Figure 4: Data sources use to construct case histories	70
Figure 5: All patients by capacity status – lacking, borderline and with capacity.....	151
Figure 6: Capacity outcome for all patients	152
Table 1. Characteristics of the 29 patient cases.....	60
Table 2. Home visit assessments by patient.....	138

Acknowledgements

This study was supervised by the Institute of Health and Society, Newcastle University. I would like to express my most sincere gratitude for the many years of support of the supervisory team, Prof Julian C Hughes, Dr Katie Brittain, Prof John Bond and Prof Elaine McColl. I would like to thank Prof Catherine Exley, Prof Carl May, Dr Ben Heaven and Dr Claire Dickinson for their guidance as annual assessors.

I owe many thanks to the Institute of Health and Society for their continued support, with specific thanks to valued colleagues in IHS, including Ms Claire Bamford and Prof Louise Robinson.

The ACBID research was funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit programme (PB-PG-0906-11122). I would like to acknowledge the input and support of the ACBID team – Prof Julian C Hughes (PI), Prof John Bond, Ms Charlotte Emmett, Dr Helen Greener, Dr Stephen Louw and Prof Louise Robinson, with administrative support from Mrs Angela Mattison. Although the team did not contribute directly to this thesis, the project work and the support of colleagues significantly influenced this work.

I am grateful to the many health and social care staff on all three hospital wards, who were supportive of the research and without their assistance and co-operation the fieldwork would have been impossible. These thanks extend to the two healthcare trusts which supported the fieldwork.

I express my particular appreciation of the 29 people with dementia and their families who kindly shared their invaluable insights and experiences at a particularly vulnerable and emotional time.

Lastly I would like to say a heartfelt thank you to my husband Andrew, and daughters Esme and Dulcie for supporting me through this long journey.

Chapter 1. Introduction

1.1 The issue

Whether a person with dementia is able to return home after an inpatient stay in hospital can be a difficult and complex decision. For people with dementia, their relatives and health and social care practitioners, this becomes a judgement about whether the person will return to their usual place of residence – their own home in the community – or whether they now require an institutional placement. Central to the decision-making process is whether the patient has capacity to make this decision, or whether they lack capacity and the decision must be made by others. On the face of it, these resemble straightforward decisions with binary outcomes: capacity or incapacity and home or a care placement. However, for all involved, this decision is characterised by numerous tensions. For example, the person with dementia has their own wishes and preferences, and their right to make choices is enshrined within the law and the Mental Capacity Act (MCA) (*Mental Capacity Act 2005*). Families may or may not support these decisions and are likely to also have their own preferences and choices. Practitioners in the hospital have a duty of care to their patients and have an ethical code of conduct which governs their work.

This grossly over-simplifies the interplay of roles and judgements involved in these decisions and does not reflect the myriad tensions which are encapsulated within such situations. People with dementia may be considered unable to make rational choices – perhaps by their families or healthcare professionals, or maybe both. Rationality determines the choices and decisions people must make in life. These range from routine to increasingly cognitively complex decisions, which involve processes such as deduction and causality and are influenced by social structures, such as the law, alongside individual values (Ritzer, 2013). Families may be reluctant or unable to agree with practitioners about the best outcome. The multi-disciplinary team (MDT) on the ward may wish to protect people from risk or harm rather than uphold their wishes for independence. Three quotes below – a quote from this research, an extract from case law and an extract from a government report – illustrate the magnitude of this decision and issues raised when thinking about hospital discharge for people with dementia and their ability, as judged by healthcare professionals, to make such decisions themselves.

The first quote is from an interview with Mrs Gardiner, one of the 29 patients with dementia included in this research. She described the dilemma which she faced about whether to return home or move into a care home for extra support.

... and that's what the debate's all about... whether do I go back into the house that I haven't sold or kept it... I haven't lived in it for a while.... it's not as if I've ever wanted to leave ...it's a semi-detached, it's nothing wonderful, and they're worried about me going back in it because it's two storey and it's got a steep staircase and they're frightened I fall."

Interview with Mrs Gardiner

The example illustrates two main issues – that Mrs Gardiner wishes to return to her home of many years where she has lived happily; and that “they” – the medical team – are concerned about her safety on discharge. These issues and tensions are commonly encountered in practice and are in no way unique to this research. An example from case law in which the judge ruled against the views of the health and social care professionals and independent experts involved, highlights the complexity of issues of capacity and best interests and how much the concept of home and independence mean to individuals.

Likewise, I consider her frank observation that ‘if I fall over and die on the floor, then I die on the floor’ demonstrates to me that she is aware of, and has weighed up, the greater risk of physical harm if she goes home. I venture to think that many and probably most people in her position would take a similar view. It is not an unreasonable view to hold. It does not show that a lack of capacity to weigh up information. Rather it is an example of how different individuals may give different weight to different factors.

Mr Justice Baker, (CC v. KK and STCC, 2012)

In this example, the judge recognised the strength of feelings that individuals attach to remaining at home in the community when faced with decisions about moving to a care home and acknowledges that these feelings are not unreasonable. The last quote, from the House of Lords Select Committee on the Mental Capacity Act, illustrates that the enactment of the MCA in practice remained problematic six years post-implementation and concerns persist that the Act is poorly understood and enacted by practitioners.

...the Mental Capacity Act, when it was passed, was rightly seen as a progressive piece of legislation. It moved away from paternalism towards the enhancement of autonomy, which is welcome. From our evidence and what we have seen, the problem with the Mental Capacity Act is really one of implementation, and a lack of understanding among those who have to apply it on the ground.

House of Lords Select Committee, ('Unrevised transcript of evidence taken before the Select Committee on the Mental Capacity Act 2005,' 2013)

This extract from the report highlights tensions between core ethical values such as paternalism and the wish to protect people from harm, versus autonomy and the rights of individuals to exercise personal and independent choice.

Considered all together, these three quotes from different stakeholders demonstrate the impact of such decisions at a societal and personal level. They highlight many aspects which make decisions about mental capacity and best interests concerning place of residence on discharge from hospital for people with dementia particularly complex. These quotes indicate the presence of multiple and differing values and perspectives and how these must be respected but balanced in practice within the context of the law. Most importantly, these quotes present a sense of the significance and enormity of the decisions faced by people with dementia, their families and practitioners, and the consequences of getting the right outcomes. In the frankest terms, the question becomes, can patients with dementia make their own choice about going home on discharge from hospital?

1.2 Addressing the research gap

When this research was undertaken, between June 2008 and June 2009, the literature evidenced that there was relatively little known about how the MCA was applied in practice in relation to judgements on mental capacity and best-interest decisions for people with dementia in relation to decisions about residence on discharge from hospital. The research therefore sought to address this gap through providing an in-depth exploration of these judgements and decisions, to facilitate better understanding and improved practice.

Although conducted almost ten years ago, this research remains relevant in our current social culture, in which there remains a lack of awareness of the abilities, capabilities, wishes

and rights of people with dementia, and the law which intends to uphold these rights. This research therefore contributes to raising awareness of the importance of recognising and respecting the place of people with dementia in our society and their rights to involvement in making important decisions about their future.

The research was conducted as part of a government funded project - the ACBID project (Assessment of Capacity and Best Interests in Dementia on discharge from hospital) - funded by the National Health Service (NHS) National Institute for Health Research (NIHR) under the Research for Patient Benefit programme (PB-PG-0906-11122). The project adopted a multi-disciplinary team approach to explore and describe the process of how mental capacity and best interests are determined in practice in relation to discharge from hospital. The ethnography had the broad remit of gaining a better understanding of how the MCA was being implemented in practice through observing the practice of assessment of capacity, best-interest judgements and hospital discharge for people with dementia in the hospital setting. I was the sole researcher involved in data collection and this thesis comprises further and new analysis of the ethnographic data, through the lens of social science theory.

As junior researcher and social scientist, my role was to conduct ethnographic fieldwork within the hospital setting to provide data which could be analysed to better understand how the MCA was enacted in practice and whether this could be improved. I had considerable autonomy in this role, which enabled me to develop my own style for conducting and recording observations and interviews and responsibility for collecting all field data. My lead role in data analysis enabled me to develop insights and themes from the data for the purposes of the research project, but also to pursue ideas through a social science lens and examine issues beyond the scope of the project. This facilitated a more in-depth analysis of the data which informs this thesis and enabled the exploration of specific issues relating to the interpretation and application of the MCA which were not addressed through the project. The team produced a range of publications and disseminated the key findings of the research and important messages for practice in terms of medical, ethical and legal issues. These have been reported in several peer-reviewed publications (Greener *et al.*, 2012; Emmett *et al.*, 2013a; Emmett *et al.*, 2013b; Hughes *et al.*, 2013b; Emmett *et al.*, 2014; Poole *et al.*, 2014; Hughes *et al.*, 2015) and presented at regional, national and international conferences (Poole, 2009; Poole, 2010; Poole, 2011a; Poole, 2011b; Poole, 2011c; Emmett and Poole, 2012; Emmett and Poole, 2013; Poole, 2014).

Informed by social science paradigms, this thesis provides an original interpretation of the research findings and the MCA in practice. Interpretation of the ethnographic data focuses on the social construction of the MCA, which is played out in discussions and documentation which inform judgements on mental capacity of people with dementia, and their ability to make decisions to return home from hospital.

1.3 Research aim and objectives

The aim of this thesis is to explore and understand the interpretive work in which practitioners engage, to make sense of, and enact the MCA when making judgements on the capacity of people with dementia to make decisions about place of residence on discharge from hospital.

The objectives are:

- 1) To understand how practitioners make sense of the legal framework and apply this in practice by describing the interactions, processes and interpretative work which take place behind the scenes and in the 'private' spaces of medical practice, which impact on judgements of mental capacity.
- 2) To explore and gain an understanding of the complex nature of social relations embedded in judgments about mental capacity.
- 3) To use social science theory to critique binary notions of mental capacity and enhance understanding of the application of the MCA in relation to discharge from hospital for people with dementia.
- 4) To describe if and how people with dementia are included or excluded in decisions about place of residence on discharge from hospital.

The thesis is the first to explore the experience of hospital discharge for people with dementia in the context of mental capacity from the view of all key stakeholders involved. It considers the social meaning of the Mental Capacity Act, addressing how it is understood and implemented in practice by the health and social care professionals working in the acute hospital environment. Interrelated to this, is the social meaning of dementia, and how the condition is understood by professionals, people with dementia and their families. This research shows how these meanings are interpreted and enacted and how this impacts on

decisions about whether people with dementia are able to make their own decisions about where to live on discharge from hospital.

Applying social science perspectives to understand this significant body of data provides new insights from the ACBID project data and supports a broader, more culturally rooted understanding of how the MCA was understood and applied by health and social care practitioners in their daily practice within the hospital setting. This facilitated providing a rich description of how capacity is assessed for people with dementia specifically relating to decisions of residence, enabling the identification of both good practice and areas for improvement. This makes the areas which prove particularly challenging for practitioners more visible, reflecting an applied Health Services Research approach (Bowling, 2014) to better understand and evaluate practice which informs recommendations for improvement.

1.4 Thesis overview

The exploratory research sets out a detailed view of the 29 cases of patients with dementia who experienced the process of hospital discharge and subsequent judgements about their mental capacity. The findings illustrate the kinds of interactions, judgements, processes and decisions involved in the assessment of mental capacity and determination of best interests relating to discharge decisions concerning place of residence. The intention is to identify how people with dementia and their families can be optimally involved in the major decision about where they live on discharge from hospital. In doing this, it also explores the difficulties which face practitioners in the medical setting, in implementing the MCA in practice. The lens of social science theory facilitates this critique.

The background sets out the literature relevant to this research. Social understandings of dementia and the influence of the medical context are considered alongside key definitions and literature relevant to assessment of capacity and determining best interests. The theoretical and methodological approaches which guided the conduct and analysis of this research, are then described.

The research findings are divided into four chapters which explore different, but interrelated aspects of the enactment of the MCA in the context of hospital discharge for people with dementia. The first presents a detailed analysis of how the MCA is interpreted and enacted through capacity assessment. The second considers key narratives of mental capacity, and

how and why certain accounts are prioritised over others. The third explores how practitioners managed binary notions of mental capacity when faced with complex cases. The final chapter focuses on 16 best interest cases, to consider the involvement of patients and their families, and impact on the discharge outcome. The findings are interpreted using relevant social science theories to illustrate the social nature of capacity judgements relating to place of residence.

Discussion of the findings enables reflection on the enactment of the MCA within the medical context, and the way in which the Act supports or inhibits practitioners in this environment to uphold the wishes and rights of people with dementia. The value of social science theory, and the strengths and limitations of the research are also addressed. The thesis concludes by highlighting the currency and relevance of the findings and the implications for improving practice. Thus this work may support health and social care practitioners who are regularly faced with making complex decisions about whether a person with dementia has capacity to make their own decisions about place of residence on discharge from hospital, and any consequent best-interests decisions.

1.5 Personal motivations

Throughout the process of this thesis, I have matured considerably as a researcher. This work has gone on to pique my interest in dementia – shaping my research career – in which I have continued to investigate many aspects of dementia care. In particular, my study and understanding of the MCA continues to influence how I conduct my work and my endeavour to press for recognition of the abilities and rights of people with dementia – both to participate in research – and more importantly to benefit from improved standards of care.

From data collection to producing this thesis has been a long personal journey. This time and process has enabled me to reflect on the social context of dementia and whether this has changed or remained the same over this time. In general, there have been many positive changes. Dementia has received increased media coverage, and continues to be central to a range of key government policies (Department of Health, 2009; Department of Health, 2012; Global Action Against Dementia, 2014; Department of Health, 2015b).

Prominent public faces, media coverage and well-known established charities have led campaigns such as Dementia Friends (Alzheimer's Society, 2017), to raise awareness of and

challenge stigma associated with dementia. These positive changes are welcomed, and are starting to challenge public perceptions of dementia. However, dementia is still feared, and evidence suggests that there is still a long way to go before people with dementia are recognised as autonomous individuals with opinions, values and rights which must be respected. I hope that my work will contribute towards this positive movement.

I care deeply that older people are often written off, or seen as 'past it', with little of value to contribute to society. This is often even more pronounced for older people with cognitive problems, perceived as people who cannot 'do' anything. They run an even greater risk of their lives become taken over by others, and their social status not only being eroded by the condition, but more importantly, by people.

This stems from the privilege I have had of being raised in a family with close intergenerational ties. I have benefited from close relationships with grandparents, great-grandparents and an extended family of many great aunts and uncles. Over the years, they have shared with me their rich and interesting stories containing personal and social experiences, which included overcoming great personal hardship and their contribution to world-shaping events such as the Second World War. What often captivated me was their determination and strength of character. To me, these people are remarkable, but at the same time unremarkable in the sense that this they are just ordinary older people, much the same as the families of many people, all of whom deserve respect and recognition for their contribution to society. These people were strong willed and often held strong beliefs, and I continue to carry an enormous amount of respect for all of them.

In common with a significant proportion of the UK population, several of these relatives experienced dementia, and they all experienced admission to hospital at some point in their condition, leading to decisions around care and residence. My interests and experiences are therefore personal as well as research-led.

Based on my continued learning during this research, and my personal experiences, this respect for older generations extends beyond my family. I feel strongly that this is the time in peoples' lives when they deserve recognition and dignity, and that we as a society should get it right for them. This is equally important for those who are most vulnerable, and most at risk of their wishes, beliefs, feelings and values being misunderstood, ignored, or not acted upon.

I intend that this work will help to continue to challenge the way people think about the abilities and rights of people with dementia to be involved in making important decisions in their lives. I hope it will encourage health and social care practitioners, and families of people with dementia to recognise the valid contribution which people with dementia are able to make. It is critical that the 'voice' of the person with dementia is heard, and not misinterpreted or silenced and marginalised by others, who are fundamental to supporting or inhibiting involvement in making important decisions about their life. Furthermore, this work may also enable people with dementia to recognise their own capabilities and rights, and challenge those who try to close down or diminish their contribution. This is important to me in a general, everyday sense of how people live their lives as well as to the specific decision about place of residence on discharge from hospital.

Chapter 2. Background

2.1 Introduction

The introduction outlined the complex nature of judgements about capacity and best interests for people with dementia in relation to place of residence on discharge from hospital. In this chapter I draw on a narrative overview of the literature relevant to this complex judgement, including issues concerning the experience of living with dementia, and the context of decision making and hospital discharge. I begin with an overview of dementia in a UK and international context, and how this has potential to impact on the hospital population and the significant presence of decisions of this nature which are likely to become increasingly more common. The medical context in which these decisions take place is then explored, including medical models of dementia which commonly influence how dementia is socially conceptualised. Particular issues facing people with dementia which impact on decision making are considered. Literature on citizenship and agency locate dementia in a broader social context considering the rights and values of individuals, which leads on to an overview of the legal framework in which mental capacity decisions are governed. This includes key definitions of mental capacity and best interests. Finally the literature on approaches to assessment of capacity and determining best interests is explored as relevant to the specific nature of decisions concerning place of residence on discharge from hospital.

2.2 A brief overview of the impact of dementia

Dementia is a chronic and progressive condition which leads to decreased brain function in areas such as memory, reasoning and communication skills, and the physical skills required to carry out routine activities of daily living (Hughes, 2011a). In the UK, it is estimated that 1 in 14 people over the age of 65, or some 850,000 people have dementia which will rise to over one million by 2025 (Prince *et al.*, 2014). Globally, the ageing world population is the biggest driver for projected increases in the prevalence of dementia and cognitive impairment (Prince *et al.*, 2013). Worldwide, more than 46 million have dementia, with projections predicting the figure to rise to 131.5 million by 2050. (Prince *et al.*, 2015). Estimates indicate that between 13% and 26% of older people in general hospitals have a formal diagnosis of dementia (Raveh *et al.*, 2005; Inouye *et al.*, 2006), however more recent

research suggests this is a conservative estimate and suggests around 40% of older people admitted to general hospitals have dementia (Department of Health, 2010b). In the UK, people with dementia occupy a quarter of hospital beds, and the need to improve their hospital care is well recognized (Department of Health, 2012). A UK study also reported that almost half (42%) of people over the age of 70 who are admitted to hospital have dementia (Sampson *et al.*, 2009). Currently in the UK, it is estimated that less than half of people living with dementia have a diagnosis (Alzheimer's Society, 2016), which suggests the proportion of people with dementia in hospital may be under-estimated, and also recognises there may also be a significant number of people who also present with cognitive impairment.

For many older people with cognitive impairment, hospital admission for acute medical treatment can be defined as a 'determining event' that may hasten the transition from home into institutional care (Brindle and Holmes, 2005). Freedom over choices regarding where and how to live can be regarded as a fundamental human right and decisions made by others must appreciate this right (Cooney *et al.*, 2004), which may be compromised when patients are judged to lack capacity. Approximately half of care home admissions in the UK occur on discharge from hospital (Bebbington *et al.*, 2001). Therefore older people in hospital with cognitive impairment – with or without a formal diagnosis of dementia – are likely to represent a significant proportion of the general hospital population and decisions regarding place of residence on discharge can be expected to be commonplace, and likely to increase. Thus practitioners will continue to be faced with complex decisions on a routine basis and people with dementia and their families will also have to make decisions about the person with dementia either living in institutional care or returning home after a hospital admission.

Although this provides an overview of the extent of the issue, it does not offer any explanation of the experience or impact that such decisions have on the lives of people with dementia and their families, therefore it is important to explore issues relating to social understandings of the experience of dementia.

2.3 Dementia and medical influences

How dementia is defined and understood in our society is significantly influenced by the medical paradigm. Clinical descriptions of dementia date back to the mid-1700s (Berrios, 2010). Negative stereotypes of dementia or 'senility' and ageing became engrained in

western cultures throughout the 19th century and into the 20th century, with medical pathology playing a prominent role (Ballenger, 2006). In the early 20th century, the medical discovery of 'Alzheimer's disease' through Dr Alois Alzheimer's famous case description of Auguste, D. which described particular clinical facts, symptoms and behaviours has continued to influence and shape current perceptions of dementia (Gubrium, 1986).

Currently dementia is defined as a collection of symptoms, and a progressive disease affecting the brain and its function, causing problems with memory loss, thinking, problem-solving skills, and language (NHS website, 2015); (Alzheimer's Society website, 2015). In addition, this condition may cause wider problems such as hallucinations, problems with empathy, difficulties with social skills and situations, and symptoms such as depression (NHS website, 2015). The International Classification of Diseases (ICD) and Diagnostic and Statistical Manual of Mental Disorders (DSM) are standard diagnostic tools used by clinicians to classify symptoms and diagnose the condition. The current version in use in the UK (ICD-10) includes mental and behavioural disorders including dementia which is categorised into five main diseases/conditions and several sub-types including delirium. Memory loss is highlighted as the key feature (World Health Organization, 1992). Political commitment to early diagnosis via the National Health Service (NHS) (Department of Health, 2009) reflects the problematic perception of the condition and champions early diagnosis as a means of accessing treatment and support. Much of the research around dementia is aimed at "defeating" the condition through biomedical research (Alzheimer's Research UK, 2015).

Access to diagnosis and treatment of dementia is medically managed. When an individual (or family member or friend) is concerned about their memory, they will be signposted to their doctor or General Practitioner (GP) (NHS, 2015). In the UK it is usually GPs, situated in primary health care, who act as a gatekeeper to further medical assessment. The GP will assess the patient, noting their account and worries, then make a judgement as to whether the patient's concerns appear valid and require further investigation. The outcome will be that the patient is either reassured about their symptoms and informed that no further investigation is required at this stage as their presentation is 'normal', or they will be monitored by the GP and possibly referred to secondary care services such as memory clinics for specialist assessment of their cognitive function.

The majority of people in England presenting with symptoms of dementia are assessed and diagnosed through memory clinics (Burns *et al.*, 2014). In this setting, the person with

dementia undergoes a series of standardised medical assessments to confirm the degree of their cognitive impairment as an outpatient. The Mini-Mental State Examination (MMSE) (Folstein *et al.*, 1975) is commonly used in clinical practice and may be used in a variety of clinical settings by a range of practitioners such as by GPs, in memory clinics and in acute hospitals. This assessment is used for diagnosing and monitoring changes in cognitive function specifically in relation to orientation, registration, attention and calculation, recall, and language. Patients are scored out of 30, with scores below 25 indicating cognitive impairment ranging from mild to severe. In addition, patients may be subject to other screening and diagnostic tools such as blood tests, CT (computerised tomography), MRI (magnetic resonance imaging) or SPECT (single photon emission computerised tomography) scans which produce images of the brain and indicate areas of damage (Alzheimer's Society, 2014).

Post-diagnosis, the treatment and management of the dementia and other associated symptoms, for example depression and aggression, are clinically managed in the community, primarily through psychiatric outpatient services and general practice. Common interventions include medical regimens, cognitive stimulation or behavioural support (Alzheimer's Society, 2013; Alzheimer's Research UK, 2016).

2.3.1 The medicalisation of dementia

It becomes clear how medical understandings and clinical management of dementia shape our knowledge; however perceptions of the condition are influenced by other societal factors. Over the last forty years, social science literature has highlighted the existence of a dominant medical model of health and illness in western society (Freidson, 1975). Medicine can be regarded as a major institutional power rivalling religion and law, not only through political means, but by medicalising many features of daily living by attaching labels of 'healthy' and 'ill' to routine, everyday practices and aspects of existence (Zola, 1972). The focus on medical or biomedical models of health and illness emphasise the management and treatment of health and illness rather than considering social aspects (Bond and Bond, 1994). However, health, ill-health, disease and sickness are understood within social and cultural contexts governed by socially agreed and accepted constructs of normality (Russell, 2009). In social models such as that of Parson's sick-role, emphasis on cure and treatment of ill health and the desire to return people to normal and functional states of health from

'deviant' ill-health, requires doctors to act as agents of control (Scambler, 2008), and thus health and illness become medicalised through social processes.

Such concepts have been extended to consider specifically the medicalisation of dementia, in which the pathology of behaviours associated with dementia are defined as a medical problem, which deviates from social norms, giving medical professionals the authority to provide treatment (Bond, 1992). This biomedical model of dementia has been critiqued through social science literature, however medical knowledge continues to dominate knowledge and understanding about dementia despite these challenges (Innes, 2009). This is reflected by examples such as the emphasis on cure and treatment from high-profile organisations such as the Alzheimer's Society who while acknowledging the role of care, prioritise research into the medical management of dementia (Alzheimer's Society, 2015a).

Although a biomedical approach has brought benefits in that it has meant a shift in perspective from 'normal ageing', and the recognition of a need for scientific research, refined diagnostics and medication, there have also been negative consequences (Bartlett and O'Connor, 2010). The negative consequences of medicalisation include expert and social control by medical professionals over diagnosis, treatment and judgements about whether the patient is ill or well; which override lay judgements, and emphasise individual behaviours rather than seeking the social causes (Bond, 1992). Finding a cure through medical research has privileged the biomedical model over the social model and relationships which are integral to providing care are neglected in comparison (Lyman, 1989). Furthermore, biomedical approaches to dementia continue to dominate within the legal context in relation to mental capacity and agency (Behuniak, 2010). In relation to hospital discharge decisions for older people, it has been suggested that reducing medical dominance within multi-disciplinary teams enhances patient care, as this gives voice to the other disciplines and enables sharing of broader relevant information, rather than focusing on medical issues (Gair and Hartery, 2001).

2.3.2 Dementia and hospitalisation

Having set out how dementia is commonly conceptualised within a medical paradigm, it is necessary to describe how hospital admission has the potential to medicalise further how people experience dementia. Inpatients with dementia are a vulnerable and frail patient

group, and have complex social and psychological needs in comparison with other patients (Sampson *et al.*, 2010). Although there have been several recent government initiatives to promote improved dementia care in hospitals in the UK (Downs, 2013b), the negative effect of an inpatient stay for people with dementia is well-documented (NHS Confederation, 2010); (Holmes, 2010; Chenoweth *et al.*, 2015).

The admission may trigger a formal diagnosis of previously undiagnosed cognitive or behavioural symptoms (Twining, 2008). Within the environment of the medical ward, consultants and other health and social care professionals who form the MDT providing treatment and care have a critical role in judgements about mental capacity and discharge decisions. The 'patient' has a medically defined cognitive impairment and, in addition, has some other medical condition(s) which led to their hospitalisation.

Whilst an inpatient, the impact of delirium or acute confusion is another factor which requires careful consideration. Whereas dementia is defined as a chronic confusion, experienced over the long-term, delirium is a short-term episode of confusion usually triggered by an underlying condition such as infection or an adverse reaction to medication. 'Acute on chronic' confusion – a short-term increase of confusion due to a treatable cause, for example a urinary infection – may appear to exacerbate symptoms of dementia (Hughes, 2011a). This may lead to overestimation of cognitive impairment, which in the context of this research may feed into judgements on mental capacity. Indeed many of the patients in this research were thought to experience delirium resulting in increased confusion. Hospital admission therefore creates a situation in which decisions about place of residence for the person with dementia occur within a medical setting and the influence of medical factors may lead to assumptions that this is a decision largely determined by the medical context.

2.3.3 Medicalisation of decisions about place of residence

The decision about residence for a person with dementia may implicitly be influenced by medical factors, even in a community setting. For example, community practitioners such as GPs, Community Mental Health Teams and outpatient Old Age Psychiatry services may become involved in the decisions about place of residence. However, within the context of this research, medical involvement is inherent through the person with dementia becoming an inpatient. The person with dementia is situated in a medical ward, and receiving

treatment for the medical condition which led to their hospitalisation. Therefore medical influences are plainly at the forefront of the decision-making process about place of residence on discharge from hospital.

Although the medical model of dementia is undeniably important to how it is understood and acted upon, peoples' lives extend well-beyond this medical sphere. Before an admission to hospital, people with dementia are leading their lives in the wider community – living at home; interacting with families, friends and neighbours; and engaging with activities and broader institutions. In this research a particular event had brought each of the 29 patients and their families into direct contact with medical services through hospital admission. During this time, normal activities such as shopping, cooking, cleaning and managing bills need no attention. Not only is the person with dementia likely to become deskilled, but their actions and behaviours are subject to clinical scrutiny and judgement over a prolonged period and are documented in medical records. This monitoring processes informs the clinical team on the patient's progress with recovery and leads to the goal of hospital discharge. In the context of capacity assessment and best interests in relation to discharge decisions there is a need for decision makers to establish the social 'facts' in a similar way to which clinical facts are evidenced.

2.4 Dementia and decision making

Decision making is part of everyday life. Some decisions are easy for us to make, whereas others are particularly complex. Decisions can be routine, occurring on a daily basis, such as choosing what to wear or what to eat, however some decisions may be occasional or made on a one-off basis. These more unusual decisions commonly have more significant consequences attached and are often inherently more complex in nature. Examples could include, where to go on holiday, whether or not to get married, have children and where to live. Of course decisions cannot be simply characterised as straightforward or complex and will be influenced by many factors – including the impact on and the influence of others.

For people with dementia, decision making can become increasingly complicated in two main ways as the condition progresses. First, impairment of the brain can affect many of the cognitive functions required to make decisions, such as comprehension, reasoning, retaining information and communication skills. The person with dementia may feel less able or

confident in making some decisions. Second, as others perceive the person with dementia to become increasingly cognitively impaired, they may take over decision making on behalf of the person with dementia. The person with dementia is then at risk of exclusion from making all kinds of decisions, and their values and wishes not respected, threatening autonomy and agency.

Commonly, people with dementia are more likely to be included in decision making when they are in the earlier stages of dementia and have been recently diagnosed, with involvement declining in tandem with the progression of the condition (Miller *et al.*, 2016). However, over time, people with dementia and their families often experience a gradual shift from shared to substituted decision making; moving through a continuum in which their contribution diminishes to the point at which the family carer takes over much of this process on behalf of the person with dementia (Samsi and Manthorpe, 2013). Families may also seek to legally formalise decision making on behalf of the person through Lasting Power of Attorney (LPA), for health and welfare, and property and financial affairs, which was created under the provisions of the MCA (Gov.UK, n.d.). Families therefore play a critical role in the extent to which people with dementia are involved in making decisions, and shared decision making constitutes a broad spectrum of involvement (Miller *et al.*, 2016).

Family members may not always be comfortable with this shift in responsibility, and decisions concerning healthcare and residence are amongst the most difficult for family carers to make on behalf with people with dementia when they are no longer able to make their own decision (Livingston *et al.*, 2010). Family relationships also have an important bearing on confidence in making decisions. In the context of everyday decisions, long term spouses were better equipped than adult children who struggle to make decisions on behalf of the person with dementia (Samsi and Manthorpe, 2013). However, for decisions concerning placement in care, spouses often faced greater difficulty, in the knowledge that they were compelled to act against the wishes of the person with dementia (Livingston *et al.*, 2010), acting in their best interests.

This highlights that people with dementia, and their families and will not always share views and values when making decisions. Carers may have an inaccurate understanding of the person's wishes, but in addition need to balance the values of the person with dementia

with their own needs and concerns about their relative (Reamy *et al.*, 2011). Discrepant perspectives and values may also be present between people with dementia and professional carers, which also impacts on decision making (Dröes *et al.*, 2006). At the root of such discrepant views between people with dementia, family carers and professionals, may be the assumption that beneficence and non-maleficence outweighs personal autonomy; becoming problematic when the person with dementia does not agree with the views of others (Woods and Pratt, 2005). Despite these complexities, and provisions afforded through LPA, many older people and their families do not choose to legally formalise arrangements for decision making when the person with dementia is no longer able to do so, opting instead just to keep arrangements informal and ‘bumble through’ the process (Kapp, 2002).

2.4.1 Dementia and communication

Communication is a key aspect of decision making which has particular significance for people with dementia and others involved in the decision making process. Section 3 of the Mental Capacity Act Code of Practice (Department for Constitutional Affairs, 2007) emphasises the importance of good communication to enable the optimal participation of the person in decision making.

Poor communication has significant consequences for people with dementia and can result in the person feeling ignored and misunderstood, which can have a profound and long-lasting effect on relationships. In addition, if the person is perceived as unable to express their needs, desires, views and wishes adequately, then decisions affecting the individual are likely to be made by others; highlighting the necessity of good communication in enabling the individual to maintain agency and autonomy (Watts and O’Connor, 2017).

To ensure that people with dementia are given the chance to communicate in all possible ways – and most importantly are understood by others – communication must be person-centered; facilitating communication by appreciating the person’s life story, their personality and their rights to express their own wishes and values (Downs and Collins, 2015). However, despite the importance of communication, family carers and practitioners receive little training in how to communicate effectively with people with dementia, which can be easily enhanced by recognising and incorporating basic skills and principles such as: verbal skills; non-verbal and emotional skills; attitudes towards people with dementia; behavioural

management skills; usage of tools, for example memory books and aids; self-experience; theoretical knowledge (Eggenberger *et al.*, 2013).

A range of technologies also exist to enhance communication between people with dementia and others. These have been categorised as low and high tech interventions; with low tech being relevant to improving communication for people with dementia as they are more simple and accessible to incorporate into practice and, commonly providing including visual cues such as writing messages; using books, pictures, objects and symbols, and importantly requiring engagement and interpretation of others (Murphy, 2009). Such technologies can be applied to assist communication and inclusion in decision making, and talking mats have successfully been used in improving everyday care decisions (Murphy and Oliver, 2013).

2.4.2 Dementia and risk

Another important facet of decision making for people with dementia is the impact of perceptions on risk. In this context this relates to perceived risks of people with dementia returning to live at home post-discharge, and how their understanding of these risks influences judgements on mental capacity to undertake this decision themselves.

Participation or exclusion of older people in decision making and hospital discharge plans has been linked to systems of risk management, centred around cognitive and physical ability and judgement on their competence take part in decision making (Huby *et al.*, 2004) .

Individual and societal attitudes to community-dwelling people with dementia shape perceptions of risk. Attitudes to risk and dementia are influenced both by perceptions of risk taking amongst older people and risk management in mental health (Manthorpe, 2004), both of which are commonly fostered on cultural values of protection and seeking to minimise risk taking behaviours. Risks for people with dementia are commonly viewed as something to be managed by others. Others include professionals who often practice within a risk averse culture, which then also influences the attitudes of families, which can lead to a reluctance by all to promote positive risk taking for the person with dementia (Clarke *et al.*, 2011)

Perspectives on the risks facing the person with dementia may not be shared by the person, their relatives and health and social care professionals. From the perspective of the older person, an admission to hospital presents the real risk of having to give up their home and move into institutional care due to illness or increased frailty (Macmillan, 1994). This may translate to risks of losing independence, autonomy, personal choice and liberty as well as removal from a familiar environment to which there may be a very strong emotional attachment. For practitioners determining risks of discharge for people with dementia, returning home from hospital for people with dementia is conceptualised as a context with a particular and specific set of risks, defined by a complex set of risk assessments completed by various members of the multi-disciplinary team, which becomes formalised (Manthorpe, 2004).

Pinpointing specific factors which make returning home risky for the person with dementia is complex. For older people with cognitive impairment, unacceptable risks of living in the community is problematic for practitioners (Strang *et al.*, 1998), and conflicting perspectives must be recognised. What constitutes risks can be defined as a 'contested territory' (Clarke *et al.*, 2010) negotiated between people with dementia, family carers and practitioners. In this negotiated process of risk construction, assessment and management; the risks associated with domestic arrangements are the most commonly disputed. These risks are amplified and attenuated by all stakeholders during this process, however, it is important that the perspectives of families and practitioners must not be prioritised over that of the person with dementia (Clarke *et al.*, 2010).

Furthermore, risks between living in the community and institutionalisation are often not given equal consideration for older people and people with dementia. Although family carers often amplify the risks of the person with dementia living in the community (Clarke *et al.*, 2010), it is unclear whether professionals or families equally consider potential negative risks associated with institutionalisation (Zuckerman *et al.*, 1984).

The association between risky behaviours of people with dementia living at home, and whether they have an understanding of such risks has important implications for judgments on mental capacity. This impacts on whether the person retains or is denied decision-making rights, and their ability to act as autonomous agents.

2.5 Dementia, citizenship and agency

The literature on citizenship and agency provides a useful socio-political lens through which to consider decision making and inclusion of people with dementia in this process.

Citizenship implies active involvement in communities in which individuals are afforded equal status and access to rights and duties without discrimination. However, people with dementia have historically faced discrimination and have been denied social and legal rights (Bartlett and O'Connor, 2007). The central purpose of critical social citizenship is to extend the concept of personhood (Kitwood, 1997) beyond that of the person with dementia as a 'sufferer' to understanding people with dementia as active social agents rather than passive care recipients (Bartlett and O'Connor, 2010). It also recognises the corporeal aspects of dementia, that the bodies of people with dementia as well as their minds have a fundamental role as a means of self-expression and way of exercising human agency, (Kontos, 2005; Kontos and Naglie, 2009; Kontos and Martin, 2013), need and will (Downs, 2013a).

Citizenship therefore has a dual focus – to encourage people with dementia to exercise choice, agency, claim rights, take control, risks and responsibilities – and also to reframe how people with dementia are understood in terms of their capabilities and potential. Thus it provides a socio-political perspective as a challenge to biomedical and psychosocial approaches (Bartlett and O'Connor, 2010). This notion of citizenship therefore resonates with the legal context in which decisions about mental capacity and best interests take place. The majority of human decision making remains private. Legal intervention occurs to evaluate decisions and decision making when the decision has legal consequences or implications for the self or others and when there are concerns over the person's ability to protect their own best interests incorporating notions of vulnerability and capacity (Hall, 2009).

2.5.1 The social movement of people living with dementia

As part of the movement towards citizenship and empowerment, people with dementia themselves are also leading the challenge to social perceptions and negative cultural stereotypes associated with dementia. This movement has its roots in the disability movement which began in the mid 1970's, to challenge and invert social perceptions of disability from physical or mental impairments as the problem, to the view that it is the way

society respond to individuals which causes disability and oppression (Thomas, 2004; Swain *et al.*, 2013). Prominent sociological theories of disability have debated whether disability is resultant of illness and impairment, causing suffering alongside social disadvantage, or that disability is centrally structured by social oppression, inequality and exclusion. The social model of disability emphasises the role of social barriers as the issue which most limits the activities of people with impairments (Thomas, 2004).

The social model of disability underpins the agenda for equality for people with disabilities by people with disabilities, with emphasis on empowerment through collective, rather than personal and individual experience. The focus is on how social and cultural values position people as 'others' and challenging this, to promote justice and freedom (Swain *et al.*, 2013). Whether it is helpful for dementia to be considered as a disability has been debated, however the social model of disability has been suggested as a helpful vehicle to advance empowerment and the rights of people with dementia (Williamson, 2015).

Well-known, publicly prominent figures have also embarked on pursuing agency and self-determination through continuing with their careers whilst living with dementia. This includes comedian Billy Connolly who performs despite experiencing symptoms of Parkinson's disease and memory loss, the musician Glen Campbell who toured amidst experiencing Alzheimer's disease, and the author Terry Pratchett who wrote about his rare form of dementia. These well-known people have done much to challenge cultural stereotypes of dementia.

However, 'ordinary' people with dementia are also engaged in work to debunk myths, stigma and negative stereotypes of dementia and demonstrate their role as active citizens. This 'struggle for citizenship' can be both rewarding and difficult for people with dementia engaging in this process (Bartlett, 2014). Rather than the focus being on individual pursuits, collective approaches have been adopted. An example of this is the Dementia Engagement and Empowerment Project (DEEP) - a national user-led movement which connects groups of people with dementia with policy and decision makers to raise awareness of dementia, challenge existing narratives about the experience of living with dementia and influence local practice and strategy (Litherland, 2015). Although dementia activism is at a relatively early stage, some people with dementia are increasingly exercising their rights to be active

agents in their own lives - and the lives of others - through self-determination and control (Williamson, 2015).

2.5.2 Human rights approach to care for people living with dementia

The social model of disability has also been considered as a framework to discuss a Rights based approach to dementia, which drives for recognition of the human rights of people with dementia in the context of national and international law (Williamson, 2015). Key to this is adherence to legislation such as The United Nations Convention on the rights of persons with Disabilities (CRPD) and how this interfaces with legislation in the UK, including the Mental Capacity Act (Bartlett, 2012). Human rights and citizenship in the care of people with dementia have commonly been overlooked; however a rights-based approach to care, which recognizes the self-determination of people with dementia, can improve practice through reducing violation of rights and an inclusive approach to care (Kelly and Innes, 2013). One area particularly relevant to this research which has been highlighted, is the violation of rights in terms of public policy for people with dementia through inappropriate and premature institutionalisation into residential care, which risks undermining agency and may expose the person to abuse; suggesting that a rights-based model can promote better engagement for people with dementia to improve services and supports (Williamson, 2015).

Approaches which consider the legal rights of people with dementia as citizens are important to challenging discrimination and long-held cultural and social assumptions, which must be considered within the legal context of the Mental Capacity Act.

2.6 The legal context and the MCA

In the last 30 years, there has been an increasing social and legal emphasis on the human rights of people with mental health conditions, which has been underpinned by factors such as the shift from institutionalisation towards community care, and the changing nature of relationships between clinicians and patients (Szmukler and Appelbaum, 2008). From the late 1980s a 16-year period of reform led by the Law Commission, motivated by carers' concerns, led to changes in legislation to reflect the principles of personal autonomy (Parliamentary Office of Science & Technology, 2011). The Law Commission report (Law Commission, 1995), recognised the increasing importance for clinicians to consider the

mental capacity of people with 'mental disability', and the need to establish capacity to consent to treatment, which if queried, required clinical assessment (Wong *et al.*, 2000). Although many of the provisions of the Act were permitted previously under Common Law, the Law Commission Report and the Mental Capacity Act endeavoured to clarify and make explicit core values such as facilitating people with impaired mental capacity in making decisions (Shickle, 2006).

The roots of the MCA can be found in the case *F v West Berkshire HA (F v. West Berkshire Health Authority, 1989)*, which centred around whether a woman with a learning disability could be sterilised against her wishes, and whether doctors had the legal authority to treat the woman who lacked capacity to consent to treatment (Cardiff University, 2014). Such decisions which were recognised under Common Law were being challenged. These challenges represent a shift away from paternalistic healthcare professionals towards greater emphasis on individual ability to make decisions. However, the MCA and the Mental Health Act (MHA) developed along different lines to meet specific needs of different patient groups (Okai *et al.*, 2007). The Mental Health Act provides a framework for provision of treatment on an involuntary basis for people with a mental disorder – based on risk reduction to self and others. However the MCA constitutes a more general framework which includes medical treatment decisions taken on behalf of adults who lack capacity, enabling individuals to make their own decisions relevant to best interests and the least-restrictive outcome (Owen *et al.*, 2009b).

The MCA was fully implemented in England and Wales in October 2007, and enshrines the rights of individuals to involvement in decisions which affect their health and welfare, whether they have or lack the mental capacity to act as the decision maker in regard to specific decisions (Department for Constitutional Affairs, 2007). The MCA Code of Practice has statutory force and provides guidance for the implementation of the Act for people working with and caring for adults who may lack capacity with regard to specific decisions (Department for Constitutional Affairs, 2007).

The MCA is founded on five statutory principles:

Figure 1. Five statutory principles of the MCA

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best-interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

(Department for Constitutional Affairs, 2007)

In this research, I focus on the enactment of the legal provisions of the MCA in the medical setting of the hospital ward. Medicine and law are regarded as two dominant institutions governing western society, both having an established history of professionalism which exerts knowledge and power of the professions over lay people (Freidson, 1975). Due to the long-established position of these systems, the law and legal decisions mount a legitimate challenge to medical decision making. Many examples of this can be found in case law. Eighty one UK cases are drawn upon to inform the legislation of the MCA (Bartlett, 2008). The Cases Re C (*Re C (Adult: Refusal of Treatment)*, 1993 Oct 14;[1994]) in which the capacity to consent to medical treatment, for which the criteria to define capacity was established is particularly relevant to this research as is the case re T (*Re T (Adult: Refusal of Treatment)* 4 All E.R. 649, 1992), which acknowledges that because a person is not capable of making a particular decision at a particular time, this does not mean that are incapable of making all decisions. Subsequently, the case of KK (*CC v. KK and STCC*, 2012), in which Mr Justice Baker recognised that individuals may attach different weight to different factors when making a decision which must not be assumed to be a lack of ability to weigh up information, is a particularly relevant example of case demonstrating how the law is interpreted and enacted in practice.

Although the Mental Capacity Act legislates how mental capacity and decision making should be managed, the social and ethical aspects of the implementation of the act are critical to those applying the legal standards and those to whom it applies. Although decisions about

mental capacity are legal decisions, in practice these are not made by legal practitioners in courtrooms but by practitioners working with vulnerable people in the community (Moye and Marson, 2009), and in this context practitioners involved in care of older people within the hospital setting. As such the Code of Practice provides guidance which sets out how the Act should be operationalised in daily practice, with examples of good practice to support decision makers (Department for Constitutional Affairs, 2007). In this particular circumstance, because the decision cannot and should not be defined as a medical decision in the way in which clinical treatment would be, the boundaries between law and medicine become blurred as medical practitioners become the agents of implementing legislation.

Before the introduction of the MCA, the same ethically complex issues around hospital discharge for people with dementia still existed, but without the legal framework. Prior to the Act, the subjective judgement of clinicians was regarded as the clinical standard to determine the competency of an individual (Brindle and Holmes, 2005; Moye and Marson, 2009). Historically the Hippocratic Oath has underpinned the moral code of doctors from diverse cultures, and these core values such as the duty to prevent harm and provide benefit to patients has extended to other healthcare professionals. These basic values have also broadened to include other desirable characteristics such as compassion, altruism and integrity when working as part of an effective multi-disciplinary team providing the best patient care (BMA Medical Ethics Department, 2013). These are all-encompassing social values which should be applicable to all patients in all circumstances and allow for decisions of any nature. However, particular decisions and certain patient groups present specific ethical dilemmas for medical practitioners. Similar to other decisions concerning people with dementia which will restrict behaviours, conflict between doing good (beneficence), preventing harm (non-maleficence) and allowing people the freedom to make their own decisions (autonomy) (Hughes *et al.*, 2009) remain at the heart of ethical challenges presented in relation to capacity judgements and hospital discharge decisions for people with dementia and their families.

The introduction of the MCA was regarded as a progressive piece of legislation, moving towards enhancement of autonomy and away from paternalism (House of Lords Select Committee on the Mental Capacity Act 2005, 2014) and addresses the previous denial of civil and human rights to vulnerable and disadvantaged groups in society through the provision

of the legal right of autonomy to people who lack capacity (Boyle, 2008; Boyle, 2010). Although the progressive nature of the Act has been acknowledged, the Act has been critiqued for failing to achieve autonomy for vulnerable people, as the empowering ethos of the Act has not become embedded in practice. The House of Lords Select Committee, set up to review the implementation of the MCA, attributes this to a lack of understanding amongst those applying it in practice (House of Lords Select Committee on the Mental Capacity Act 2005, 2014).

2.7 Defining and determining mental capacity

How mental capacity is defined in the Code of Practice is central to the understanding, interpretation and enactment of the Act. This influences how practitioners apply the Act in practice to comply with legal standards. When assessing mental capacity, the first principle of the MCA states that individuals should be assumed to have capacity unless it is otherwise established. A diagnosis of dementia is not sufficient grounds for an assumption of a lack of mental capacity to undertake decisions. The importance of correctly assessing mental capacity is further highlighted in Section 4.34 of the Code of Practice, which emphasises that individuals who are assessed as lacking capacity may be denied the right to make a specific decision; furthermore people are at risk of harm if the wrong decision is made. The importance of correctly determining the mental capacity of individuals is clear. In this study, the specific decision was about whether a person with dementia is given or denied the right to decide if they can return home after being in hospital.

Section 4 of the Code provides a two-stage test for assessors to determine if an individual lacks mental capacity to undertake a specific decision. Assessors first have to prove that the person has an impairment of, or a disturbance in the functioning of, their mind or brain. Secondly, they have to assess whether this impairment or disturbance means that the person is unable to make a specific decision when they need to. The box below sets out the four key criteria on which a person is judged to lack capacity.

Figure 2. The legal test of mental capacity

MCA 4.14 A person is unable to make a decision if they cannot:

1. understand the 'relevant information' about the decision to be made
2. retain that information in their mind
3. use or weigh that information as part of the decision-making process, or
4. communicate their decision

These four aspects of mental capacity provide the cornerstone to judgements on mental capacity in England and Wales. Practitioners must apply these within the context of each individual and their set of circumstances.

2.8 Judgements on mental capacity

Each country has its own legal systems which reflect definitions and conceptualisation of mental capacity. In the UK alone, the MCA applies only in England and Wales. Scotland has its own legal system and decisions around capacity are governed by the Adults with Incapacity (Scotland) Act 2000 (*Adults with Incapacity (Scotland) Act 2000*). In Northern Ireland there was no specific guidance around mental capacity until the recent introduction of The Mental Capacity Act (Northern Ireland) 2016 (*Mental Capacity Act (Northern Ireland), 2016*). However, although capacity can be determined in a legal context, conceptualisations of mental capacity extend beyond the legal paradigm and can be understood more broadly in terms of peoples' mental abilities, capabilities and competency to undertake a range of decisions relating to different situations.

In acknowledgement of the complexities of assessment of capacity and determining best interests for people with dementia on discharge from hospital, the Code presents a scenario (Chapter 10) which reflects the conflicting opinions of Mrs Nolan who wishes to return home and the hospital care team who recommend care home placement. Practitioners are routinely faced with such ethical and practical dilemmas in their daily practice in the acute hospital setting. However, there is little empirical research which explores the complex nature of capacity judgements and best-interests relating to residence decisions for people with dementia.

The literature acknowledges the ethical tensions which exist in determining the mental capacity of people with dementia in relation to residence decisions on discharge from

hospital. The main tension lies in striking a balance between preserving the autonomy of the individual, respecting their rights to make choices about their care and welfare, and protecting the person from harm in the name of beneficence (Strang *et al.*, 1998; O'Keeffe, 2001; Brindle and Holmes, 2005).

Although much of the literature which explores determining mental capacity in relation to place of residence is specifically related neither to hospital discharge nor dementia, many of the factors are relevant to understanding the decisions faced by practitioners in the acute medical context, such as: risk of neglect of personal care (Strang *et al.*, 1998; Barbas and Wilde, 2001); the role of help from families and social agents (Cooney *et al.*, 2004); the contribution of practitioners from other disciplines (Darzins, 2010); and increased disability and multiple medical needs (Durocher and Gibson, 2010). Specifically in connection with judgements of capacity relating to residence and hospital discharge, patients who are advanced in age, have moderate cognitive impairment, variable communication skills, demonstrate behavioural or psychiatric manifestations of dementia, questionable competency, and express wishes to return home with limited insight into levels of dependency and need, represent the most challenging decisions for practitioners (Brindle and Holmes, 2005).

The literature addressing how clinicians should assess mental capacity in relation to decisions about residence suggests a range of standards and assessment tools which can support medical practitioners in evaluating the abilities of older people and people with cognitive impairment. Since the 1970s there has been considerable debate around whether specific, objective instruments can be developed to legally determine whether an individual has capacity (Moye and Marson, 2009) and whether individualised or standardised approaches are most suitable for determining mental capacity (Naik *et al.*, 2010). It has been suggested that assessments should include psycho-social aspects of peoples' lives rather than solely relying on assessment of cognitive function (Newberry and Pachet, 2008), although it might be suggested that here the waters become muddied between determining capacity and best interests.

The significance of an admission to hospital is noted to change the landscape for vulnerable older people in terms of acting as a trigger on whether the person has sufficient mental capacity to decide where he or she lives on discharge. This "discontinuity in the status quo"

(p432) marks the change from gradually declining function to a marked change in which the ability of the person to function in the community is questioned (Twining, 2008). Within the hospital setting, mental capacity assessment of older people was considered most complex in relation to residence decisions and was the most common reason for referral for specialist input from Old Age Psychiatry services (Mujic *et al.*, 2009) and a high proportion of cases were characterised by uncertainty within the MDT as to whether individuals had the ability to make their own decisions about place of residence on discharge (Mackenzie *et al.*, 2008). Lack of certainty can lead to errors of judgement and over- or underestimation of decision-making capacity – linked to agreement and disagreement with practitioners' views (Volicer, 2008).

In addition, it has been suggested that people with dementia who are regarded as marginal in terms of competency present the biggest challenge in terms of decision making to practitioners (MacCourt and Tuokko, 2010). This is considered particularly complex when the person is considered at the very margins of just having or just lacking capacity, and can be the most difficult to assess even for the most experienced practitioners (Herring, 2008). The MCA requires a binary outcome that the person either has or lacks capacity to make a specific decision, however it has been suggested that competency assessment cannot be reduced to a dichotomous variable and that individuals with dementia occupy a continuum with considerable variation in the moment and in relation to tasks (Kane, 1998). Furthermore, a significant proportion of people are thought to occupy these 'grey' areas between those clearly competent and clearly incompetent (Holm, 2001; Kapp, 2002).

2.9 Determining best interests

One of the fundamental principles of the MCA is that any decisions made on behalf of a person who is assessed as lacking in capacity to do so, must be made in their best interests. In simplest terms, deciding what is in the best interests of someone, relies on the judgement of another to make decisions about what they think will be to the benefit of the person. In the context of hospital discharge for people with dementia there are a complex array of opinions, wishes and values which must be considered. These encompass the views of the person, their family and a range of disciplines in the MDT, and consideration of long-held preferences versus current and future need. I consider legal approaches and ethical approaches to best interests, and introduce alternative models of deciding what is 'right' for

a person who lacks capacity.

Prior to the MCA, best interests were not defined by any authority in relation to personal decisions, and guardianship was the closest legal mechanism which enabled others to act on behalf of the individual. This required the individual to be classified as suffering from a specific mental health disorder (Bartlett, 2008). However the MCA sets out legal parameters for determining the best interest for people who are deemed unable to do this for themselves.

The provisions of the Act state that once mental capacity has been assessed and a person is found to lack capacity in relation to a specific decision, the fourth principle of the MCA states that any act done for, or any decision made on behalf of a person who lacks capacity must be done, or made, in that person's best interests (Section 1(5)). This concurs with the UN Convention on the rights of persons with disabilities (Article 12) (United Nations, 2006). The convention states that persons with disabilities should enjoy legal capacity on an equal basis with others in all aspects of life and that parties should take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

The Code of Practice is clear that working out what is in someone's best interests is only relevant when the person has been assessed or reasonably believed to lack capacity (Section 5.3). Definitions of best interests are ambiguous to allow for a range of individual circumstances (Section 5.5). Although best interests are not defined in the MCA, a best-interest checklist is provided (Section 5.13). The purpose of the checklist is to assist practitioners in the process of determining best interests. In Figure 3, seven common factors are identified which must be taken into account when trying to work out the best interests of a person.

Figure 3. Best interests checklist

When working out someone's best interests:

- Decisions must not be based simply on someone's age, appearance, condition or behaviour
- All relevant circumstances should be considered
- Every effort should be made to encourage and enable the person who lacks capacity to take part in decision-making
- If there is a chance that the person will regain capacity to make a particular decision, then consider the possibility of delaying the decision until later if it is not urgent
- Special considerations apply to decisions about life-sustaining treatment
- The person's past and present wishes and feelings, beliefs and values should be taken into account
- The views of other people who are close to the person who lacks capacity should be considered, as well as the views of an attorney or deputy

(Section 5.13)

As there is no clear definition of what is in someone's best interests, only guidance about exploring the wishes of people and their relatives or nominated others is provided in the Code. In practice, this means that practitioners must judge and interpret the information they have to make a decision which they believe to be in the best interests of the person with dementia. Section 5.21 – 5.24 suggests how people who lack capacity may be optimally supported to be involved in the decision-making process and how a person's wishes and feelings, beliefs and values affect such decisions (5.37 – 5.48). Consideration should be given to the patient's past and current views but will not necessarily be the deciding factor (5.38).

Rather than defining best interests, the Code sets down the process, with the purpose of the process being to arrive at a decision that health and social professionals reasonably believe is right for individual, not the one that fits with the outcome of professional desire (Ruck Keene *et al.*, 2016).

Recommended good practice in the assessment and recording of best interests requires practitioners to detail the process of the route to the judgement and a clearly set out, and reasoned conclusion. This is considered particularly important in cases of dispute and to

justify why no less restrictive course was identified. To guide practitioners through this process, the use of a table or bullet points balance risk and benefits is suggested, emphasizing that benefits should be given overriding importance although many risks may be identified. This document should not be set in stone, and the balance sheet should be redrawn if changes in wishes or circumstances occur (Dunn and Foster, 2010; Ruck Keene *et al.*, 2016).

The Code states that when working out what is in the best interests of the person who lacks capacity, decision makers must take into account all relevant factors that it would be reasonable to consider, not just those that they think are important. These factors are often complex and situation specific. For example, the urgency and gravity of a situation would considerably differ when a best-interests decision must be made at 3am in the Accident & Emergency department compared with a decision about whether a person moves in to a care from their home of 60 years. In addition, any departure from the wishes of the person must be justified; and the reason must be more cogent, the further away the wishes are from the person (Ruck Keene *et al.*, 2016).

The decision maker must not act or make a decision based on what they would want to do if they were the person who lacked capacity (Section 5.7). The best-interest model of decision making is dependent on the decision maker to arrive at a judgement of what they think is the best course of action for the person who is no longer able to make this decision for themselves. This requires someone else to act on behalf of the incapacitous person. However, it is not always clear who the best-interest decision maker should be (Ruck Keene *et al.*, 2016)

Although the person who lacks capacity has 'failed' the test of mental capacity, the MCA stipulates that the person should still be enabled to express their wishes and preferences, and that these preferences are subject to change over time just as with a person who does have capacity to make their own decisions (Hope *et al.*, 2011). However in terms of determining best interests concerning place of residence, it has been suggested that the rights to choose where to live are restricted by a lack of social rights, the shortfall of domiciliary and community services and limited access to appropriate funding of these services to avoid institutional admission (Boyle, 2010). In relation to hospital discharge, being found to lack capacity in relation to decisions about place of residence was found to be

strongly associated with a best-interest decision of placement in institutional care (Mujic et al., 2009).

As well as best-interest approaches to decision making for people who lack capacity, there are other models which may be considered. These include a risk-benefit approach, adherence to advance directives, a substituted judgement approach and a consensus-based model (Barbas and Wilde, 2001), valid choice, hypothetical choice, and best-interests (Hope et al., 2011), and a recovery approach, which emphasises including the person with dementia in the decision-making process as fully as possible (Martin, 2009). Although the 'best-interests' model is applied through the MCA, this approach contains elements of other approaches such as substituted judgement (Joyce, 2010; Hope et al., 2011). Substituted judgements rely on knowledge of the person's previous wishes and to act as if they were in the 'patient's shoes' (Volicer, 2008). The best-interest approach of the Act has been critiqued for providing restricted rights only, as the views of the person lacking capacity can be overridden by those of others. These decisions reflect the wishes of relatives and practitioners – rather than what the person would have wanted, which fosters a paternalistic approach (Boyle, 2011). Acting in the persons' best-interests may be a difficult task which may invoke feelings of guilt, stress and being overwhelmed for relatives acting as proxy-decision makers, who must decide from their own perspective what is 'best' (Volicer, 2008). When determining best interests, Dunn and Foster suggest an alternative to the pragmatic approach of considering benefits and burdens to weigh-up the best outcomes, which reflect choices between risk and autonomy. Instead, they propose conceptualising best interests as autonomy interests and welfare interests to present the interests of the incapacitous person with dementia in a way that better reflects past and present interests (Dunn and Foster, 2010).

There are clear tensions in determining the best interests of people who lack capacity. It has been suggested that the best-interest approach enshrined in the Act places emphasis on the best interests of the vulnerable person, and not those who have often been routinely involved in their care and decision making (Fullbrook, 2007). Although upholding the autonomy of the person with dementia, it may not support how people with dementia routinely make decisions with close support from family. In determining best interests there will be conflicting interests between the duty of practitioners to promote patients' wellbeing and respect their wishes (Carrese, 2006). Aside from tensions in the implementation of the

Act in practice, the Act itself may create tensions in that there is some mismatch between the fourth and fifth principles of the Act in that reaching the decision which is in the person's best interests and the least restrictive option may be unfeasible and leaves uncertainty over which should be prioritised (Herissone-Kelly, 2010).

2.10 Summary

The literature demonstrates that conceptualisations of dementia extend well beyond the medical paradigm which has come to dominate perceptions of dementia in western society and that other lenses can broaden perceptions and understanding of dementia. This is particularly important in the context of the medical environment in which decisions about capacity, best interests and place of residence are made. The legal framework which governs such decisions has evolved to recognise the need to protect the rights of vulnerable people in society. However understanding of capacity and best interests exists beyond the legal definitions in practice, and is understood amongst a range of personal and professional ethical tensions.

Although practitioners within the hospital setting will be influenced by the medical context in which decisions about capacity, best interests and place of residence take place, the literature introduces the broader social and legal landscape, influencing understanding about dementia and the ability to make decisions.

Chapter 3. Theoretical and methodological approach

3.1 Introduction

Having set out the aims and background relevant to this thesis; this chapter outlines the broad theoretical and philosophical approaches which underpinned the conduct of this research. The first part of this chapter introduces the main theoretical approaches which guided the process of fieldwork and analysis of the findings, and the relevance of social gerontology, social constructionist theory and cultural sociology to this research topic. The second part of the chapter is concerned with the application of the research methods chosen to explore mental capacity judgements and best-interest decisions for people with dementia and decisions regarding hospital discharge. This includes highlighting the main methodological challenges encountered.

3.2 Social gerontology

Theories relating to social attitudes towards older people were important to the conduct of this study. Social gerontology was therefore a useful paradigm to consider the experiences of older people with dementia. Social gerontology is defined as the application of social science disciplines to the study and understanding of aging individuals and populations and the interrelation of each with social forces and social change (Phillipson and Dannefer, 2010).

Gerontology has its roots in hospital-based medicine and the medical specialism of mental and physical health and care of older people, separating older people as a group who are 'different' to the rest of the population. This separation may have had some positive implications in that a previously neglected and under-funded area of care gained recognition with the establishment of the NHS; however separation also contributed to a negative emphasis on social and economic ageing of the population (Phillips *et al.*, 2010). Problems associated with old age, rather than more positive cultural dimensions of aging were made prominent. The dominant paradigm in the UK and US in the mid-20th Century, being that the growing ageing population contributed little to society, but needed much. This 'roleless role' of retirement reflected a functionalist paradigm, situated in economics, assuming disengagement with work and family roles as inevitable and normal and was reinforced in UK social policy through dependency and entitlement to state pension (Higgs and Jones, 2009).

However, growing attention turned to problems facing older people in community and institutional care in the UK in the 1950's and 1960's amongst an expansion of gerontology to encompass the social, as well as the health needs of older people. This movement gathered pace throughout the 1980's and critical gerontology raised awareness of the social construction of aging and change, with emphasis on how attitudes which lead to the marginalisation and pathologising of older people in society must be challenged. The role of older people themselves in mounting this challenge was considered critical (Phillips *et al.*, 2010). This disengaged position became recognised as a social construction of both policy and individual attitudes, requiring a more egalitarian experiencing of aging, which could be achieved through full citizenship rights for older people (Higgs and Jones, 2009).

There is also growing recognition that the experience of ageing is not limited to 'being old' and life course approaches highlight that ageing is not based only on organismic changes but fundamental on social circumstances, opportunities and experiences over prior decades experienced at an individual and institutional level. (Dannefer and Settersten, 2010).

However, cultural attitudes towards aging and growing old are deep-rooted, and common negative stereotypes of ageing concerning the physical and mental attributes and attitudes of older people, are reflected in older people feeling that they are not treated with the respect due to them. This is not a phenomenon of 21st century western culture, but consistent across recorded time and cultures (Davidson, 2011). Life course approaches to ageing may therefore help to break down such entrenched attitudes by emphasising ageing as a process experienced by all rather than reinforcing 'otherness'.

Despite significant social barriers to recognising favourable aspects of ageing, positive understandings have emerged through challenges to cultural assumptions and the emergence of perspectives which recognise the valuable contribution to society of older people. This is linked to meaningful social engagement and fulfilment defined by responsibilities as well as leisure, and better health. However there is also recognition that some older people may be unable to engage "positively", further socially disadvantaging these groups. (Higgs and Jones, 2009). People with dementia may potentially fit with this experience due to limitations of the condition and the actions of others.

Social gerontology emphasises the need to reframe dementia more positively and challenge mainstream social narratives of dementia. It questions traditional cultural and historical dementia narratives and highlights the need to continue to increase understanding of the

social and cultural context in which our 'medicalised' conceptions of cognitive ageing have emerged; calling for a new cultural narrative supporting continuation of wellness and quality of life for citizens (George and Whitehouse, 2010).

Social gerontology is therefore a valuable perspective in understanding how people with dementia may experience a 'double-whammy' of societal discrimination, but also in promoting how these negative assumptions can be challenged to promote the rights of this commonly marginalised group in society. This offers a paradigm in which to understand collective, negative societal attitudes and behaviours associated with ageing, which are significantly influenced by institutionalised medical approaches. However, amidst the significance of societal factors, the experience of person with dementia must also be understood in the context of interactions with others.

3.3 Social constructionist theory

Social constructionist theory is a multi-disciplinary approach influenced by disciplines such as sociology, philosophy, linguistics and social psychology. It enables social scientists to critically examine taken-for-granted knowledge and to challenge accepted norms, values and beliefs. Emphasis is placed on social interactions and how through such interactions we create and sustain knowledge and understanding of the world (Burr, 2015). The social constructionist paradigm reflects a relativist ontology which recognises the existence of multitudinous social constructions of our knowledge and experiences. Individuals and groups in society interact with each other and the world around them to interpret and act on events to create multiple and relative realities within society. Furthermore social constructions can be interpreted in many different ways by individuals and groups, reflecting a subjective epistemology in which the values of people mediate interpretation of facts and events (Lincoln and Guba, 2000).

A social constructionist approach was therefore the most suitable research paradigm to explore decisions about mental capacity in relation to hospital discharge as several stakeholders are involved in the decision – reflecting numerous perspectives and interpretations of such experiences and decisions. Although the MCA legislation was passed in 2005, it had only come into force seven months prior to the beginning of fieldwork in June 2008, therefore the decision-making process itself was little understood in practice, not routinised and subject to the individual circumstances of each patient and their relatives. Given this context, the nature of the decisions of mental capacity, best interests and hospital

discharge were likely to reflect several 'realities' of the experience of many people and require interpretation of the facts of these multiple realities.

The exploratory nature of the research enabled a responsive approach to data collection, based on gathering information, interpreting the 'facts' or messages in the data and influencing what data were further required. The social constructionist paradigm also complemented analysis of the data, as there were no set hypotheses, therefore an interpretivist approach was fundamental to trying to gain an understanding of the multiple and varied data sources. In addition, the creation of the narratives of the 29 patient cases reflects my understanding and re-construction of the data to contribute to a better understanding of judgements on mental capacity for people with dementia and best-interest decisions relating to hospital discharge.

3.3.1 Social constructionism and dementia

Social constructionist theory has been applied to improve understanding of the social world of people with dementia, and provides a lens through which to critically examine the interactions between people with dementia and those without dementia. Of particular prominence is how interactions with people with dementia are often misinterpreted or misunderstood, resulting in negative perceptions of the person with dementia and their capabilities and abilities (or lack of). These negative perceptions are likely to lead to negative actions and thus limit the extent to which people with dementia are enabled to participate in society. Social constructionist theory has done much to shift the focus from the person with dementia being the 'problem', highlighting the actions and reactions of 'normal' others as disabling and inhibiting people with dementia as much as the condition itself. This has been achieved by demonstrating how people with dementia still have many cognitive functions and deeper-rooted social and emotional feelings intact. In short, this literature emphasises the need for individuals and wider society to acknowledge and act on the many positive attributes people have despite having dementia (Sabat and Harré, 1992; Kitwood, 1997; Sabat, 2001; Kontos, 2005; Sabat, 2005; Hughes *et al.*, 2006; Hughes, 2011b; Kontos and Martin, 2013).

In considering how people with dementia are conceptualised by others, Kitwood identified 17 elements of malignant social psychology which devalue people with dementia and erode

their personhood (Kitwood, 1997). When misperceptions of dementia are acted upon, the person with dementia becomes disadvantaged and regarded in terms of a catalogue of problems rather than a person who can positively contribute to many social situations.

Notions of selfhood and self-identity contribute to further understanding of how the person with dementia may be knowingly or unknowingly unfairly positioned within society.

Through categorising different expressions of selfhood, Sabat emphasises how 'healthy' others interact with people with dementia. Three aspects of self-identity are presented to understand how people create and present themselves to others, and how the interactions of others support or undermine these presentations. Self 1, 2 and 3 are defined and compared to explain how our personal identity is expressed through language and attributes which can be fixed or change over time. Central to this theory is the way in which others accept or reject such manifestations of self and how these social descriptors are contingent on our interactions with others. Control over presentation of the self depends on interpretation, acceptance or rejection of identity by others and how they position the person with dementia (Sabat, 2001; Sabat, 2002).

Models of personhood and self-identity provided a challenge to taken-for-granted assumptions about dementia and a relevant theoretical lens to examine the experiences of people with dementia and judgements on their mental capacity in relation to residence decisions on discharge from hospital. This approach emphasises that people with dementia are often negatively perceived within society, usually in terms of their diminishing cognitive function, and are therefore disadvantaged and excluded from normal participation in social life. Furthermore, most relevant to this research, people with dementia are seldom regarded as active human agents capable of making choices and decisions and acting upon these (Kontos, 2005; Kontos and Martin, 2013; Martin *et al.*, 2013). In the context of this research, this extends to the important decision about place of residence on discharge from hospital.

Social constructionism inverts this negative viewpoint, proposing that the problem lies not in the physiological changes in the brain of individuals, but the way in which others interact with people with dementia. Recognition of the individual's unique personal biography, life circumstances and personality is necessary alongside an understanding of neurological impairment (Downs, 1997). Sabat highlights that nothing can be done to stop damage to the brain, but that dysfunctional social interactions can be minimised (Sabat, 2001). The

following quote highlights the significance of social interactions for people with dementia rather than the physical, clinically-defined aspects of the disease.

...In many cases the fundamental cause [of dementia] is to be found not in the neurofibrillary tangles and senile plaques in the brains of sufferers, but in the character of the social interactions and their interpretations that follows in the wake of their symptoms.” (Sabat and Harre, 1992).

These ‘others’ may be family members or people in the street, but in this case it is the interpretations and subsequent actions of the health and social care practitioners within the hospital environment which are of particular significance. In this research, the concepts of social positioning and malignant social positioning can be considered alongside the important institutional and power relationships (Burr, 2015), in this case, in the practice of medicine.

In addition to the fundamental nature of personal interaction to social constructionism, the notion of how the hospital environment impacts on judgements of mental capacity must be acknowledged. The context in which these interactions take place influences and shapes the interpersonal exchanges. Critical realist perspectives have highlighted the relationship between structure and agency, pointing to the complex nature of patient care which is significantly influenced by macro-level factors such as legislative and organisational care mandates as well as the micro-level interrelations occurring between professional care providers and patients, which has often been the focus for research (Kontos *et al.*, 2010).

In relation to judgements on mental capacity and subsequent discharge decisions, many aspects of identity become challenged as a result of becoming a patient, and having mental abilities assessed and scrutinised. First, the person who previously lived at home with confusion and perhaps a diagnosis of dementia is ascribed the identity of ‘patient’ once they are admitted to the hospital. The “medical messages” given to older people are fundamental to how people with dementia act and interact with others (Harding and Palfrey, 1997). Secondly, how the person is able to present themselves to the medical practitioners is assessed both formally and informally. In addition, a version of the patient is presented to the medical practitioners from others such as relatives and community practitioners. The person with dementia may believe, and tell the MDT that they can manage fine at home – presenting themselves as a capable person, whereas their relatives present a picture of

struggle, vulnerability and increasing confusion. The reason for admission may bring about a change in circumstances for the person with dementia such as new mobility problems caused by injury sustained during a fall or a family who may no longer be able to cope with their caring needs. In these examples, their identity changes from being able to get around home and the surrounding community to immobile or reliant on mobility aids; or someone who can manage with the support of their family to someone who is now unsupported at home. The double-impact of how cognitive problems may impact on ability to process this new information and how practitioners and family convey this new situation may mean that understanding, accepting and assuming such new identities is difficult for the person with dementia. Thirdly, as part of the decision-making process, the person's mental capacity to make their own decision about place of residence is assessed.

Subjective questioning and standardised cognitive assessments conducted by medical practitioners' results in the patient being positioned as either having or lacking sufficient mental capacity to make their own decisions about going home from hospital. During this process the MDT gather 'evidence' about the person with dementia and construct their own version of the person. There are only limited opportunities for the person with dementia to directly contribute to this version of themselves. The patient becomes either positioned as capacitous – an identity which brings with it the rights to decision making – or incapacitous, resulting in others making a best-interest decision on behalf of the person with dementia. Finally, the outcome of this decision may further challenge the identity of the person with dementia and how they are able to position themselves as they are discharged from hospital with some maintained and possibly restored identities, for example returning home to be a wife again, or taking on a whole new identity as a care home resident.

In addition to the influence of the hospital environment, the legal context of the MCA and how this is constructed also demonstrates how the identity of the person with dementia becomes positioned as either having or lacking capacity to make decisions and how this ascribed status affects the outcomes for the person with dementia. One of the fundamental concepts of the MCA is to protect and empower vulnerable people. The legislation was created to prevent disadvantaged people becoming further disadvantaged through exclusion in making decisions which affect their lives (*Mental Capacity Act 2005*). However, implementing the Act in practice relies on the person with dementia to fit a binary notion of having or lacking capacity. To apply the law in practice requires an "assessor" (in this case of

hospital discharge a health or social care practitioner) to make judgements on the person's cognitive ability to undertake a specific decision. This requires practitioners to position the vulnerable person as either having or lacking capacity to make a decision about place of residence on discharge from hospital.

It becomes clear that social constructionist theory supports the investigation of these judgements, as it enables the interpretation of how practitioners on acute hospital wards interact with people with dementia, their families and other practitioners, and importantly how these interactions are interpreted and acted upon in making judgements on mental capacity and best interests in relation to hospital discharge. This theory facilitates the examination of how, why and by whom people with dementia are positioned as having or lacking capacity to make their own decision about going home from hospital. It provides a context in which to demonstrate the implications and outcomes of positioning people with dementia as either having or lacking mental capacity to make their own decision about returning home after an inpatient stay. In summary, this research highlights the importance of ensuring that people with dementia are fairly positioned in the context of the law by practitioners within the acute hospital environment and given optimal opportunities to be positively acknowledged and contribute to decisions about where they live after an inpatient episode.

3.3.2 Cultural sociology

Cultural sociology provides a useful theoretical lens to accompany social constructionism, as the emphasis is placed on the importance of culture and how this impacts on meaning to individuals. It encompasses the meaning of culture to the individual, shared meaning through networks, meaning-making and the role of institutions (Lamont, 2000). Culture can be understood as a social construction not an objective reality, recognising diversity of cultures and meaning making created by a shared process and embedded and used in interactions. (Crane, 1994).

By recognising the impact of collective ideas, beliefs and emotions, cultural sociology focuses on the unconscious cultural structures which regulate society. Ideas and emotions are central, as subjective and internal feelings shape the rules of organisations in society (Alexander, 2006). Thus, the importance of how the rules of social organisation and

behaviours are constructed is recognised, but the emphasis is on how these are collectively interpreted and enacted. In this research, this brings in the role of the institutions of medicine and law and how these interact in the implementation of the MCA.

Culture influences both our individual and institutional behaviour. Cultural meanings attached to health and wellbeing have significant cultural impact on society and highlight the power and influence of culture on individuals and society (University of Maryland, n.d.). The practices of medicine and law each have their own long established cultures, and are both culturally understood in western societies as powerful and central institutions (Freidson, 1975). Medical culture is particularly relevant in this context as this is the setting in which the legal framework was enacted.

Medicine and healthcare are sociocultural constructions which influence both medical practitioners and lay people, and include the study of illness, disease and healthcare workers, portrayed through familiar mass-media representations of the doctor-patient relationship and power dynamics (Lupton, 2012). The culture of medicine has been studied and critiqued through classic and modern studies, including student culture in medical school (Becker *et al.*, 1961), cultural practices of doctors and “inmates” in mental health institutions (Goffman, 1961), surgery (Fox, 1992), the body (Klaver, 2009) and satirised (Kaye, 2017).

Dementia can be understood as a culturally determined phenomena, understood through biomedicine, which gives a name to the compilation of physiological changes, behaviours, and experiences associated with the condition (Hillman and Latimer, 2017). Individuals with dementia derive meaning and make sense of their experience of the condition through consideration of their own situation and the desire to maintain normal social and cultural practices (Menne *et al.*, 2002).

Recognising the cultural factors influencing medicine and dementia can be extended to think about how the MCA is not only constructed, but interpreted and understood, taking into consideration individual practice alongside the cultural context of medical and legal systems and institutions.

3.4 Medical ethics

Whilst recognising the social, cultural and constructivist paradigms influencing the enactment of the MCA, judgements on mental capacity and best interests are interpretive in nature. This requires those enacting the MCA to draw on the moral and ethical codes which guide our decisions and behaviours in the decision-making processes. Given the hospital context, medical ethical codes have particular significance. Medical ethics and decision making are often understood as being underpinned by four core principles: Autonomy - based on the principle that people are able to decide what happens to them and what others do to, and for them; Beneficence - founded on doing good for people; Non-maleficence - the avoidance of causing harm to others; and Justice - which relates to the fair and equal treatment of people (Beauchamp and Childress, 2001). Although referred to as the principles of medical ethics, they are also principles used in everyday life (Hughes and Baldwin, 2006). Such codes influence and govern the values which individuals draw on to make sense of situations and guide actions and, as such, the values of practitioners will influence judgements and decisions concerning mental capacity, best interests and place of residence on discharge from hospital.

3.5 Methodology

Ethnography is a qualitative research methodology, through which the interaction of people within a range of cultural settings and situations are documented and analysed (Hammersley and Atkinson, 1995; Reeves *et al.*, 2008). Ethnographic methods complement social science theory and social constructionist approaches, as ethnography captures the subjective experiences of individuals and groups. This facilitates eliciting multiple perspectives and records interactions and events reflecting these many realities. These approaches acknowledge and allow for diverse experiences, interpretations, values and actions of individuals in society, and therefore support the well-established methodology of ethnography for conducting research within the hospital setting. In this research, ethnographic methods enabled me to gain insight into how decisions about mental capacity and best interests were made and enacted in relation to place of residence on discharge.

3.5.1 Hospital ethnographies

The hospital embodies an intense environment, in which people are removed from their everyday environment and usual roles and identities (van der Geest and Finkler, 2004; Long

et al., 2008; Porock *et al.*, 2015). Hospital ethnographies encompass the study of a variety of medical conditions, care, processes and participants. To establish the relevance of the application of this methodology to the research question, I focused on ethnographies which captured the hospital experiences of older people.

Several ethnographies capture aspects particularly relevant to this research such as multi-disciplinary team decision making within hospitals (Huby *et al.*, 2004; Reeves and Lewin, 2004; Ellingson, 2005; Iedema, 2007a; Waring, 2009; Lane *et al.*, 2010); and include issues such as risk (Ballinger and Payne, 2002; Huby *et al.*, 2004; Waring, 2009), negotiating decision-making processes, (Latimer, 1999; Gair and Hartery, 2001; Penney and Wellard, 2007), ethical issues (Dill, 1995; Robertson, 1996; Beard, 2008), and decisional capacity (Dill, 1995).

In particular, in relation to older people and their hospital care, there are ethnographies which capture general care experiences (Latimer, 1998; Latimer, 1999; Latimer, 2000; Tadd *et al.*, 2011) and more specifically dementia care (Fick and Foreman, 2000; Norman, 2006; Beard, 2008; Edvardsson and Nordvall, 2008; Schneider *et al.*, 2010; Jurgens *et al.*, 2012; Porock *et al.*, 2015). Although, there are some ethnographies which specifically explore hospital discharge for older people (Jewell, 1996; Wells, 1997; Gair and Hartery, 2001; Huby *et al.*, 2004; Lane *et al.*, 2010), at the time of this research, no other ethnographic research had been conducted which specifically explored mental capacity relating to hospital discharge for people with dementia. A small number of the hospital ethnographies presented multiple perspectives of participants (Dill, 1995; Wells, 1997; Fick and Foreman, 2000; Ballinger and Payne, 2002; Beard, 2008; Porock *et al.*, 2015), though more often focusing on one particular group such as practitioners or carers or older patients.

Few ethnographies specifically presented the viewpoint of people with dementia, especially those in the more advanced stages of their condition (Edvardsson and Nordvall, 2008). However, key to this research was capturing the perspective of people with dementia despite advancement of their condition. Such an established methodology in this setting supports the appropriateness of this approach to data collection, but applying the methods to study judgements of mental capacity and best-interest decisions for people with

dementia in relation to residence decisions presented a range of methodological challenges. These challenges needed to be acknowledged and addressed to complete this research.

3.5.2 Challenges of conducting observations in the acute hospital environment

The practicalities of collecting data as a non-medical in a busy ward environment was one challenge encountered in conducting this research. My approach to ethnographic observations in the hospital was influenced by my role as a non-medical health-services researcher who was external to the hospital teams working in the acute medical wards. This influenced how I managed data collection in this environment, in which my position and role needed to be carefully negotiated in order to gain the trust of participants and to carefully manage expectations about my presence on the ward.

Although I had previously conducted ethnographic observations in care home settings, I had no prior experience of conducting research in acute hospitals and had a limited understanding of how the wards functioned. This was advantageous in that my 'outsider' status (Bonner and Tolhurst, 2002) facilitated an objective perspective of life on inpatient wards. My objective was only to observe, not engage, in the processes of capacity assessment and discharge decision making; and report events as I observed them from as impartial a perspective as possible. This enabled as full and objective accounts of events as possible to be captured in the ward environment (Savage, 2000). However, aware that my presence alone was likely to influence actions and behaviours, I adopted a subtle realist approach (Hammersley, 1992) to balance between realist and relativist paradigms. Subtle realism acknowledges the existence of objective realities whilst also acknowledging that we can only know and understand realities from our own perspective. This approach recognises the need to capture events and interactions objectively but enabled me to acknowledge the influence of my role on the events which I was observing. This also shaped my own understanding of my role to represent, rather than reproduce, what I observed on hospital wards.

Relationships with practitioners also needed to be carefully managed. Negotiated interactive observation (Wind, 2008) provided a useful approach to hospital-based ethnography, defining the opportunities for participation of the ethnographers conducting observations within a highly specialised healthcare system as limited and contingent on

visibility as a researcher (and not assuming the role of a member of the team as in covert research), clear role management and negotiating relationships with different professionals and patients. Recognising that my presence could influence the actions and interactions of practitioners - for example, prompting them to remember to consider mental capacity issues during ward rounds or MDT meetings - I spent time on the wards to enable the team to become familiar with my presence. The aim was that I would become less 'visible' and that my presence would be less likely to significantly influence their practice. This also gave me the opportunity to reinforce my position as observer rather than participant. My role was not to participate fully or become part of the team and immerse myself in their culture, but to remain distinct from the team. However, research roles are not fixed, and some level of participation in observations is inevitable (Pope, 2005). Although this was generally a successful approach to managing my role and participants expectations, on occasion, practitioners did seek my direct input. For example, practitioners sometimes asked for my opinion on mental capacity as they considered me to have an expert view. I had to remind them that of my observational role, but in some cases I suggested referring to the Code of Practice for guidance.

More generally, in the busy ward environment, whilst observing, nurses would ask for my help in duties such as "keeping an eye" on a patient prone to falls, or going to fetch a colleague. If not compromising the research, I felt it was important to interact with participants in a helpful manner, to reciprocate their assistance with the research. Families and patients were also made fully aware that participation would not influence their care, however participants on occasion expressed expectations that I might influence or improve certain situations on their behalf and mediate with the practitioners providing their care. This demonstrates tensions between their perceptions of my role as a professional participant, rather than observer, in the hospital environment.

Establishing a good relationships with the MDT was also important in enabling access to the field. The MDT, and in particular the ward consultants, were the 'gatekeepers' to my involvement with the ward and then in accessing the spaces where judgements and decision making took place, such as MDT meetings, case conferences and ward rounds (Lee, 2005). I was not involved in the care of the patients and people observed were not my colleagues or

patients, therefore negotiating access to patients was managed and governed by their perspective of whether the patient was appropriate to participate in the research.

3.5.3 Methodological challenges of including people with dementia in research

Including people with dementia in research is a well-documented challenge. People have been excluded due to practical and ethical challenges (Bartlett and Martin, 2002; Sherratt *et al.*, 2007) and negative perceptions of the validity of responses provided by people with dementia (Wilkinson, 2002). This has resulted in people with dementia being excluded from participation in research about healthcare services, relying on responses from family carers, resulting in research which does not represent the experiences of people with dementia and thus lacking in information and insight (Aggarwal *et al.*, 2003). In this research, consent to participation and conducting interviews with people with dementia were the main methodological and ethical challenges which I encountered.

Inclusion and consent

Including people with dementia in research is contingent on opportunities to approach them about participation. In gaining initial access to people with dementia to participate in research, negotiations with gatekeepers must take place initially to then access the views of people with dementia. In the hospital environment the “gatekeepers” to approaching the person with dementia was a healthcare professional, whereas in the community, this is often someone such as a relative. Therefore in this research, initial access to the patient was easily achieved – although occasionally I was advised to avoid certain patients and families, which were considered to be particularly complex cases with complicated family dynamics (such cases may have provided particular insights into the issues). However, relatives also acted as gatekeepers, particularly when the patient did not have capacity to consent to participation and a consultee agreement was necessary. Personal or Nominated Consultee involvement was sought for people who lacked capacity to consent to research in accordance with Department of Health, Ministry of Justice, Office for the Public Guardian and Welsh Assembly Guidance, (DH Scientific Development and Bioethics Division, 2008; National Care Association, 2009). In the majority of cases, relatives supported participation. However, some would not agree to the person with dementia taking part in the research. This resulted in the views and experiences of some people with dementia being silenced.

Gaining consent from participants relies on participants being able to understand the nature of the research and what their involvement means. To do this, participants draw on their beliefs and values to consider whether they would like to take part. In addition, my role as researcher was to make an assessment of whether participants had the mental capabilities to do so, based on the principles of the Code of Practice (Department for Constitutional Affairs, 2007) as set out in Chapter 11, in which the same fundamental principles of the Act apply in determining mental capacity for research apply as to any other decisions. This research is therefore situated and embedded within the contexts and issues it is intending to investigate. Whilst my role was to conduct research on decision making about the capacity of people with dementia to make specific decisions, I was also required to enact the MCA in practice and make judgements about capacity.

Based on my interpretation of the Act, I judged that 18 of the 29 participants in this research had capacity to provide their own consent to participation in this research. Parallels therefore exist between my judgements of how others apply the MCA in practice, and how others judged my application of the legal framework in relation to participation in this research. The decision to participate in this research was likely to have significantly fewer far-reaching consequences on the impact of the lives of participants than judgements on their capacity to make decisions about their place of residence on discharge from hospital. As such, I judged more patients (18/29) to have capacity to consent to participation, compared with 13/29 of these participants who were judged to have capacity to make their own decision regarding place of residence. Although there was some overlap, in that I judged some participants to lack capacity to consent to research and they were also judged by practitioners to lack capacity to make their own decision regarding place of residence on discharge, my judgement on capacity was decision-specific to the issue of participation in research and not determined by the capacity judgement regarding place of residence.

My judgements on the capacity of individuals to participate in this research were generally accepted and challenged only on one occasion. A social worker doubted my decision, suggesting that the participant did not have capacity to consent to the research. I was able to defend my opinion by referring to the central tenets of the act which I had used to make my assessment, and to reassure the practitioner that I had sought advice from the clinical team. The participant's daughter also supported my judgement.

Including people in the more advanced stages of dementia who do not have the capacity to consent to participation often presents significant challenges (Sherratt *et al.*, 2007) resulting in exclusion from participation. However, it was vital to this research to include people in all stages of dementia – including people in the advanced stages of the condition which required consultee approval of the person’s agreement. This resulted in the inclusion of eleven participants which I assessed as lacking capacity to provide their own consent and for whom a personal or nominated consultee was approached to advise on their participation. A person-centred approach to consenting people with dementia into social research (Dewing, 2002) ensured that although the views of carers were sought, this was not as a proxy respondent but to elicit their views alongside the views of people with dementia. The person with dementia was approached first and their views explored prior to approaching carers for their views on participation, even when carers provided personal consultee agreement to participation.

Interviewing people with dementia

The challenges of interviewing people with dementia, in particular those who are in more advanced stages of the condition are well-documented (Wilkinson, 2002; Hubbard *et al.*, 2003; Beattie *et al.*, 2004; Hellström *et al.*, 2007). These issues include accurate recall of information and events, interpretation of the questions, applying literal meaning rather than relating to more abstract concepts, and managing emotional issues. Interviewees may have problems concentrating or understanding the questions or reasons for interview and may lose their train of thought and become confused. However, there is increasing recognition of the need to include the perspective of the person with dementia rather than rely on proxy responses (Whitlatch, 2001; Aggarwal *et al.*, 2003) and the voice of people with dementia is becoming more visible in research and literature (McKeown *et al.*, 2010).

In this research, ignoring the voice of the person with dementia would have given a skewed perspective of judgements on capacity and the decision-making process. Participants with dementia were able to provide critical insight into their personal experiences of how the decisions made by practitioners and their families affected them. This enhanced the findings of whether the right decisions had been reached by practitioners by presenting the personal perspectives of the people on the ‘receiving-end’ of the decisions – the people whose lives the decision affected.

A further challenge in this research was presented by the environment in which interviews with patients were conducted both at the time of discharge and at follow-up. McKillop (McKillop and Wilkinson, 2004) emphasises the importance of the setting and environment where the interview is conducted to ensure the comfort of the person with dementia. In terms of conducting interviews in the ward environment, finding a private and quiet space in which to interview patients was difficult. Many patients were interviewed in their beds on the ward, although where possible I offered patients the alternative of moving to a quiet space such as a day room. Although efforts were made to preserve privacy to facilitate openness, such as drawing the curtains around the bed, many distractions such as noise and interruptions which could affect the person's concentration were still present. Follow-up interviews, conducted three months post-discharge, were either at home or in a care home. This presented a particular challenge in that participants were asked about their experiences of hospital discharge in a different setting. This lapse of time and change of environment may have affected recall of events given the different context of either the patient's own home or care home in which the interviews were held.

Despite many of the methodological challenges encountered, methods and approaches influenced by the social science paradigm which were applied to this research resulted in the collection of a rich source of ethnographic data to gain insight into decisions about mental capacity and best interests in relation to place of residence on discharge from hospital. Furthermore this approach enabled the valuable participation of people with dementia, irrespective of the advancement of their condition.

Chapter 4. Methods

This chapter describes the qualitative methods employed to address the aim of exploring the interpretive work in which practitioners engage, in the enactment of the MCA, when making judgements on the capacity of people with dementia to make decisions about place of residence on discharge from hospital. Ethnographic methods provided the most appropriate tools to tackle the following research questions, which are linked to the key research objectives set out in section 1.2. These questions are addressed in the four findings chapters:

1) How do practitioners interpret their interactions with people with dementia and their families and interact with each other and to reach a judgement on mental capacity?

(Objectives 1 and 2)

2) Which sources of information do practitioners draw on to make mental capacity judgements and whose narratives are regarded as most credible and why? When and why narratives of people with dementia are doubted and what impact does this have on capacity judgements? *(Objectives 1 and 2)* How do family narratives influence capacity judgements?

(Objective 2)

3) How do binary notions of capacity and incapacity fit with the reality of making judgements about mental capacity for people with dementia concerning place of residence on discharge from hospital? *(Objectives 1, 2 and 3)*

4) Which patients are likely to be included/excluded in the decision-making process and how are they involved or denied participation? Are the wishes and preferences of people with dementia and their families sought and acted upon and how does this compare with the provisions of the MCA? *(Objective 4)*

In addition, the following research questions address the role of social science in interdisciplinary research:

- How can social theory enhance understanding of the application of the MCA in relation to discharge from hospital for people with dementia? *(Objective 1, 2 and 3).*
- How can social constructionist theories of dementia be applied to consider understanding of mental capacity? *(Objectives 2 and 3).*

- How did theoretical perspectives shape the collection and analysis of data? (*Objective 2 and 3*).

These questions are addressed throughout the findings and in the discussion chapter.

4.1 Ethnographic methods

Ethnographic methods best-enabled data collection to explore judgements of mental capacity within the hospital environment. Ward-based observations, interviews with key informants, medical record review and reflexive engagement with the data enabled the exploration of specific cases for an in-depth analysis of the key research questions.

Ethnography facilitates the study of groups in society through watching, listening and asking questions, and utilising whatever data is available to highlight the focus of the research (Hammersley and Atkinson, 1995). It is an iterative-inductive method (O'Reilly, 2008), allowing the findings of fieldwork to guide the research, which is refined and revisited in an ongoing process. This facilitates the naturalistic enquiry of the subject (Savage, 2006). With its roots in the sociological studies of urban life, ethnography supports the study of social interactions, behaviours, and perceptions occurring within groups, teams, organisations, and communities (Reeves *et al.*, 2008). The flexibility of the approach therefore complemented data collection in the hospital setting.

Ethnography is a well-established methodology for capturing rich and detailed descriptions of events in institutions such as hospitals (van der Geest and Finkler, 2004; Pope, 2005; Savage, 2006; Long *et al.*, 2008; Wind, 2008). It provides greater public insight into how hospitals work (Finkler *et al.*, 2008). Furthermore ethnography has been identified as a useful tool in gaining multiple perspectives of differently positioned individuals, in the context of how some voices seem privileged over others (Savage, 2006), which is particularly relevant in terms of dementia care, the medical setting and the legal context.

4.2 Research approvals

Ethical approval for the ACBID research project was granted by the NHS regional ethics committee (Newcastle and North Tyneside 2 Research Ethics Committee Ref No: 08/H0907/50). Dixon-Woods and Angell highlight some of the issues in gaining ethical approval to include people who lack capacity to participate in research as per the MCA (Dixon-Woods and Angell, 2009). The ACBID project ensured that appropriate participant

information, consent and consultee agreement forms were provided for all participants (Appendices B and C). Approval was also granted by the Research and Development departments of both NHS Trusts from which participants were recruited. Permission was granted via the Trust Caldicott Guardians for safe use of confidential patient data. The ACBID project was also registered with the appropriate UK Clinical Research Network (DenDRoN).

4.3 Consenting participants

Everyone working or receiving care on the wards was given an information leaflet (tailored to their situation) about the research. In addition, posters about the research were displayed on the wards to alert staff, patients, families and visitors to the research. Written consent or approval was obtained from participants using appropriate standardised consent forms. In accordance with ethical approvals, observation data was only included in the research from those staff and patients for whom I had written consent. All participants were recruited under terms agreed by the Research Ethics Committee and in compliance with the MCA.

The recruitment criteria for patients was broad and inclusive. Patients were required to have cognitive impairment thought to be caused by dementia (including suspected or differential diagnosis), not caused only by delirium, and that discussions about discharge included consideration as to whether the patient would be able to return home or not.

If a patient met the inclusion criteria, myself and a senior member of the clinical team considered their participation. If, based on factors such as clinical judgement, social circumstances and sampling, we agreed participation was appropriate, one of the clinical team approached the patient on my behalf. If the patient was agreeable, the practitioner provided the patient with the relevant information sheet, then introduced me to the patient asking if I could discuss participation with them. If the patient declined participation, their decision was respected and they were reassured that they would not be approached again and their clinical care would not in any way be affected. If the patient was agreeable to participation we discussed the research and participation in further detail.

During this process, I made an initial judgement as to whether the person seemed agreeable to participation and whether they would have mental capacity to consent. My judgement

was based on the test of capacity as defined in the Mental Capacity Act and Code of Practice (Department for Constitutional Affairs, 2007), taking into account their ability to understand and retain the relevant information, weigh up the pros and cons of participation and communicate their decision back to me. For example asking them to paraphrase their understanding of the research and their involvement. If I had concerns about their capacity to consent, the patient was given a simplified information sheet and I sought their permission for me to contact a relative of their choice to discuss their participation.

To ensure that the patient was given time to reflect on participation, I revisited the patient after a minimum period of 24 hours to review their decision. I again assessed their mental capacity to consent to participation as outlined above. If the patient agreed and had capacity, consent was sought and documented. If I considered the person to lack capacity to consent, a personal or nominated consultee was sought in agreement with the patient and in accordance with the requirements of the MCA (Section 32) and guidance from the Department of Health, Ministry of Justice, Office for the Public Guardian and Welsh Assembly (DH Scientific Development and Bioethics Division, 2008; Ministry of Justice *et al.*, 2009). A personal consultee is defined in the code of practice as someone who knows the person well and whom they would trust with important decisions concerning their welfare. A nominated consultee is someone who knows the person in a professional capacity such as a GP or social worker. Eleven patients lacked capacity to consent to participation. Personal consultees were sought for ten patients, and a nominated consultee for one via the ward consultant as no relative was available and the patient had been under the care of the ward consultant for a period of several weeks.

Regardless of my judgement about the patient's ability to provide their own consent, participants were encouraged to discuss participation with their family and friends if they wished. In addition, patients were asked if I could approach a family member to participate in the research.

Consent was sought to observe the care that patients received during their inpatient stay; to interview health and social care professionals about their care; to review their medical records; and to take part in a recorded interview. Participants were reminded and reassured that taking part or declining would in no way affect their care or legal rights. At the time of the first interview both patients and their relatives were asked to consent to a follow-up

interview three months after the date of discharge from hospital. Consent and mental capacity were again revisited at the follow up interview, in accordance with the MCA.

4.4 Sampling strategy

Three general hospital wards in two hospital Trusts in the North East of England were specifically selected by the ACBID project PI and agreed to participate. Orthogeriatrics, care of the elderly and rehabilitation wards were selected as representative of wards where people with dementia were expected to receive care for a range of conditions. General wards, rather than wards specialising in dementia care or mental health were selected for three reasons. First, practitioners on specialist wards may have had greater expertise around the MCA; secondly, owing to the lack of dementia-specific hospital care, patients meeting the inclusion criteria were more likely to be admitted to a general ward; and thirdly, this facilitated the inclusion of patients who were admitted for a range of conditions as well as dementia.

Theoretical sampling of patients and staff took place to ensure a broad spectrum of situations and relationships were included (Silverman, 2013). Participants were selected to ensure representation of a number of key characteristics including: stage of dementia (defined by the clinical team); cognitive impairment (MMSE scores); the presence of informal carers and support; formal social support; and pre-admission living arrangements. Patients were also selected based on the outcomes of the capacity decision and place of discharge. In total 29 patient participants were included in the research to reach data saturation, reflecting no new relevant data emerging around key characteristics, circumstances or events (Bryman, 2012). An overview of the key patient characteristics is presented in Table 1.

A wide range of health and social care professionals were approached to participate. Most of these staff were part of the multi-disciplinary teams on the ward, but other professionals who provided additional services were also included. No staff objected to participation in the study or the observational nature of the research conducted on the ward. Medical, nursing, therapy, social work and Old Age Psychiatry staff were recruited. This represented the breadth of disciplines observed to be involved in both the care of the patients and in decisions about mental capacity, best interests and discharge. The majority of practitioners were interviewed in connection with a particular case. The views of practitioners who had

limited and infrequent involvement were not sought, for example Speech and Language Therapy (SALT); and pharmacy.

Table 1. Characteristics of the 29 patient cases

In alphabetical order, divided by capacity status. Pseudonyms are used throughout to uphold anonymity of participants.

Patient	Age	Living arrangements prior to admission	Average MMSE score (range)	Capacity Decision	Discharge destination
Mrs Bailey	90	Alone, home	18 (15-20)	Capacity	Nursing Care
Mr Cook	91	Alone, home	20 (20)	Capacity	Home
Mrs Friar	79	With husband, home	15 (15)	Capacity	Home
Mrs Gardiner	79	Alone, home	24 (20-26)	Capacity	Home
Mrs MacVicar	76	Alone, home	22 (19-24)	Capacity	Nursing Care
Mrs Mason	92	Alone, home	23 (20-28)	Capacity	Home
Mr Mills	80	Alone, home	21 (14-26)	Capacity	Home
Mr Miner	74	With wife, home	Not assessed	Capacity	Home
Mr Priestly	84	With wife, home	18 (18)	Capacity	Home
Mrs Porter	69	Alone, sheltered accommodation	19 (17-20)	Capacity	Residential Care
Mrs Shearer	88	Alone, sheltered accommodation	21 (18-24)	Capacity	Home
Mr Saddler	92	With son, home	14 (14)	Capacity	Nursing Care
Mr Walker	79	Alone, sheltered accommodation	21 (16-25)	Capacity	Home
Mrs Baker	89	Alone, home	12 (11-15)	Lacked capacity	Home
Mrs Butler	74	Alone, home	9 (5-14)	Lacked capacity	Residential Care
Mrs Carter	90	Alone, sheltered accommodation	9 (9)	Lacked capacity	Residential Care
Mr Coleman	82	With wife, home	19 (17-21)	Lacked capacity	Nursing Care
Mr Collier	74	Alone, home	28 (26-30)	Lacked capacity	Residential Care
Mr Day	91	Alone, home	14 (14)	Lacked capacity	Deceased

Mr Fisher	82	With wife, home	Not assessed (8 prior to admission)	Lacked capacity	Residential Care
Mrs Miller	90	Alone, sheltered accommodation	13 (11-14)	Lacked capacity	Nursing Care
Mrs Parker	78	Alone, home	13 (13)	Lacked capacity	Nursing Care
Mr Ryder	87	Alone, home	12 (10-13)	Lacked capacity	Nursing Care
Mrs Salter	88	Alone, home	7 (7)	Lacked capacity	Residential Care
Mr Shepherd	89	Alone, home	20 (20)	Lacked capacity	Nursing Care
Mrs Tanner	85	Alone, sheltered accommodation	13 (8-18)	Lacked capacity	Nursing Care
Mr Tyler	83	Alone, home	15 (15)	Lacked capacity	Residential Care
Mrs Woodward-Jones	80	Alone, home	22 (18-24)	Lacked capacity	Residential Care
Mrs Wright	91	Alone, home	19 (19)	Lacked capacity	Residential Care

4.5 Fieldwork

Data from the wards were collected over a nine-month period, between June 2008 and June 2009, which included a three-month period for analysis. Data comprised ethnographic observations, interviews, a review of patients' medical records and reflexive fieldnotes. The MCA was implemented seven months prior to the start of the research. This allowed time for the provisions of the Act to become incorporated into practice before research was commenced.

4.5.1 Observations

Over the 9 month period, 111 sets of daily fieldnotes were collected. Using Gold's typology of participant observer (Gold, 1958), which defines four possible approaches which observers can take, my role was most similar to observer as participant, in which the

researcher is not already part of the social setting, and not already involved in the social group being studied. The intention was that in conducting my observations I would not directly contribute to or influence practice, and that over time, my presence would become less noticeable and also less likely to indirectly affect practice. Theoretical tensions about observer participation are addressed in Section 3.52.

Initially, ward-based observations were intentionally broad, providing a wide-angle view of the ward environment (Spradley, 1980). These general observations were often made from the vantage point of the nurses' station. This was observed to be a natural hub of activity (Reeves and Lewin, 2004) where various healthcare professionals on the ward would exchange information, take telephone calls and make notes. This was also an unobtrusive distance from the patient bays in which interactions between healthcare professionals, patients and visitors could be observed. These broad, general observations enabled me to gain an understanding of the environment, interactions and processes on the ward. Observations of impromptu, informal "off the record" interactions which happen in spaces such as corridors in which healthcare professionals exchange information and make decisions are important sources of data and particularly insightful for providing information about how professionals learn, reflect on their practice and engage in complex clinical decision making (Iedema, 2007b; Long *et al.*, 2007). General observations on the ward also allowed me to capture the spontaneous events and interactions between practitioners, patients and families which influenced judgements on patients' mental capacity and best interests in relation to discharge from hospital.

General observations also determined which events, situations and interactions were particularly relevant to the research. In keeping with the principles of grounded theory, ethnographic observations became more selective to collect more focused, structured and detailed data (Atkinson *et al.*, 2001). Thus, observations became more focused around routine and planned events such as ward rounds, planning meetings/case conferences, MDT meetings, and meetings between relatives and doctors. These emerged as the forum where key decisions relating to judgements on mental capacity, best interests and discharge were frequently discussed and made.

Although observations became more focused, general observations were continued throughout data collection. This provided context to specific observations and events, and allowed spontaneous events and interactions to continue being captured alongside. Keeping

a broad approach to observations limited the chance of overlooking or missing important data.

In addition to ward-based observations, some observations were also conducted in the community. On the invitation of the Occupational Therapist, I shadowed the practitioner conducting a community-based home visit assessment with Mrs Friar. When conducting follow-up interviews three months post-discharge, observations were also collected in the homes of patients and their relatives and care homes.

All observations were recorded at the time or as near to the moment of observation as possible (Walsh, 2012). Note-taking in the context of the ward was routine and unremarkable and also provided a visible sign of demonstrating purposeful activity to the ward staff (Latimer, 2000). Fieldnotes were all digitally recorded, transcribed verbatim and anonymised.

4.5.2 Reflective notes

Personal reflections on observations and interviews were recorded as part of daily fieldnotes. Making these notes performed a vital function in allowing me to process emotions, chart my learning and experience and engage theoretically with the data throughout the processes of data collection and analysis. The visible use of my reflective notes adds transparency around the importance of reflexivity to collection and analysis of the data (Ortlipp, 2008).

The reflexive process of engaging with and interpreting the content of these notes informed my research practice and generated ideas for exploration as part of the overall analysis (May, 2011). Reflective notes included contemplation on the processes of data collection and the acceptability of the methods to address the research questions. They also included personal musings and feelings – acknowledging my role as a researcher in influencing the particular set of ‘facts’ recorded and my interpretation of events. Producing and interacting with these notes is essential to grounded theory (Atkinson *et al.*, 2001) and started the formative processes of data analysis from the beginning of fieldwork. This enabled the inductive process of the generation of new ideas, the identification of themes, case comparison and shaped the direction and focus of data collection. Reflective notes also

became an important part of the data set which were analysed in the same way as other data sources to address the research questions.

4.5.3 Interviews

The purpose of formal interviews was to gain an understanding of unobservable phenomena and to ask participants to explain and elaborate on events which had been observed.

Interview topic guides were developed to guide discussions (Appendix D). The topic guides included grand tour, mini tour and experience questions (Spradley, 1979) to provide a broader context to events, details of specific events and elicit personal experiences. Grand tour questions allow the interviewee to provide contextual information through time and events; in this research this enabled the person with dementia to orientate themselves, for example around the events leading to their hospitalisation. Mini tour questions are more specific, and enabled me to encourage the participant to elaborate on grand tour responses. Experience questions were then used to explore participants' feelings about the events described. This method was particularly useful in understanding responses of people with dementia which benefited from exploration of the broader context to probe and clarify responses to specific questions.

The topic guides were developed after spending two weeks in the ward environment, to ensure that they reflected observed processes, interactions and events. Separate topic guides were developed for each stakeholder group reflecting the different experiences of each and the different purposes of the interviews. Additional guides were also developed to capture the post-discharge experience. The guides provided a focus for discussion ensuring that key issues were addressed but it was also important that participants were able to discuss issues which they considered important. This enabled new topics to emerge. Topic guides were developed iteratively to reflect these changes.

The purpose of the interviews varied according to the stakeholder group. Interviews with patients enabled the patient to share their personal opinions and experiences of hospital discharge. To facilitate this, patients were interviewed whilst still an inpatient but as close to the time of discharge as possible. Follow-up interviews were carried out in the community approximately three-months post discharge to gain an insight into whether the person with dementia thought that the right discharge decision had been made. In total, 30 patient

interviews were conducted. Similarly, carer interviews allowed for the exploration of carers' own feelings and experiences of the discharge decision, but also incorporated an element of proxy questioning, asking the relative to respond about the experience of the discharge on behalf of the person with dementia. A total of 25 interviews were held with carers. Interviews with health and social care professionals differed in that they were more specifically focused around the practitioners' knowledge and understanding of the MCA in relation to hospital discharge, than their general experiences and feelings. Where possible, these interviews were based on a specific case or cases rather than practitioners drawing on their general experiences. 35 practitioners participated in an interview.

Interviews were digitally recorded, transcribed and anonymised. In addition to formal, audio-recorded interviews, informal interactions and exchanges with participants were also recorded in fieldnotes. These included face-to-face conversations on the ward with practitioners, patients and relatives and also telephone conversations with relatives.

4.5.4 Review of patient medical records

Data obtained from a review of each patient's records supported the observational data. Medical records provided information about unobserved events and perspectives of other practitioners not present on the ward, for example from other departments and previous admissions. The records held additional information about patients which often could not be obtained through observation or interview.

Information in the medical records provided clarity about the sequence of events as they occurred throughout the admission. Documented evidence relating to decisions about mental capacity, best interests and discharge were sought, noting when and by whom events occurred and were documented. Also comparing events which I had observed with those recorded by professionals in medical records, enabled comparison of my interpretation of events noted in fieldnotes with those documented by the multi-disciplinary team (May, 2011).

The medical records of all 29 patients were reviewed. Where possible, records from all disciplines including medical, nursing, therapy, social work and Old Age Psychiatry were reviewed. Details were recorded from the start of the admission through to discharge. This sometimes involved recalling notes from hospital record storage post-discharge. The review

was comprehensive – and included general information about the patients’ physical and mental health and their social situation – as well as information specifically relating to judgements and decisions on mental capacity and hospital discharge. Whilst ensuring that key data was collected on judgements and decisions on mental capacity, taking a more holistic approach allowed exploration of other factors which influenced such judgements and decisions but were not made explicit in the notes.

Data were collected relating to routine care, treatment and assessments. In addition, documentation from specific assessments such as cognitive and functional assessments was collected. Data such as images were not included as these were computer-based although interpretation of such investigations was documented within the medical records. Patient records were digitally recorded, transcribed and anonymised.

4.6 Data Analysis

The ethnographic fieldwork yielded a rich and varied source of data for analysis. Analysis of the large volume of data transcripts required a theoretical framework which enabled analysis to start at the beginning of fieldwork, and in which to coherently organise and interpret the data through coding, producing memos and constructing case histories.

4.6.1 Analytical framework

A Grounded Theory approach (Glaser and Strauss, 1967; Atkinson *et al.*, 2001; Charmaz, 2006) guided the analytical interpretation of the research findings. Grounded theory is a qualitative method which supports concepts to emerge from or be ‘grounded’ in the data with potential to offer new insights rather than test pre-defined hypotheses (Corbin and Strauss, 2014). With an emphasis on comparative methods, grounded theory assisted interpretation of the data through: making comparison of data from the beginning of fieldwork; comparing data with categories emerging from analysis; and examining between concepts and categories or themes in the data (Atkinson *et al.*, 2001).

4.6.2 Coding

Coding the transcripts of data collected through fieldwork was the first stage of analysis. Coding transformed the data into smaller categories, enabling analysis of the data by distinct themes (Charmaz, 2006). Although coding enabled individual transcripts to be fragmented

and sorted by labels, these categories were also conceptual and analytical which facilitated the development of themes (Dey, 2004). Open coding strategies (Strauss and Corbin, 1990) were applied to a range of data transcripts to enable the data to be deconstructed into new concepts and themes. During this process, a total of 183 codes and subcodes grouped into 18 themes emerged from the data. The codes represented a broad range of concepts including codes used for identification of attributes or values (such as Ward A), category/event codes (such as home visit assessment) conceptual codes (such as Judgements on capacity), theoretical codes derived from literature (such as labelling from the social science literature and Unwise decisions from the MCA) and codes which captured specifics about the research process. These 'common sense' or heuristic topic codes have particular strength in exploratory, interpretative research (Kelle, 2010). These codes were then applied to data transcripts and refined during an iterative process and later applied to patient case histories. Coding was managed using NVIVO software (NVIVO, 2009). The codes were reviewed and agreed by supervisors JB and JCH, and JB double or multiple coded a sample of documents to verify the validity, authenticity and meaning of the codes (Barbour, 2001; Dey, 2003). A series of data workshops with supervisors JB and JCH allowed discussion of themes emerging from data coding and the construction of a coding framework for further analysis of all data.

4.6.3 Memos

Writing memos is an essential methodological tool of grounded theory, creating the link between processing the data and exploring emergent patterns (Lempert, 2007). This facilitated the detailed exploration of concepts found in the coded data and constructing memos became an important part of developing central themes which emerged from the data. The first stage involved analysing the data coded under each subcode, making notes on the content and comparing this to highlight similarities and differences in the data which would allow codes to be linked together to form themes.

Key concepts and themes were further developed in advanced memos which are more analytical than early memos and move beyond descriptions of concepts in the data to incorporate comparisons such as across categories, between cases, and comparisons with concepts in the literature (Charmaz, 2006). Data, theory and literature were embedded in these memos to integrate data findings within a wider context to move the data towards the

key findings of the research. Advanced memos were produced to explore the key emergent themes of assessment, capacity, best interests, narratives, risk, insight and awareness. These six advanced memos were then further compared to establish cross-cutting or shared messages or areas of difference. This led to the emergence of concepts which shaped the direction of this thesis including informal and formal conceptualisations of mental capacity; information sources and how these are interpreted and shared and the relevance of the patient's journey pre and post admission as well as their inpatient stay.

4.6.4 Case histories

Constructing case histories was a significant part of the analysis process, which facilitated the use of the Constant Comparative grounded theory method of analysis (Glaser and Strauss, 1967). Cases were compared to explore similarities and differences between individuals and groups. This clarified whether emergent concepts and themes from the data fitted with the patient experiences, and cases are compared throughout the data chapters to demonstrate key themes and how these applied to a diverse range of experiences.

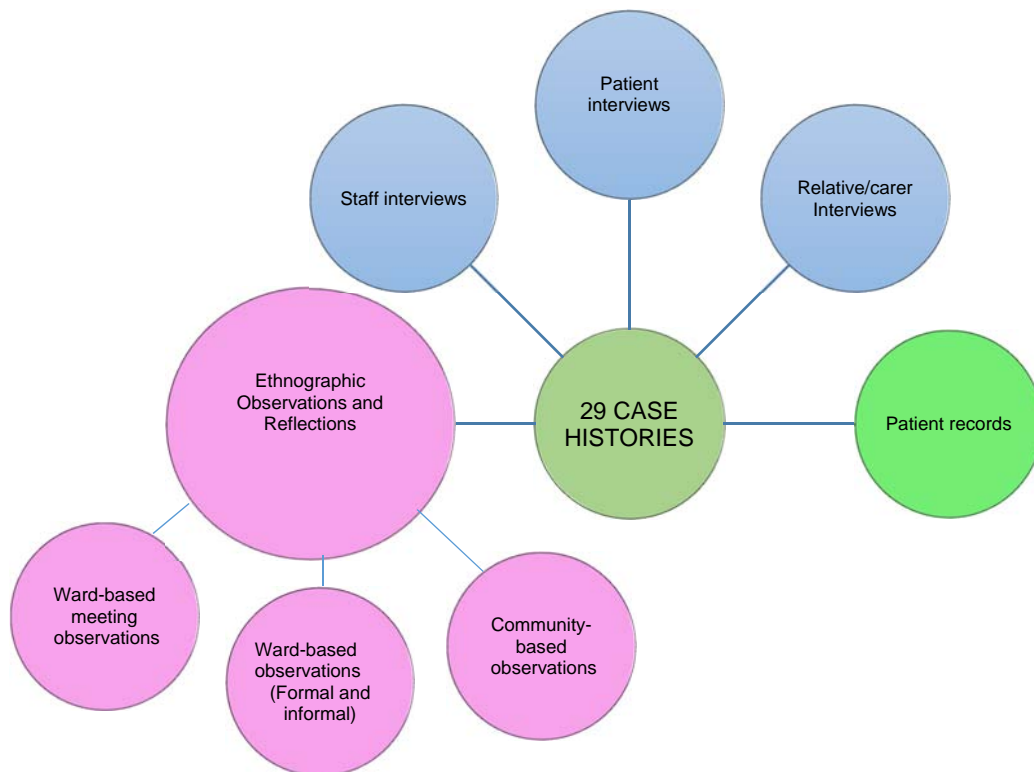
Case histories were written for each of the 29 patients. The case histories were constructed reflecting principles of biographical case construction. This entails reconstructing the accounts of individuals to enable general statements to be made, which facilitates an understanding of individual cases but in the context of the experiences of others (Rosenthal, 2007). In this research each patient narrative was reconstructed around common themes including patient background, key events experienced during the admission, processes such as assessment, and the discharge outcome. Patient cases also included the perceptions of others such as families and health and social care practitioners involved in their care. This process facilitated multiple data sources of observations, interviews and patient records to be incorporated into a single narrative of the patient's journey from pre-admission to three months post-discharge. Figure 4 provides a pictorial representation of the range of data sources used to construct case histories.

Case construction enabled a systematic and chronological way of organising the data for comparison. Case histories also enabled the multiple perspectives of people with dementia, their relatives and health and social care professionals to be integrated. However, in the spirit of the social constructionist paradigm influencing this research, it must be

acknowledged that the production of biographical cases reflects my perception and portrayal of the participants involved.

In addition to comparing patient experience, comparisons between the different wards and settings of acute and rehabilitation care were examined to consider the influence of broader factors such as the physical environment, ward culture and the type of care provided.

Figure 4: Data sources use to construct case histories



Chapter 5. Interpretive work and assessment of mental capacity

5.1 Introduction

The aim of this chapter is to consider the first aspect of the enactment of the MCA in practice for people with dementia in relation to discharge from hospital. I explore the interpretative work health and social care professionals engaged in to make sense of and enact the provisions of the MCA when assessing mental capacity. How mental capacity was assessed in relation to decisions about discharge from hospital for the 29 patients with dementia who participated in this research was analysed. Interactions between practitioners, and with people with dementia and their families are explored in detail to illustrate the ways in which practitioners made sense of, and judged mental capacity in this context. Exploring this process highlights the complex nature of social relations embedded in judgements about mental capacity and supports a better understanding of how professionals practicing in a medical environment interpret and apply the legal framework provided by the MCA, meeting objectives 1 and 2 of this research.

Two key areas emerged from the analysis of the interpretive practices adopted by practitioners. First, that practitioners assessed mental capacity both informally and formally, but whilst informal assessment - influenced by a large range of social factors - was routine, formal assessment was often not undertaken. Second, the factors influencing these interpretative judgements on mental capacity were broad in nature, rather than decision-specific. Thus, capacity decisions in this context were significantly influenced by cultural understandings of ageing and dementia and the complex social interactions required to enact the MCA, rather than the legal test of capacity.

To begin, I define informal and formal approaches to capacity assessment, describe the meaning of these approaches and how they influenced practice. I then highlight the difficulties practitioners faced, when making judgements on mental capacity in a clinical environment, when many of the factors which impact on decisions are social in nature. Often, these related to living in the community, rather than decisions of a medical nature. The chapter is summarised by considering the value of interpretative approaches to mental capacity, and whether such an approach provides people with dementia the best possible

opportunity to receive a fair assessment of mental capacity and the ability to remain involved in the important decision of whether they will return home from hospital, or be discharged into institutional care.

The perspectives of health and social care practitioners involved in the process of mental capacity assessment and my interpretations and reflections on these processes are drawn upon. This illustrates how practitioners understood and enacted capacity assessment, and whether these processes gave people with dementia the best advantage to have full and fair assessment of their mental capacity to undertake decisions regarding place of residence on discharge from hospital. Patient cases are used throughout the chapter, however I then focus on an example of a patient who was assessed as lacking capacity to make his own decision about going home (Mr Collier) and a patient judged to have capacity to make his own decision (Mr Miner). Comparing the cases enables depth in analysis and highlights similarities and differences in the assessment process. Findings from the other 27 cases are drawn on for further comparison.

5.1.1 Defining informal and formal approaches to assessment

Distinguishing between the assessment of mental capacity as informal or formal was rooted in the way in which the multi-disciplinary team described the process of assessment. These terms are commonly understood by practitioners who enacted the MCA (Manthorpe and Samsi, 2016). Analysis and interpretation of the data led me to make the distinction between informal and formal judgements on, and assessment of mental capacity in relation to ability to make decisions about place of residence on discharge from hospital.

My definition of informal judgements on mental capacity describes the interpretive views expressed by health and social care practitioners about the ability of the person with dementia to be able to make their own decisions about going home from hospital. This includes undocumented accounts in which mental capacity was discussed (such as in MDT meetings, on ward rounds or during ad-hoc conversations during daily practices), and decisions made about capacity (documented or observed), but which are not framed within the context of the two-stage assessment of the MCA (See section 3.2).

I define a formal judgement on mental capacity as assessment of capacity specific to the decisions regarding place of residence on discharge from hospital with clear evidence of the

application of the 'two-stage test' detailed in the MCA. This was evidenced either through observations or documented in patients' medical records. Practitioners themselves distinguished a formal capacity assessment from other judgements and used this term to describe the finite judgement and subsequent status ascribed to a person.

5.2 Informal and formal approaches to mental capacity assessment

To identify factors which may facilitate or inhibit fair assessment of mental capacity, the interpretative, interpersonal strategies and processes practitioners engaged in to form informal judgements are first considered. The processes which lead to informal judgements requiring formalised assessment are then examined to exemplify how failure to fully and consistently explore mental capacity may disadvantage the person with dementia by not meeting with the provisions of the MCA.

Comparing observations with interviews suggested some incongruence between understanding and application of the Act amongst practitioners. Interviews revealed that the multi-disciplinary team appeared to understand the principles of the MCA and were comfortable with the four criteria defined in the Act (See Figure 2); and practitioners across a range of disciplines – including senior and junior clinicians, social workers, therapists and senior nursing staff – seemed confident of the general principles. However, observations of daily practice indicated inconsistencies between people's knowledge of the criteria of capacity assessment and how this was applied in practice. This area of incongruence raised important research questions around why there seemed to be a gap between knowledge and practice of the MCA, and the interpretative work which practitioners engaged in to understand and make sense of mental capacity in relation to place of residence on discharge from hospital.

The findings evidenced that, although the MDT expressed doubts about the mental capacity relating to decisions about place of residence on discharge for all 29 patients in this research; capacity assessment was most often limited to an informal process rather than the two-stage test. For two thirds of participants, mental capacity in relation to place of residence on discharge from hospital was not formally explored and remained subject mainly to value judgements (Greener *et al.*, 2012). This raises questions about full and fair assessment. Furthermore, in a small number of cases no definitive judgement of the patient

having or lacking capacity was recorded in patients' notes. So, although practitioners professed to understand the Act, this raises questions around interpretation of the MCA, the broad nature of the MCA, and whether this translates into practice which appropriately supports people with dementia and provides adequate and fair assessment of mental capacity.

The basic principles of the MCA support that doubts about impaired mental capacity should be evidenced and fully explored. The Code of Practice states that a proper assessment of capacity must be carried out when professionals question mental capacity, and the appropriate two-stage test should then be applied (Section 4.52). I therefore explore whether informal processes of assessment of capacity alone can provide people with dementia sufficient opportunities to remain autonomous and empowered with relation to important decisions regarding place of residence on discharge from hospital.

Through early reflections on discussions about mental capacity, I mused on discussions in MDT meetings and became interested in how practitioners talked about people having or lacking capacity. I wondered whether informal impressions of capacity would influence the outcome.

...there was quite a bit of debate about capacity. The senior nurse thought this patient didn't have capacity but the physiotherapist did think the patient had capacity and they agreed that the patient probably did have ...The senior nurse said that the patient seemed to lack capacity and then this was passed on to people who were present at the MDT's and ward rounds and I wondered if decisions like these impact on the final decision about capacity for patients

Reflective notes: 030708

It became apparent that mental capacity of individuals would be interpreted differently within the team, and that mental capacity was often considered broadly, rather than decision-specific. This is important, given the decision-specific nature of decision making set out in the MCA. Discussion of mental capacity in relation to discharge and residence decisions was often implicit in the ultimate goal of discharging the patient. I was interested

in how the practitioners constructed their knowledge about the patient to arrive at such judgements.

5.2.1 Getting to know the patient

When patients arrived on the ward, they were usually unknown to the multi-disciplinary team. Practitioners needed to acquire knowledge of the patient during the admission. As part of the informal assessment process, the team made a number of interpretive judgements about the person, including their physical and mental abilities and their social situation in the community.

To understand how practitioners constructed their knowledge of the patient over the admission, reflections on early observations of interactions between patients and medics highlighted consultant-led ward rounds as a significant context.

... just generally some of the things that sprung to mind whilst I was observing the ward round, things that seemed to be taken into account when making an assessment of patient's awareness and understanding seems to be whether the patient has an awareness of the condition, if they have an awareness of their present situation, if they have an awareness and can recount details of their past or prior to coming into hospital, and the kind of plausibility of the accounts that patients give, the stories that they tell, information they give about the family, their health, their home circumstances, what they're doing on the ward, their eating and drinking, how they're feeling. So really I think this kind of breaks down into a couple of factors - there's judgements made on the observable factors, so the physical state of the patient, how the patient presents, how the patient speaks, some of them there's an immediate judgement that can be made on that and then I think there's a judgement given of the narrative given by the patient (pause) is the patient able to communicate how they are, do they seem to understand the consultant's questions, do they comply with the consultant's questions, so if the consultant asks them to do something such as raise their arms do they understand and can they follow this, and then there's also judgements made on the patient's medical notes.

Reflective notes: 050808

It became apparent that the ward round was a key social exchange which was structured in a way to enable medics to make a range of judgements about the patient. Many aspects of this interaction had the potential to influence judgements on mental capacity decisions relating to place of residence on discharge.

Consultants were only likely to interact directly with patients during weekly ward rounds, although registrars and junior doctors often had more regular contact with patients as part of daily rounds. During this interaction, physical examination and review of the patient's progress occurred. Doctors described forming judgements on the mental capacity of patients through this exchange. One doctor explained the routine judgements made about mental capacity on a daily basis.

I don't often get asked to make a formal capacity decision... We do it but a lot of the time it's something you assess as you're speaking to the patient on your day to day ward rounds anyway because, if they can't remember having seen you the day before they don't know they're in hospital, they're unable to retain the information, you're kind of informally making capacity decisions day to day anyway.

Interview: Registrar 01BsM-0611

Due to this limited contact, senior medics described several strategies which they used to engage with the patient which enabled them to make judgements on patients' mental capacity. Many of the medics were observed or described using visual prompts during ward rounds to inform their judgements. Examples included engaging with patients using magazines, books and food on the patient's tray to open up conversations about their cognition. A consultant at Site 1 explained how she looked at the puzzles completed by patients to see if they are able to do them to help with judgements about cognition. I observed this consultant asking Mr Saddler about the newspaper he was reading to gauge his cognition. Another strategy for informally assessing mental capacity included having 'chats' during ward rounds about current events, and subjects not particularly related to their current health or plans for discharge. One consultant expressed his frustrations when,

during a ward round, Mr Shepherd's daughter answered all the consultant's questions on behalf of her father.

...afterwards he said to me that it really annoys him when the relatives respond on behalf of the patients, he said it's not the facts that he's interested in, he knows those already before he goes into the room, he said it's the interaction he's interested in, it's the eye contact, it's the responses that the patient gives and that's all part of his informal assessment ...he's trying to get a feel for how the patient is...

Fieldnotes: Site 2 30.03.09

This exchange formed the basis of how the consultant made sense of his direct interaction with the patient. He referred to the social and cultural norms expected in the context of doctor-patient relationships (Emanuel and Emanuel, 1992), and how this was compromised by the family. The consultant felt that families didn't have an awareness that directly questioning the patients served a function beyond finding out the facts, and was more about "trying to get a feel" for the patient.

However, the ward round was just one context in which patients and practitioners engaged. Nurses and therapists often engaged daily with patients, sometimes enabling extended periods of interaction through routine care or assessments. The medical team were therefore reliant on information provided by others in the team to enhance their knowledge about patients. A junior doctor described this limited direct interrelationship with patients and explained how doctors were dependent on information from the rest of the team to supplement their observations in relation to judgements on mental capacity.

the good thing about having MDTs and things is you've got a great big wealth of experience and people who know the person probably better than the consultant because quite frankly the consultant comes along twice a week, sees them for maybe five, ten minutes each so I would say that a good consultant will certainly take on board what everybody says to them and use that information in deciding where we go with capacity.

Interview: Junior Doctor 02sD-1505

The MDT meetings therefore played an essential role in informing the medics. Practitioners from other disciplines also described how they engaged in their own informal processes of capacity assessment. In the extract below, the social worker at Site 2 described how he interacted with people to make sense of their mental capacity.

...well I don't do MMSEs or anything like that. That's nursing or social workers from Old Age Psychiatry. I'm more about where are you, who are you, tell me a wee bit about yourself, tell me a little bit about your family, your past history. Do you know why you're here? You know, what are your wishes for the future? If they're married tell me about your wife, you know and if they're able to give me that information then in the main we're talking about someone who has capacity.

Interview: Social worker 02sJ-0206

The social worker described a process of exploring mental capacity through conversation and intuitive practices rather than using assessment tools, but unlike the interaction during ward rounds, this is in a one to one context and more socially focused. The social worker emphasised the relevance of gaining an understanding of the person's social context, and their understanding of this rather than using cognitive testing. This recognises the importance of situating the person as a social being and considering their relatedness to others (Kontos *et al.*, 2017), rather than simply testing function. The social worker also explained that this interaction was not intended to be a single assessment but one conducted over an extended period.

I've had ten goes at Mr Collier. I've had you know, and I'm not really very much further forward but I think that's partly because he's not very well and I do think he's depressed, and that is in tandem with his illness really you know.

Interview: Social worker 02sJ-0206

The social worker described the ongoing nature of this process. Multiple and informal assessments of capacity were observed to be routine for many patients, especially for those whom the MDT found it particularly difficult to arrive at a decision on mental capacity, such as Mr Collier. This process required time, and practitioners felt they got to know patients

through often lengthy inpatient stays. Some staff felt competent to establish the 'norms' for such patients and judge when the patient was "not themselves" or "back to normal". Knowing the idiosyncrasies of individuals represents a person-centred approach to care (Kitwood, 1997), and reflects best practice for people with dementia (National Institute for Health and Clinical Excellence, 2006).

...people have good days and bad days, you could argue you have to wait for a good day to get somebody's best but countering that argument, you wait for a bad day, I bet you that's the one they decide to walk in front of a bus or... So you've, you've got to wonder, when you assess it, so for me part of the challenge of capacity is knowing the patient over a long time.

Interview: Junior Doctor 02sD-1505

Patients often spent considerable periods of time as inpatients, especially in the rehabilitation setting and through readmission. The average length of stay on the acute wards was 35 days (5 weeks), and over double that on the rehabilitation ward – 87 days (12.5 weeks). Mr Collier and Mr Miner were both patients on the rehabilitation ward. Mr Collier was under the care of the MDT for three and a half months following a fall at home. Mr Miner's admission was considerably shorter at five and a half weeks for treatment of complications following an elective procedure. However, despite a lengthy admission the MDT reported finding it difficult to build up a good level of knowledge and understanding about Mr Collier's mental capacity.

....He's got quite a good façade when you talk to him but I think if you get underneath that he really doesn't have the capacity to understand what is safe and what isn't safe. We've offered him carers at home and he refuses them. He confabulates, he just "well we'll do it next week or the week after", we've offered him the opportunity to consider re-housing sheltered accommodation and it's the same response basically, "not just yet but at some point we will". So engaging him at any meaningful level has been quite difficult.

Interview: Social worker 02sJ-0206

The multiple and informal social exchanges whilst the person with dementia received care on the ward, also influenced by factors such as the approach of the practitioner and length of admission, illustrate how the interpretative work in which practitioners engaged played an important role in informal judgements on mental capacity relating to place of residence.

5.2.2 Formalising the informal

It is clear that practitioners engaged in a considerable amount of interpretive work in informal assessment, however formal assessment of mental capacity was only the tip of the iceberg for the majority of the patients in this study. The distinction which practitioners made between the two interrelated processes of capacity assessment emerged early in the research and patients commonly had several informal assessments of capacity during their admission, before a final decision of capacity or incapacity was reached.

Although capacity was assessed informally for of all patients, not all received a formal assessment of their mental capacity in relation to decisions about place of residence on discharge. Practitioners considered this necessary only in certain cases.

(Date) Ward round with (Consultant) 10:50 [...] Impression; medically ready for discharge. Patient keen to go home, feels daughter's very supportive and will help her manage. Not willing to consider alternative care and says 'no way'. NB; cognitive impairment MMSE less than or equivalent to 15 out of 30 at present. Home assessment visit with OT did not go well, thinks there won't be any potential problems re. going home; not sure why can't. Impression; medically ready for discharge, lacks insight of the problems, not sure if has health capacity, needs a full assessment. Plan; await planning meeting, discussion with MDT, consider repeat home visit, may need formal capacity assessment.

Medical records: Mrs Baker 011008

This extract from Mrs Baker's note alludes to the point that complex capacity decisions were more necessarily considered to require formalisation. Formalising and documenting complex capacity assessment was considered a greater priority than more straightforward cases, concurrent with guidance in Section 4.42 of the Code of Practice, which states that

complex decisions are likely to require more formal assessment. Making this distinction may cause confusion for practitioners, and is open to misinterpretation that only complex cases require formal assessment.

Practitioners described how formalising previously informal judgements about mental capacity moved judgements from general exploration to a more defined conceptualisation of whether the person was considered to have or lack mental capacity to make their own decisions regarding place of residence. In the example below, the consultant described the circumstances which led to formalising informal judgements, highlighting sources of conflict as a particular reason.

You get a feeling about people's general capacity, but then that's kind of then... if a decision is being taken or being made or about to be taken I think then we'll be slightly more specific about going to the patient and actually exploring the issues in more depth. So I think there's a gut feeling and then sort of you know hopefully, I think it mainly comes about if there's conflict or if there's concerns that we investigate that further by sort of direct questioning.

Interview Consultant 01AsO-2111

In the following example, the registrar described complexity caused when it is unclear whether the person seems to have capacity or not and how this impacts on formalisation of capacity judgements.

And the capacity...um, I think the patient, it's more complex then because you wonder whether they do have capacity so you've actually got to make the effort to make that formal assessment in those more complex cases whereas in clear cut ones you don't actually, as I say, you don't formalise it because you don't think it's necessary.

Interview: Registrar 01BsM-0611

In this example, the consultant referred to the "extra effort" required to make a formal assessment of capacity in comparison with more informal assessment. The findings exposed a reluctance by practitioners to take informal assessment of mental capacity to the 'next

step' despite the time and effort already invested in making judgements. This informal approach may result in a lack of evidence to support how and why practitioners formalised some capacity assessments and not others and could be further taken as evidence that mental capacity had not been adequately assessed for the person with dementia. This perceived additional layer of exploration and assessment may account for the reason that two-thirds (19 cases) of the participants in this research never had their mental capacity formally assessed. This means that the two-stage test was not applied, in keeping with the legal requirements of the MCA.

Although I observed concerns about mental capacity discussed in MDT meetings, of which some were documented in medical records, there was often no evidence of a specific assessment of capacity having been undertaken. An assessment of mental capacity relating to the decision of place of residence on discharge from hospital was clearly documented for only 10 patients. For 10 cases, nothing at all was documented about mental capacity in the patients records despite the MDT expressing doubts about their ability to make a decision about returning home, which were captured through observations of MDT meetings and conversations with the team. Seven of these patients were judged to have capacity, while three patients were judged as lacking in mental capacity. The findings suggest that practitioners assumed that formalising their judgements was not required, particularly in cases where the patient had capacity and could be viewed as upholding the provisions of the MCA in assumption that the person had capacity. However, Section 4.34 of the Code of Practice states the importance of carrying out assessments if there is doubt about capacity, and furthermore, an assessor must be able to justify conclusions.

Focusing in depth on Mr Miner, in this case, there was no evidence of a formal capacity assessment having been undertaken. Although, several members of the MDT expressed concerns implicitly about Mr Miner's mental capacity during discussions in MDT meetings, there was nothing documented in his medical or nursing records relating to his mental capacity. The extract below illustrates that although some members of the team expressed doubts, these views were not held by the consultant who had recently discussed hospital discharge with the patient during the weekly ward round.

There was then some discussion about the case conference that was to go ahead. The consultant commented that this patient has a lot of falls but he feels that the patient's wife will want the patient to go home. The physiotherapist commented that the patient was so variable in terms of cognitive impairment last week. She described him as talking "gibberish" on some days and how today he'd been talking about a judge and a trial that was going ahead but she wasn't sure of the context of the conversation. She's informed the MDT that the patient required constant prompts to mobilise. The consultant said that when he'd seen the patient the previous Wednesday he said that he hadn't been that bad.

Fieldnotes: MDT 150509

Although the phrase 'mental capacity' was not used in relation to discharge, it is implicit in the doubts raised about his cognitive ability to participate in rehabilitation and his understanding of the risks of going home due to frequent falls caused by Parkinson's-related mobility issues. However, the physiotherapist in particular doubted Mr Miner's mental capacity based on interactions during therapy sessions.

I do think he knows he wants to go home, I don't think he has the capacity to know how unsafe he is with regards to falling. Because he, he falls constantly and, I think he remembers that he fell but then he forgets further down the line because it's just a very recent thing and I don't think his short term memory is particularly good.

Interview: Physiotherapist 02sF-2005

The perspective of the therapist suggests that a mental capacity assessment was not undertaken for Mr Miner because the emphasis was placed on the safety of his discharge rather than his ability to make decisions. This represents an outcomes-driven approach to capacity assessment and does not meet with the provisions of the MCA (Emmett *et al.*, 2013a). The team knew that Mr Miner wished to go home, and this was supported by his wife. Furthermore, in contrast, the consultant had few doubts about Mr Miner's awareness of the risks of the discharge, and therefore despite others in the team questioning Mr Miner's mental capacity in relation to discharge, his capacity was not assessed.

The consultant was confident that Mr Miner seemed “with it” and understood the risks involved in returning home, suggesting good practice and the presumption of capacity to make his own decision to return home in accordance with his wishes. This may be why Mr Miner’s capacity was never fully explored. Although not documented anywhere in the patient’s records, it was implicit from observations of ward rounds and MDT meetings and in the case conference that the consultant took the lead in informally assessing Mr Miner’s mental capacity in relation to place of residence on discharge, and his opinion prevailed over the physiotherapist. Mr Miner described his exchange with the consultant during his case conference.

MP: there was a meeting the other day that you went to, yourself and your wife and the doctor was there and I believe you were meeting to talk about the possibility of you going home. How did you feel that went?

INT: I thought it was quite good, maybe a bit cautious, you know, on the cautious side not building my hopes up, I bothered to seem, you know, do your best like an examination in school (laughs).

MP: And did the doctor or the consultant, did he ask you about your opinions about going home?

INT: He was a wee bitty, not too sure.

MP: Right, what did he say, can you remember?

INT: Just that the biggest fear is me falling because I do quite a, well, I did quite a lot and err he, he just showed a bit of caution and like that but err eventually he’s you know, we’ll give it a go and err, so tomorrow is starting day.

Interview: Mr Miner 220509

Mr Miner expressed how he felt he was being tested in the meeting, indicating that his mental capacity was still being informally assessed by the consultant, and reinforces the outcomes-driven approach, with the emphasis being on the discharge plan, rather than formally addressing the issue of capacity and assessing Mr Miner’s cognition prior to the meeting. It is unclear why, despite the interpretative work undertaken to explore Mr

Miner's mental capacity remained undocumented and informal, when such evidence is fundamental to meeting with the provisions of the Act. This suggests a lack of clarity in the Code, as the consultant complied with the act insofar as presuming capacity (Stage 1), the doubts expressed by others were not evidenced, and could be interpreted as not fully explored as set out in the Act. This provides a clear example that although observations and interviews revealed a significant amount of interpretative work, requiring time, effort and resource to explore the mental capacity of patients with dementia to make decisions about place of residence on discharge from hospital, this was often rendered invisible, and good practice was obscured through a lack of documentation.

5.2.3 Documenting assessments

Through regularly observing MDT meetings, ward rounds, and talking to staff, I was aware of the judgements which staff had made about the mental capacity of patients in relation decisions about place of residence. However, many of these views remained unrecorded. Reviewing medical records revealed a lack of documentation relating to the process of capacity assessment or the decision that the patient had or lacked capacity to make their own decision regarding place of residence.

Reviewing notes this afternoon, I think I've been quite surprised by the lack of documentation about how capacity is being assessed for various patients. I think all three patient notes who I've reviewed this afternoon are considered not to have capacity and there's very little information about how this decision [that Mrs Gardiner lacked capacity] was actually arrived at, but it may just be that I'm seeing the notes disjointedly and when I read up the case it will be more fully explained but I don't feel that it has because I've had a flick through the notes this afternoon.

Reflective notes: 240709

Being assessed as either able or unable to make such critical decisions has considerable consequence. The paucity of information on such a significant aspect of a person's fundamental rights, further underscores the incongruence between the interpretative work observed and what was officially recorded in patients' medical notes.

When assessments of mental capacity were documented in the patient's medical records, these varied greatly in detail, quality and quantity of the information recorded. This ranged from single words or sentences such as "lacks capacity", through to presenting the reasons for why the patient was considered to have or lack capacity. Section 4.61 of the Code of Practice states that capacity assessments conducted by healthcare professionals should be recorded in clinical notes, but does not provide guidance about the content. Some descriptions of capacity assessments were very lengthy and documented in detail. Detailed documentation was often recorded when a specific and separate assessment of mental capacity was completed by a social worker and/or Old Age Psychiatry.

(Date) psychiatric liaison nurse. Appearance, a slim gentleman, laid on bed to ease his back, catheter in situ, it leaked a little with no apparent awareness. Note prior to hospital unkempt, speech slightly slow and of low volume but content appropriate, animated and initiating conversation. Sleep, feels sleep is currently disturbed by constipation but otherwise very well, appetite poor but feels he eats enough, at home admits he was unlikely to gain weight because he "can't be bothered", feels he eats mainly burgers or sausages which he microwaves, he says "they do him". Mood feels is alright but fed up being in hospital for weeks but he makes the best of it, says he cheered up "when the wife left and that was years ago", he scored 0 out of 4 on abbreviated GDS and denied ever being depressed, laughed during conversation but with short delayed reaction. Thoughts, thinks he is a "man who doesn't see stuff like women, only women see housework etc as important, used to be done by his mother then his wife", enjoys thinking, listening to radio and going to (local Club) three times a week. Cognition, declined MMSE, "too many questions" but I note a score of 26 out of 30, no evidence of hallucinations, delusions and no evidence of disordered thinking, note comment of NAD on CT head scan. Plan is one I will try to gain further background information from family and GP, two to obtain a CT head report and discuss with Old Age Psychiatry, three patient is thinking about moving to somewhere where meals will be provided and have help (with social worker) but waiting to

see if mobility increases and would insist on own space plus radio if he did move to residential care.

Medical records: Mr Collier 220609

In contrast, the reasons for capacity assessment and the outcomes recorded by the medical team were often brief and lacking in detail, although key aspects of the two stage test are evidenced in this extract below.

(Date). Consultant. Discussed with social worker, all agreed best interest equalled residential care. Dithering about decision but generally says wants to go home. Has unrealistic views that help would be enough via two week carers plus help from disabled daughter, do not think he “understands the issues to make this decision” and cannot “use and weigh” these therefore judged not to have mental capacity to know decision re place of residency.

Medical records: Mr Collier 010709

Such variation in documentation often resulted in inadequate evidence of the process of assessment and would be problematic if a mental capacity decision were to be legally challenged.

At Site 2, a pilot proforma for formally assessing capacity was already in place. The two-sided document included the four key criteria of the MCA and space to record reasons why the patient was considered to have or lack capacity in relation to a specific decision. A flowchart to aid decision making was also included on the reverse of this document. Although a clear example of good practice, evidence of its use was limited to only three of the nine participants at this site.

The findings indicate that practitioners did not routinely document their interpretive work around mental capacity, despite confidence in expressing this verbally during MDT meetings. There may be many reasons, including uncertainty of the Act, and organisational and time constraints of practicing in the NHS. However, this lack of documentation seems to sit at odds with a culture of accountability in modern medicine. Such decisions are also made in the context of a culture of traditional medical relations in which the senior clinicians judgement is authoritative and accepted (Freidson, 1975; Gabe and Monaghan, 2013).

Therefore the need to justify such a critical decision may be overlooked in the context of normal practice.

5.2.4 Formal or finite?

Formalisation of judgements on mental capacity represents a shift in the patient's status to a person who is defined as having or lacking capacity, and the person with dementia becomes positioned (Sabat, 2001) as either able or unable to make decisions. This is a significant label to attach to the person with far-reaching consequences (Scheff, 1971) for involvement in decision making. Observation data and medical notes showed that once capacity had been formally assessed and documented, this was rarely revisited or revised. Further exploration of mental capacity relating to discharge was limited, even if the outcome had changed. For example, Mrs MacVicar was assessed as having sufficient capacity to make her own decision about a move to nursing care. Mrs MacVicar continued to have medical complications, and the team felt that by the end of the admission she probably lacked mental capacity to undertake decisions. However, the discharge into nursing care did not seem to be altered by this change in perceptions about mental capacity and therefore was not revisited.

"She probably did [have capacity] to start with, however at the end when she ended up going into nursing care she didn't have capacity".

Interview: OT 02sC-1305

An awareness that mental capacity must not be 'set in stone' once it has been formalised and documented is necessary. This is particularly important to preserve the rights and wishes of patients with dementia, due to fluctuations in their condition.

5.3 Insight, awareness and the decision-specific nature of capacity assessment

The previous sections focused on the interpretive process of mental capacity assessment which practitioners engaged in. The following sections consider the social relations between people with dementia and practitioners in more depth, and how these influence judgements on mental capacity. The meaning and content of these interactions are explored with an emphasis on considering whether more significance is attached to social or medical issues. I also explore whether the decision-specific nature of the MCA is problematic for practitioners in making decisions relating to place of residence on discharge from hospital. I consider how

the concepts of insight and awareness relate to unwise decisions and how the social context influences capacity judgement. This underpins many of the concerns around the mental capacity of patients with dementia to make their own decisions about going home from hospital.

5.3.1 Judgements on insight and awareness

Reflecting on interactions observed between patients and medics during ward rounds, it became apparent that medics were trying to gauge awareness in a multi-dimensional way.

So again just generally some of the things that sprung to mind whilst I was observing the ward round... things that seemed to be taken into account when making an assessment of patient's awareness and understanding seems to be whether the patient has an awareness of the condition, if they have an awareness of their present situation, if they have an awareness and can recount details of their past or prior to coming into hospital,

Reflective notes 050808

This suggests that patients with dementia are judged on their awareness comprised of understanding the requests of the medic and responding in an appropriate way to questions of a personal and social nature. Compliance with, or deviance from, these socially accepted norms (Becker, 1963) caused by dementia was understood as a lack of awareness on the part of the person with dementia (Sabat, 2001).

During interviews, the MDT commonly referred to interpreting their interactions with patients with dementia in the context of whether they seemed aware of and had insight into their 'situation'. Patients who seemed able to understand multiple dimensions of their social world, and convey this in a meaningful way to practitioners were more likely to be thought of as capable of making decisions about place of residence. This interpretation seemed to be based on whether the person with dementia was aware of and able to correctly interpret their social context and furthermore, able to act accordingly to social norms (Sabat, 2001). This was observed to translate into judgements on capacity, and thus interpretive judgements on insight and awareness appeared to form a fundamental part of mental capacity assessment in relation to discharge.

I observed that such judgements were contingent on how the verbal expressions of the person with dementia were perceived by practitioners and how they interpreted and positioned the person as being in touch with, or removed from, the reality of their current situation and needs (Sabat, 2001). This influenced the decision of capacity or incapacity. The data show that practitioners interpreted patients' insight and awareness as an understanding of the 'reality' of their current and future situation often in a general sense, rather than specifically in relation to decisions about place of residence. This suggests that capacity judgements were often based on a more global conceptions of capacity rather than decision-specific assessment in keeping with the provisions of the MCA.

Practitioners described how patients' awareness of their social location was key to assessing and arriving at judgements about mental capacity. In the example below, the consultant highlighted the significance of patients' general awareness about their home situation.

For people with cognitive impairment it's about the fact that they think their mother's still alive and they need to get back to school and you know that's not true but that's their belief and you can't shake them in that belief, so that person you know, is believing untrue things about their home situation so they may therefore not have capacity to make a decision to go home.

Interview: Consultant 01BsQ-1212

In this example, failure to understand the reality of their current social situation and needs was regarded as a clear indication that the patient lacked capacity to make a decision to return home. This seems a reasonable approach which is specific to understanding about arrangements for care. Judgements on patients' insight and awareness were commonly and frequently expressed, and practitioners across a range of disciplines commonly used the terms awareness - usually in terms of deficit (Sabat and Harré, 1992; Sabat, 2001). The concepts are at times applied to a specific situation, but at others are more abstract and global.

I know that when we are doing capacity it should be only on one sort of, you know, area and it can't be for everything but I think if they have the capacity to make decisions for, in other areas also, you have more

confidence in saying that they have the capacity for this because you know that they can make decisions on, you know, for various other things. So it also draws that, they can make decisions of where they want to go and they have the insight, right?

Interview: Consultant 02sE-2005

This more global view of capacity is not in keeping with the decision-specific nature of mental capacity as espoused in the MCA. The data indicated that patients were required to have awareness of and insight into multiple factors relating to their discharge, such as their memory problems, physical health and medical conditions e.g. falls or incontinence. More specific to discharge was an expectation that patients were aware of their functional ability to do tasks and any support needs on discharge – either from services or family. In addition, an awareness of the hospital environment, and if they understood their current context was also required.

MP: do you have to make any decisions on capacity while you're out doing these home visits as part of your OT role?

[...] What I look at is insight. Do they have an insight? Do they understand the consequences of behaviours that they're doing? And that's a lot of the time how I base my decisions on. [...]. She didn't have insight that if she needs a frame she's going to fall. Equally the same lady has quite bad incontinence and she has carers but she's declined carers, so the consequence of being so incontinent she has very sore areas, she can't make that link that she needs help to maintain hygiene. So for me these things are just insight. Do people understand the consequences of what behaviour?

Interview: OT 01BsD-1709

Although in the example above, insight is considered specifically in relation to functional physical outcomes, evaluative judgements were often made more globally. Patients were often described as having no insight or awareness in general rather than in relation to specific phenomena. This is exemplified by the OT in which she questions Mr Collier's insight. It is only implicit that she was referring specifically to his home situation.

I don't think they've done a formal capacity assessment with him yet. His MMSE was something like 28 out of 30, or 30 out of 30. He's capable of telling you, I mean, when I went to do... started doing an MMSE with him for thisapparently he'd already had one before but I didn't realise that, and he's going, "oh this is the one where they ask you about this" and he could reel it off before I'd even asked him the questions. So his memory, there's nothing wrong with his memory but ...I question his insight. He can relay the information back and he would technically – which is why I have a bit of an issue with the whole capacity thing.

Interview: OT 02sC-1305

The OT related insight directly to assessing Mr Collier's mental capacity. She has no doubts about his memory but queried his insight into his former living arrangements which led her to doubt his mental capacity. The practitioner struggled to make sense of how to make the patient 'fit' with the requirements of the MCA, rather than recognising his intact cognitive abilities and appreciation of his situation (Sabat and Collins, 1999; Sabat, 2001). It demonstrates confusion around the decision-specific nature of the test of capacity and broader conceptualisations of understanding.

In Mr Miner's case the physiotherapist and others within the MDT felt that Mr Miner lacked awareness and insight relating specifically to safety and the risks of going home. The physiotherapist pointed to his lack of awareness of his mobility problems.

He's well aware when he struggles to do things but the problem is he also lacks the awareness that when he stands up he's not stable enough and he falls and luckily he's not hurt himself but he's had quite a few falls in hospital. He even fell yesterday and he just, he doesn't know why he falls and it's because he stands up and loses his balance and forgets that he's got a frame because he didn't have a frame before he came into hospital"

Interview: Physiotherapist 02sF-2005

During the interview, she related lack of awareness of his risks of falling and how this would be dangerous at home to being indicative of a more global lack of insight and awareness into his physical and cognitive condition. Furthermore, this illustrates that the judgement was

based around a general understanding of the situation rather than the patient's decision-making ability. Unawareness in dementia is used to justify withholding autonomy, however awareness and competency must be understood in the context of social interactions (Woods and Pratt, 2005), which in this case should be his decision-making competencies.

5.3.2 Fluctuating insight and awareness – Mr Miner's questionable insight?

Practitioners described that establishing whether patients had insight and awareness was often difficult. This was most complicated with patients whose awareness was thought to fluctuate and when patients could not be readily categorised as having or lacking insight in a similar way to having or lacking capacity. Difficulties in interpreting the behaviours and expressions of people with dementia therefore translated into difficulties in positioning people with dementia as having or lacking mental capacity in accordance with the MCA.

The next patient discussed was Mr Collier. The patient has been assessed by Old Age Psychiatry and has been seen by (Liaison Nurse). The plan for this patient was to gain further background information from the family, there was general consensus that this patient tells everyone what they want to hear. There was a feeling that there would need to be clarification as to whether this patient had insight into the situation at home.

Yesterday the patient had been described as accepting of care and the OT asked if everyone thought he would be agreeing to a placement. The social worker responded that this was a very different situation to last week and last week he was against any kind of care

Fieldnotes: MDT meeting 270509

Judgements were considered easier when patients seemed unaware of their current social context. This was indicative of a lack of capacity to make their own decisions about discharge. In the interview extract below, the consultant described how it was easier to make judgements on capacity and subsequent best-interest decisions when a patient lacked insight and awareness of their current circumstances.

...you know for some people it's actually very straightforward, they plainly don't have capacity because they can't remember you know, anything, they don't know where they are, they think they're at home, they think I'm their

daughter, you know they think they still live with their mother, you know things that are plainly not true and they plainly, even when we treated over in medical problem, they plainly do not, cannot understand or retain relevant information about the home situation so then it's easy to make a decision that they don't have capacity

Interview: Consultant 01BsQ-1212

In addition to recognition of their current environment, patients were required to understand the concept of 'home'. One consultant summarised the difficulties of differentiating between whether patients are truly aware of their home circumstances and whether they are using a default response when exploring their wishes which made capacity assessment complicated.

Well in some cases with moderate cognitive impairment my feeling is that it is still subjective as to know whether they really understand what you are telling them right, or they can weight you know the pros and cons you know of the situation and whether they get, well they always say "I know, it is my home", you know, "I erm, I wish, want to go home", but sometimes if you really like do a home visit or something and if they've been in the ward for a few months they don't even know that it is their home. Although they keep on saying "it's my home I want to go home", I think it's, it's an automatic thing that they say rather than actually knowing it and sometimes it is very difficult to differentiate you know.

Interview: Consultant 02sE-2005

The concept of home seems to be taken literally, rather than in the broader cultural context of what home represents such as security, familiarity and connection (Frank, 2005). Returning to the case of Mr Collier, whether he had insight into the condition of his home environment required extensive investigation by the MDT. Although his daughter had reported that he was unable to cope prior to his admission Mr Collier was unconcerned by the state of his home. Furthermore, a home visit assessment by the OT had revealed the house to be in a condition which the MDT described as "unkempt", "filthy" and "squalor". Mr Collier refused the offer of social services to have his house cleaned. Mr Collier was positioned by practitioners as difficult to gauge in his understanding and awareness of his

situation, which was attributed to his cognitive deficiencies rather than a mismatch of values around standards and expectations (Sabat and Harré, 1992). An extract from Mr Collier's medical records below, demonstrates how the psychiatric liaison nurse explored his preferences around home.

(Date) Old Age Psychiatry, discussion with (ward sister) this morning ... FAS [a word naming exercise to test executive functioning skills] abandoned after two answers for F, poor motivation and asking if I thought he was "daft" influenced patient's responses, perhaps someone familiar with patient whom he trusts could try with this testing as the first time I met patient. Has agreed today to carers at home, can see pros and cons, rather passive, "yes" response, didn't communicate back to me benefits of cons of carers but that he would agree for them to help, agrees he has falls, likes clubs three nights a week, two to three pints a night. Can own team/ plus SW, do own MCA assessment and get back to me if necessary. Sounds like he is agreeable, try home. Old age CMHT could follow up, patient doesn't seem depressed but I think would be better for further assessment from [CMHT] team in own environment, did not discuss residential care with patient.

Medical records: Mr Collier 030609

In short, he clearly wished to return home and live the life he had prior to admission and provided explanations to substantiate his wishes. However, these were interpreted as unreasonable and the MDT considered this evidence of a lack of insight as to how poor his living conditions had become, influencing the judgement that the patient lacked the capacity to make a decision about his discharge. Mr Collier deviated from what is 'normal' (Becker, 1963) as defined by the medical team in terms of his perceptions of his home environment and his refusal to have help from social care agencies, which was interpreted as evidence of his cognitive deficiency.

Mr Collier's clear wish to return home was considered alongside the account of his home supplied by the occupational therapist, and the concerns expressed about his inability to cope at home by his daughter. This led the team to question Mr Collier's insight about the

appropriateness of his home environment. Although Mr Collier provided valid reasons for his lack of concern about the condition of his home, and initially the team accepted his wishes, ultimately the MDT interpreted this as a lack of insight, and furthermore a lack of capacity to make his own decision to return. In the example below, the doctor notes the evaluative and subjective nature of the judgement, and relates this to Mr Collier's capacity to make the decision about returning home.

I guess it's all a little bit subjective that we can't understand his want to live in perhaps you know, unpolitically to say squalor but you know. So we want to make absolutely sure we're not missing a borderline case and doing the wrong thing for this gentleman when he doesn't have the capacity to make the decision.

Interview: Registrar 02sA-0104

Therefore, it was observed, that there was a link between patients who expressed insight and awareness of the multiple aspects of their situation and having capacity, and those who seemed to lack such insight and awareness were considered to lack capacity.

5.3.3 Insight or agreement with the MDT?

Despite Mr Collier's seeming insight into his home circumstances, this judgement changed as he refused to engage with the MDT about the issues. In comparison, although Mr Miner is thought to lack understanding of his mobility problems, he seems responsive to the suggestion of the consultant about managing at home. The professional perspective on insight and awareness therefore seems to be based around acceptance of the 'problems' relating to going home and agreeing with the MDT about how these would be best managed. Whether patients were thought to be realistic or not about the plans for their discharge impacted on capacity judgements, rather than their ability to make this decision themselves.

The quote from the consultant below highlights the link between mental capacity judgements and perceived insight, or lack of insight into potential problems likely to face the patient should they return home, defines the capacity decision.

The personal thing that I use is, we need to identify what the problems are, discuss that with the patient, see whether they've got any insight into the problems and the consequences and all them to weigh the information up and make that decision. So that's the process I kind of follow internally when I'm looking at or asking somebody about capacity decisions about discharge.

Interview: Consultant 01AsO

This indicates that judgements into insight and awareness were problems-focused (Bond *et al.*, 2002) emphasising whether patients concede their cognitive and physical limitations, and were willing to accept the perspective of the team. Furthermore a lack of perceived insight into these problems and the consequences of these was considered indicative of a lack of mental capacity. Labels such as 'lack of insight' reinforce negative assumptions about people with dementia and imply a constant state of confusion, incompetence and inarticulateness (Bartlett and O'Connor, 2010).

5.3.4 Lacking insight? Mr Miner talks "gibberish"

Mr Miner was an exception, and an example of a patient who was considered to lack insight and awareness into his current deficits and resultant needs, but considered to have capacity. Specifically he was considered to lack awareness of his mobility problems.

11.5.09 MDT, falls, PD, patient walked on a Zimmer frame today, needed ++prompts, very variable. Physiotherapist: No awareness of risks, no real improvement. Nursing: agitated overnight, more settled now, does stand without. The plan is he would need 24-hour care with supervision. To discuss with wife next Monday.

Medical records: Mr Miner 200509

Despite concerns expressed by the team that Mr Miner lacked insight into the risk of falling at home, the team were confident that he and his wife acknowledged the risks and his wife would be capable of managing her husband's cognitive and mobility problems. I observed how the patient and his wife interacted with the medics during a consultant-led ward round. In this exchange, I picked up on the non-verbal cues which the team used to express whether they thought the patient understood his condition and the implications.

The patient responded to all the consultant's questions. He appeared to be very responsive. I think he appeared to be perceived as giving reasonable answers to the questions he was asked. [...] There were no clues when the patient was talking...the staff seem to think that the information the patient was giving them was plausible there was no kind of looks to, when the patient was explaining what he does and how he feels, there was kind of no glances or anything to indicate that the patient wasn't giving sensible or accurate information when he was telling the team about his falls and about his mobility and after the patient was seen the consultant commented that he thought this patient would need a lot of rehab in order to get better. So that's another interesting patient who has memory problems, has Parkinson's, he has a wife who's seen as very sensible by the team. He's seen as able to articulate what he experiences [...] when the ward manager says that the patient's wife is realistic it's difficult to delve into that to, to know what she means by realistic so that's maybe something that I can have a bit of a chat with her about ...

Reflective notes: 060509

In this context, Mr Miner's insight and awareness was unquestioned. This may reflect the work of the consultant in recognising Mr Miner's intact abilities and enabling a positive role and relationship (McGovern, 2011). However, not all of the team seemed convinced that Mr Miner had adequate insight into his physical condition and cognitive deficits. During an interview, the physiotherapist described how she had doubted Mr Miner's insight, especially when she had discussed the forthcoming discharge planning meeting with Mr Miner during a therapy session. The therapist had misunderstood his interpretation of events and had put his comments down to a reaction to the regular hallucinations which he experienced. Furthermore, after this assessment she had shared her views with the MDT later that day that Mr Miner was talking "gibberish" (See section 5.2.2). Only on reflection, and in the context of the planning meeting, did the physiotherapist realise that the patient had more insight into the purpose of the planning meeting than she had credited.

...he [Mr Miner] was talking to me on Monday morning about trials and juries and prison and I was like, ooh what's he talking about i.e. Do you feel

okay? And then in the case conference he was like “well I am on trial here, this is you deciding if I’m going home” so it was his perception of what that meeting was about that we were going to be the judges of him. So he, I kind of suddenly thought you know he has a lot more insight than you think and what I pick up is thinking, oh you know he’s talking rubbish [...] And it was literally he was referring to the meeting and in that instance it kind of, I thought oh you know maybe he does have more of an idea.

Interview: Physiotherapist 02sF-2005

Although the therapist realised that she had misunderstood Mr Miner, there is little evidence that this changed her overall view of the patient and she still felt that he lacked insight in his risks of falling and doubted his mental capacity to make an informed decision about returning home. The therapist belatedly realised that Mr Miner had a rather astute grasp of his situation and had interpreted this and tried to express it in a socially acceptable and quite sophisticated way. However the therapist had taken Mr Miner’s expression of his feelings at face value and attributed this to his cognitive deficiencies which reinforced her assumptions about Mr Miner’s lack of insight and lack of capacity. If the therapist had reflected on her own incorrect interpretation of their interaction, this may have led her to consider Mr Miner’s mental capacity in a more positive light.

5.3.5 Unwise decisions

Allowing patients to make unwise decisions was another area which often proved challenging for practitioners, in keeping with the decision-specific nature of the MCA. However, the freedom to make an unwise decision is one of the fundamental aspects of autonomy which is often diminished by assumptions that cognitive deficits caused by dementia are at the root of the decision, rather than choice, based on personal values and beliefs. The MCA upholds the rights of vulnerable people to make unwise decisions. The third principle of the Act states that a person should not be treated as unable to make a decision because they make an unwise decision. Section 2.10 of the Code of Practice highlights the importance of individual values, beliefs, attitudes and preferences, which may not be in accordance with others such as family members or health and social care professionals. Whilst practitioners were aware that people should be allowed to make unwise decisions, they acknowledged that this was often problematic in practice.

Observations supported that unwise decisions significantly impacted on capacity judgements.

...I think quite often capacity is used or the issue around capacity is used as a basis for saying that somebody's made a decision that you don't agree with yeah? So I think just knowing that social worker, if [patient] had said actually I want to go home, the social worker would have said well in that case I'm querying your capacity to make an informed decision, which I would have argued and it wouldn't have worked, We would have said she has got capacity, I don't think people are given enough opportunity to make a capacitated but unwise decision.

Interview: OT 01BsB-0808

Showing a sound understanding of applying the MCA in practice, the OT considered this approach as limiting patients' chances of making their own decisions as people are denied the chance to make unwise decisions. Encouraging capacitated but unwise decisions resonates with decision making approaches which support agency (Boyle, 2014) and citizenship for people with dementia (Bartlett and O'Connor, 2010) upheld by the MCA (Social Care Institute for Excellence, 2011). One consultant mused over the difficulties in establishing whether a patient was making an unwise decision and on the implications for judgements on mental capacity.

.... then it comes down to that thing of whether it's an unwise decision but one made with a full understanding of the risks, or whether it's you know a decision, you know and completely no insight what the problems may be, what the consequences are and I think that's when you start to get very concerned about somebody's capacity to make decisions.

Interview: Consultant 01AsO-2111

The consultant highlighted the tensions practitioners faced when trying to understand the relationship between fully informed and cognisant decisions, and when these become uninformed as a result of cognitive impairment rather than choice, to fit with the binary distinction between capacity and incapacity required to fit with the MCA.

Mr Collier's case is a good example of the impact of a perceived unwise decision on judgement of mental capacity. His expressed wish to return home could be defined as an unwise decision, influenced by his perceived lack of insight into his home situation. The main concerns were around the cleanliness and upkeep of his home, behaviours such as smoking in bed, and eating a poor diet. Many of the practitioners involved in his care found it difficult to engage with the patient who was considered evasive around these issues, which led to difficulty in ascertaining whether Mr Collier had capacity to make this unwise discharge decision.

The social worker highlighted Mr Collier's reluctance to engage with the MDT about safety issues as a particular issue influencing judgements about his capacity. Choosing to live in a potentially risky environment and declining support at the heart of the unwise decision. Both are contrary to the advice of the medical team.

I mean I think Mr Collier could return home. I think however very quickly he will refuse any services we put in and I think he would then be at great risk. He has fallen, he can't manage the stairs, his mobility is very, very poor and I think he would be very quickly readmitted to the hospital in some form or another. [...]He has said that he wants to go home. He certainly wants to go home, but then when you talk to him about the risks that are involved, the potential risks, he doesn't recognise them, he's very ambivalent about all of that, you know it's just "oh it'll be alright".

Interview: Social Worker 02sJ-0206

The social worker describes the 'necessary' support the patient had been offered to return home safely. This suggests that had Mr Collier agreed to this support, the capacity judgement and discharge outcome may have been different. If he had accepted the help, Mr Collier may have been enabled to return home, and importantly may have been able to make his own decision. Alternatively, had Mr Collier been supported in making a capacitous 'unwise' decision, he would also have returned home in keeping with his expressed wishes. Instead, Mr Collier was considered to lack capacity, and reluctantly accepted a trial discharge to a residential home. During his follow-up interview Mr Collier continued to express his dissatisfaction with the placement, and still expressed a wish to return home. He felt he had

been 'tricked' into moving into care and powerless to challenge this. This highlights the importance of adequate capacity assessment in connection with deprivation of liberty (Poole *et al.*, 2014)

Well I mean, you see, one of the things that ... gets my goat sometimes is they says "we'll let you go there for a trial ... and then we'll see how we get on". Well I've never had any interviews since then. [...] one of the consultants said "you could go on trial and see what happens". The social services said "once you move, that's it", bam.

Follow up interview: Mr Collier: 021009

The case revealed tensions between preserving the rights of the individual, and also protecting wider society. For example, at the MDT, when discussing Mr Collier's behaviours such as smoking in bed, they considered the risks to the patient, but also to neighbours, if the house were to burn down. This relates to the concept of risk and risk management which often prevails in health and social care (House of Lords Select Committee on the Mental Capacity Act 2005, 2014), and the 'contested territory' of risk relating to living arrangements between people with dementia, their families and practitioners (Clarke *et al.*, 2010). Furthermore, Mr Collier was positioned due to his cognitive deficiencies as someone who did not fully comprehend his living situation rather than a person who could understand and choose to live his life in a way that was considered socially unacceptable to the MDT. However in his discussion with the liaison psychiatry nurse he was able to defend his lifestyle choices and preferences. This demonstrates discordance with values between the person with dementia and the health and social care professionals, in which the person with dementia was denied the right to exercise agency and choice with regard to his wishes about place of residence. This reflects the 'squeaky wheel' principle of values-based medicine (Fulford, 2004) in which Mr Collier's values are noticed because they are problematic.

Several healthcare professionals suggested that mental capacity is more likely to be queried when there is disagreement between the MDT, patients and their families about the 'right' discharge outcome (e.g. an unwise decision). It may be suggested that if Mr Collier had been compliant with the MDT and agreed to have support at home, his mental capacity to undertake that decision may not have been questioned or subject to so much scrutiny.

Being labelled as lacking in insight into his home situation may also have made him more vulnerable to loss of independence and his social and political rights (Bond, 1992; Bond *et al.*, 2002). Indeed the registrar seemed surprised when it was mentioned at an MDT meeting that Mr Collier did not have capacity, as throughout the majority of the admission, the patient was considered to have sufficient mental capacity to make an 'unwise decision'.

It was described by the ward manager that the patient went to see some residential places and that it had been quite successful. Mr Collier had reported that he liked the places that he'd seen and there seemed to be a general sense of relief in the MDT until the ward manager highlighted that there was a problem. This was that the patient had said that he liked the places he had seen and that they were fine but then after returning to hospital, told the social worker that he still wants to go home. The registrar reviewed the patient's notes and the medical notes stated that the patient did not have capacity.

Fieldnotes: MDT Meeting 220609

In this case, the registrar revisited the records to double-check that the patient was now deemed to lack capacity, seemingly influenced by the discharge decision. When visiting Mr Collier after the ward round, the registrar expressed further discomfort about the encounter in which they discussed Mr Collier's trial in a residential care home (Hughes *et al.*, 2013b).

5.4 Chapter summary

The overall findings of this section highlights the interpretive work required by practitioners in the hospital environment to understand and enact the MCA for people with dementia in relation to decisions about place of residence on discharge. Practitioners described, and were observed, to engage in informal capacity assessment, which they considered important and necessary work to ensure an understanding of the person's decision making abilities. However, this interpretive work, which formed a substantial and important part of practice, was not routinely translated into formal assessment. Only a third of patients in this research had their mental capacity formally assessed using the two-stage test. This indicates a lack of understanding and/or awareness to use the legal framework of the two-stage process set out in the MCA. Furthermore, the lack of documentation of the process and decision of

capacity or incapacity does not reflect the gravitas these decision were often afforded in practice.

Social theoretical approaches applied to interpret the interactions between the person with dementia and the multi-disciplinary team, illustrate how practitioners relied on intuitive and interpretive factors, based on cultural understandings of dementia (Hillman and Latimer, 2017) and whether patients interacted with professionals 'normally' within the context of traditional models of practitioner-patient relationships (Lorber, 1975; Emanuel and Emanuel, 1992), particularly doctor-patient relationships. The extent to which patients conformed with or deviated from cultural norms, for example, during ward rounds with senior medics was considered in the context of impairment caused by dementia. Deviance from the norm (Becker, 1963) was presumed caused by deficits arising from cognitive changes (Sabat, 2001) rather than exercising agency and individual choice, (Bartlett and O'Connor, 2007) and indicative of a lack of capacity.

Conceptions of whether patients had or lacked insight and awareness were embedded in general perceptions of the ability of people with dementia to engage with practitioners rather than the ability to undertake a specific decision. This is further apparent in the case of unwise decisions, in which deviation from the social norms as defined by the clinical team was interpreted as a lack of capacity to engage in decisions about place of residence on discharge from hospital.

Relying on informal judgements of mental capacity, and a tendency to focus on non-decision-specific aspects of insight and awareness of the social factors important to decisions about place of residence on discharge from hospital may mean that although practitioners engage in considerable work to explore mental capacity in this context, this may not translate into full and fair assessment as set out in the MCA. This may compromise access to decision-making rights afforded by the MCA, especially in judgements of incapacity. Although interviews with practitioners suggests that the Act was well understood, the application was often inconsistently applied in practice in this context. Consideration must be given as to whether the MCA and Code of practice provides an adequate framework to guide the practice of health and social care professionals involved in

the assessment of capacity for people with dementia concerning place of residence on discharge from hospital.

Chapter 6. Invisible and visible work - capacity narratives, and specialist assessment

6.1 Introduction

In addressing the second aspect of enactment of the MCA for people with dementia on discharge from hospital, this chapter explores the range of accounts which practitioners drew on to make those capacity judgements. This relates to the key research questions of which sources of information practitioners drew on to make mental capacity judgements, whose narratives were regarded as most credible and why. I explore the reasons narratives of people with dementia were doubted, why some narratives were considered more credible than others, and the impact this had on mental capacity judgements. This relates to objective 2 - gaining a better understanding of the complex nature of social relations embedded in judgements about mental capacity, and objective 1 as much of the interpretation of narratives influencing capacity judgement takes place in the spaces of practitioner-led interaction, which is usually invisible.

Narratives are explored in the context of subjective and objective accounts, to demonstrate how different sources were prioritised within the context of decisions regarding mental capacity and hospital discharge. First, I demonstrate how competing accounts of the patient, their families and practitioners added to uncertainty around mental capacity judgements – these are defined as subjective accounts. I then consider how more objective accounts - provided primarily through specialist assessments - were used in addition to specific mental capacity assessments as a means to address uncertainties and establish whether a patient with dementia had capacity to make decisions about place of residence on discharge from hospital.

I focus on the cases of Mrs Friar, who was judged to have capacity to make her own decision about discharge, and Mrs Carter, whom practitioners judged to lack capacity and a best interest decision was made on her behalf. Examining the key narratives which influenced these patient cases illustrates how and why certain narratives were sought, interpreted and used by practitioners to make judgements on mental capacity. Further comparisons are made with other patient cases to show differences and similarities.

6.1.1 Defining objective and subjective approaches to capacity judgement

Before exploring the range of narratives, I distinguish between two main types of accounts which informed capacity judgements and were used to substantiate the judgement reached. I have classified these as objective and subjective approaches to capacity judgements, in keeping with how practitioners described these processes.

The distinction between subjective and objective approaches to mental capacity assessment are grounded in the data. During interviews, practitioners from a range of disciplines commonly described capacity assessment as a subjective process, embedded in complex social relations.

the interface between the patient and their carers and relatives and us is extraordinarily complex and we have no idea what goes on at home or it's just extremely difficult and you know, we see a microscopic snapshot of their lives and try to make decisions based on that, I think that's very, very difficult. We're influenced by our relationship with the relatives, we're influenced by whether we perceive them to be sensible or not which God knows is completely subjective decision.

Interview: Consultant 01BsQ-1212

In this extract, the consultant realised that they have little understanding of the social world of the person with dementia and how judgements are influenced by relationships with family and personal perceptions.

In the quote below, the senior medic stressed the difficulties of relying on information provided by family and the importance of having 'objective' evidence to inform the decision.

You have to take on board what they (family) say but at the end of the day for my mind, capacity is, has to be a medical decision because if you involve emotion into all these sorts of things you get bogged down. Plus then you get the families who half of them want this and half of them want that and you have to look them in the eye and say, "I take on board what you're saying but from an objective point of view, this is what we've found and we really don't think that he or her will be safe in their environment there at the moment".

This distinction was further explored in data workshops and the construction and analysis of memos on narratives, assessment, relationships, and mental capacity (Charmaz, 2006).

I define subjective accounts as a set of 'facts' which practitioners drew upon, and which were considered much more open to interpretation, query and dispute than other objective evidence. This was mainly the accounts presented in narratives (usually verbal but sometimes documented in medical records) by the person with dementia, their families and other healthcare professionals. These judgements extended beyond the patients to their social interactions and circumstances such as living arrangements and familial relationships. Subjective evidence informing capacity judgements was routinely scrutinised and selectively applied, in comparison with formal approaches.

In contrast, I define objective approaches to gathering information as an attempt to quantify, qualify and measure factors which practitioners considered to affect cognitive and social function in patients with dementia. These were often presented as undisputable evidence to support conclusions. These methods were usually structured and formulaic and included the direct attempt to measure cognitive function such as the MMSE, which yields a score on cognitive function; and medical factors, which were usually clinically generated and rarely disputed. For example: results from CT scans showing atrophy to the brain; urine, blood and sputum tests denoting infection; acute problems such as broken and fractured bones; and co-morbidities such as cancer, chronic lung, heart and kidney disease and Parkinson's Disease. In addition, the assessments provided by specialist services such as old age psychiatry were also regarded as conclusive. Other assessments such as social work and home visits were mainly considered as objective evidence although the outcomes were sometimes debated more readily than other assessments which yielded clinical outcomes.

6.2. Doubting the patient account

In this section, I address the research question of when and why the narratives of people with dementia were doubted and what impact this had on mental capacity judgements. In all 29 patient cases, I observed that the narratives provided by the person with dementia were questioned by practitioners, leading to doubts about their mental capacity to make their own decision about going home from hospital. Although the Code of Practice refers to

a number of reasons why people may doubt a person's capacity to make a specific decision such as: their behaviour; someone else raises doubts; a previous diagnosis of impairment; and lack of capacity to make decisions in other areas of their life (Section 4.35), ability to provide certain information is not specified. Nevertheless, the role of family and close friends as providers of valuable background information are included as an information source which can be accessed as part of the practical steps for assessing capacity (Section 4.49). However, the Code states that their personal views and wishes about what they would want for the person must not influence the assessment itself. Relating to these reasons, the data indicated that doubts about mental capacity were specifically triggered when patients' accounts of events were considered doubtful and challenged by relatives and practitioners.

Certain narratives were particularly observed to "trigger" such doubts about mental capacity (Twining, 2008). Doubts about mental capacity were often observed when practitioners questioned the reliability of the information provided by patients with dementia. In particular, concerns emerged when patients expressed beliefs which did not seem plausible (for example that their mother would care for them if they went home); or reported events or beliefs which did not correspond to the accounts by family or other practitioners. Uncertainty and doubt were based on the interpretation of practitioners who had to balance their own observations with the narratives given by patients and their families.

In the example below, I had observed the team talking about Mrs Butler during several MDT meetings. They often reported her confused behaviour, and often disbelieved what she said, attributing this to hallucinations.

I think one thing that struck me as interesting was is they [Mrs Butler and her daughter] spent some time talking about a world tour they'd done and I know that that was one of the things when Mrs Butler was on the ward she'd been caught 'swimming' on the bay and saying that she was on a world cruise or something like that and everyone had thought she was just kind of making things up, and ... I think it was the ward manager at the time had said something like well you don't know she might have been on a world tour or a world cruise and it turns out she had and they spoke to me at some

length about (Country 16) and various other places they'd been on this tour, (Country 17).

Reflective notes 090209: Follow up interview with Mrs Butler and her daughter

However, it is possible that Mrs Butler was trying to make sense of the unusual environment she found herself in when she talked about being on a cruise. Many of the patients understood they were not in their own home and drew on narratives to explain being in a different situation. Some believed themselves to be in hospital but in a different context, for example a maternity hospital, and some believed they were on holiday, or in a hotel, or at work. They seemed to draw on earlier life experience to make sense of their current situation (Sabat, 2001) and these accounts were often shared with practitioners, leading to doubts about mental capacity.

It was often less clear whether patients with dementia were giving an accurate account of their circumstances, and accounts were often nuanced, leading to ambiguity. Examining key narratives in the cases of Mrs Friar and Mrs Carter, illustrates doubts expressed about the patients' capacity to decide to return home. This highlights the "triggers" and the means by which practitioners investigated complex patient narratives to establish whether the patient with dementia had the mental capacity to make decisions in connection with residence on discharge from hospital.

A clear example of suspicion and lack of belief in the accuracy of Mrs Friar's account of her social circumstances influenced the judgement on mental capacity. Fundamental to this concern was the MDT perception and expectation that Mrs Friar lived in a chaotic and dysfunctional home in which none of the family had capacity to undertake decisions about place of residence. Mrs Friar was confused and struggled to tell the team about herself and her home situation. The OT described some of the difficulties in trying to interpret Mrs Friar's dialogue when she first met her.

The first time I went to meet Mrs Friar she was very disorientated to time and place, and person, as in she didn't know if the patients in the bay were her sister and completely...you know she was talking about being in the land

of love and just totally like inappropriate and irrelevant conversations. So I went back to the MDT, spoke to the MDT and clarified that she did actually have an infection.

Interview: OT 01AsH-2010

The therapist realised that Mrs Friar's inability to provide a relevant account was influenced by a clinical cause, a possible delirium which was potentially reversible, however the team needed a credible information source on which to start making decisions. The case was discussed in an MDT meeting, in which none of the family were considered able to provide adequate information to the team. However the team also had information from a community practitioner.

This patient is a 79 year old female with increased confusion with a UTI, but then there was some discussion about whether they think it is increased confusion or whether this is it. The husband and son, who has special needs and they think that the daughter has special needs too and they are not sure who the main carer is. ... I think the ward manager brought it up that she felt that although... because the general feeling was well how has this family been managing, but the Ward Manager very strongly felt that they would have been managing before we'd come along, and they must have been managing and I think the Consultant felt this way too. There was some discussion on how it's very difficult to get a collateral history and the consultant suggested accessing the GP. Also querying whether there was a social worker involved and if more information could be obtained by these other sources other than the family. [...] again the Consultant said they must have been managing for years like this. The OT passed on how they'd had a community OT assessment who'd said it was 'like a circus', 'like a madhouse', and they felt that the delirium; the confusion wasn't acute. They felt that this was really a case of social breakdown [and queried] have they got a social worker in the community and they felt they should have, not possibly for the mother but for the son. The patient was started on UTI treatment yesterday and there was discussion how they would need a home visit with the social worker who is looking after the

family when she's here. They spoke about the husband and could they get any sense out of him. They spoke about how they'd had to get this patient's [husband] a taxi home earlier in the week and when it comes to visiting, the patient's [husband] wants to stay on the ward. [...]. The consultant spoke about getting the duty social worker involved if he thought there might be a crisis in the community, but the first port of call was to follow up with the GP who they felt may have all this sorted and they spoke about, this case was going to be very difficult to sort out.

Fieldnotes: MDT meeting 071008

There is much to unpick from this extract from the MDT meeting, and I will return to this example throughout the chapter. The MDT made judgements on the relevance and credibility of such multiple accounts. In this example, Mrs Friar and her family were positioned by practitioners as unreliable informants owing to their perceived mental deficiencies (Sabat, 2001). In response, the team felt that community practitioners would be a useful, reliable and valid source of information to establish key facts around discharge amid concerns that neither the patient nor her family could provide this information. The narratives provided by other people, information prior to admission and the construction of narratives by the MDT will now be explored in detail.

6.2.1 Collateral history – the narratives of family and others

In response to difficulties obtaining necessary information from patients, the MDT sought 'collateral histories' from relatives, community-based practitioners and medical records from previous inpatient admissions. This is evidenced in Mrs Friar's account above in which information was sought from her family and community OT. Collateral history is a term used to describe information obtained from family or primary care giver about the social situation of the person with dementia (Pimlott *et al.*, 2006) and is considered particularly important for practitioners caring for patients with dementia in the acute setting (Harwood, 2012). Fundamental to collateral accounts is that the information is obtained from others and then used comparatively with the account of the patient. These various accounts provided by patients, their families and other practitioners were discussed, analysed and interpreted, to identify consistencies and incompatibility, with the aim of establishing the most accurate account of the patients' capabilities. The importance of collateral histories is illustrated

through the cases of Mrs Friar and Mrs Carter. Proving or disproving the patient's version of events influenced subsequent judgements about capacity. Assumptions about the validity of the patient's narrative was observed to influence decisions about capacity by, for instance, creating an impression of competence or incompetence.

6.2.2 Pre-admission narratives – Mrs Carter at home

A clear temporal theme emerged from the findings as particularly relevant to capacity narratives. Accounts from the patient's past, present, and future appeared important when ascertaining whether a patient had mental capacity to make a judgement about returning home. In his classic work, Erving Goffman conceptualises these stages as pre-patient, inpatient, and ex-patient (and also re-patient for readmissions) (Goffman, 1961). For example, the patient's own account alongside collateral histories from others about their home life was compared to how the person presented whilst on the ward. This was interpreted by practitioners to inform the mental capacity judgement and subsequently future discharge plans.

Past narratives and the stories of events which preceded the admission emerged as a particularly complex narrative. These were unobservable to practitioners and usually undocumented. Therefore practitioners were reliant on patients and/or their relatives to supply certain 'facts' about the events directly prior to hospitalisation. In some cases, events of several months and even years were considered key information in forming this pre-admission narrative. The social aspects of the patients' lives prior to admission were considered as relevant as key medical facts, and information such as how they were coping with day to day life, formal and informal support relationships and unusual or unsafe behaviours were routinely sought. Unlike medical aspects, past events were difficult to evidence. Therefore obtaining the social facts was contingent on patients and their family giving honest and truthful accounts of events. Practitioners interpreted these narratives and made judgements about the plausibility of these accounts.

When the account of the person with dementia was questioned, family were considered as the next legitimate source of information. Both the accounts of the person with dementia and their family could be further compared with evidence supplied by the MDT. In the examples below, the accounts of Mrs Carter, her daughter and the OT are presented to

illustrate how practitioners managed uncertain narratives around patients' social situation and living environment prior to admission. In this case, Mrs Carter appeared genuinely to believe that she could cope at home, and expressed this to the MDT during assessments and ward rounds.

MP....did you have anyone come into help you when you lived at home?

INT No

MP No, did nobody come into help you with...?

INT Well it's only small and I've only got the one bedroom. I've got a bedroom, bathroom, sitting room and kitchen, so I can manage all that.

Interview: Mrs Carter 091208

Compared with their observations of the patient on the ward, the MDT disbelieved that Mrs Carter was able to care for herself at home, unaided. They therefore sought the account of her daughter. In contrast to her mother's account, her daughter informed the team (and me in an interview) that her mother struggled to cope prior to admission, reporting the extent of support family were providing with activities such as meal preparation, cleaning, shopping and medication management.

MP So how often was someone going in to assist with her meals and medication?

INT They were going in and she was getting like three times a day for medication and like (Grandson 1) was going and (Grandson 2) was going nearly every night to put her meals out; but I mean, as I said, she wasn't eating them, but she was getting thinner and thinner do you know?

Interview: Mrs Carter's daughter 091208

In this example, the mismatch is clear between the accounts of Mrs Carter and her daughter. Later in the interview, Mrs Carter's daughter described her mother as deliberately attempting to "pull the wool" over people's eyes and was concerned that her mother sounded convincing to other people. This suggested that she thought her mother

understood the consequences of not coping and sought to mislead people about her abilities, rather than assuming that Mrs Carter actually believed she could still manage.

Like Mrs Carter, many patients with dementia were noted to “confabulate” about their past as they struggled to evaluate their capabilities. Confabulation is a psychiatric term used to describe cases in which the person compensates for gaps in their memory by inserting false memories (Puri and Treasaden, 2009). Although confabulation is not defined as a deliberate attempt to deceive people, I observed that families and practitioners at times interpreted this as a deliberate and deviant action (Lorber, 1975) (as in this case). Relatives often believed this to be a deliberate attempt to persuade practitioners that they could manage at home rather than forgetting or trying to cover embarrassment (Sabat, 2001). Sabat refers to strategies which people with dementia might use to cover their embarrassment, and whilst these require complex cognitive function, may be open to misinterpretation by others, leading to the person being malignantly positioned, as in Mrs Carter’s case. However, instead of convincing practitioners that patients were capable at home prior to admission and therefore would be just as capable on discharge, any mismatch in narrative was often interpreted as a lack of understanding of capabilities and influenced judgements of incapacity. Comparing the past and the present to establish the most factual narrative often required further exploration. In the example below, the OT assessment brought the past into the present, focusing on what the patient could currently do, in comparison with past functioning.

But it became very clear, on her home visit, apart from the physical aspect, we do visit, ‘how do you do meals?’ Even if we know the answer we would ask. ‘I do all my own cooking, I cook from fresh, I do...’ And she doesn’t and as I’ve said before the family have supported her a lot. She struggled with making a hot drink and that was something that she had been doing sort of up to a couple of months before she came into hospital, and then it sort of deteriorated. She wasn’t managing. Couldn’t figure out how many she was making, how full she had to fill the kettle. She did say “What happens now? What are we doing?”

Interview: OT 01BsD-1709

The OT described how the assessment clarified discordance between the different versions of events presented by Mrs Carter and her daughter. The account as observed by the

therapist concurred with that of Mrs Carter's daughter and the practical assessment established her daughter's account as most plausible. However, even without such assessment, the version of events provided by family was commonly accepted as the 'real' version. The MDT considered the OT report to provide evidence of a lack of capacity although the assessment was an evaluation of practical skills, rather than assessment of decision-making ability.

Initially, it is the account of the patient and family which were dominant in establishing the facts about the past. In the case of Mrs Carter, it is clear how her version of home did not square with her daughter's narrative. Furthermore, the account did not match with how the OT observed the patient to function presently. Her daughter's account became legitimised through an objective assessment of the current situation, moving the narrative from past to present, and subjective to objective. This shifted the balance of power away from the patient. Furthermore, the assessment introduced new narratives – those of the practitioners.

6.3 Practitioner narratives

Although their own and families' perspectives contributed, I observed that the patient's present narrative was predominantly defined by the many practitioners involved in their care on the ward. These accounts were constructed on the basis of events directly observed and narratives shared by others. The consultant-led ward round and the MDT meeting emerged as key processes used to establish the 'facts' in cases of discrepancy between the narrative of the patient with dementia and others. As such the MDT meetings and ward rounds themselves enabled practitioners to construct a narrative which influenced judgements on mental capacity relating to decisions concerning residence.

6.3.1 Ward round narratives

Analysis of observation data showed that the weekly consultant-led ward round provided the main opportunity for patients to give information directly to the medics and for the team to form first-hand judgements about this account. Typically, the ward round included the medical team and a member of nursing staff. Before reviewing the patient, the medical notes were reviewed, and one of the team summarised key facts about the case. This summary narrative was used to compare the patient's responses to the consultant's

questions. The medic examined the patient physically and asked questions, selecting which topics were important to discuss and note in the medical records. Patients were routinely 'tested' on their ability to recount key facts or pieces of information such as the reason why they were in hospital, details about their home, including who they lived with, the type of accommodation they lived in, how they managed at home prior to admission, and how they thought they may or may not manage in the future. Most patients were observed as able to give their own account – irrespective of how factual this was considered – which was duly noted, along with any concerns about the accuracy of the information given. After the review, the outcomes of the interaction were discussed as a team. The medics compared their observations, and the senior medic questioned the team about the case, deciding on the next phase of management. The interaction between patient and medic during the ward round enabled the patient some, if limited, agency in the way in which they could present a version of themselves, and co-construct their identity (Sabat and Harré, 1992), but was constrained by the medical context.

... a lot of the time the consultant appeared to speak to the Registrar rather than to the patients and it wasn't a very conversational format, it seemed quite formal but that doesn't mean he wasn't pleasant and patient. The consultant seemed to ask about very specific things, so ...sometimes generally "How are you?" but usually very specific things and it was less conversational in tone but approached all of what seemed to be the key issues and also the key medical examinations and did spend a lot of time asking what people wanted and what people's wishes were, and was very positive and just conveyed a general sense of positive-ness, but did ask the accompanying registrar a lot of questions in terms of almost assessing the registrar, so would ask what would an expected range of something be or what would he suggest, so it seemed more formal and almost educational

....

Fieldnotes: ward round 020708

This example of interaction between the patient and medics was routinely observed. The ward round has been defined as a tightly managed strategy, which helps the clinician retain power and authority (Fox, 1993). So, although present, the patient was invited only to respond to specific questions and often talked about rather than to. This limits the scope of

the dialogue and the contribution of the patient during this exchange and creates a lack of narrative agency (Baldwin and Bradford Dementia Group, 2008) .

6.3.2 The MDT meeting and Mrs Friar's "madhouse"

In MDT meetings, the patient had no influence over the construction of their narrative and thus even less narrative agency as this work goes on behind the scenes. Erving Goffman's classic sociological work in *The Presentation of Self in Everyday life* makes the distinction between frontstage and backstage work. Events, processes and behaviours which occur 'behind the scenes' constitute backstage work, are compared with events which are open, public and subject to scrutiny (Goffman, 1971). The practitioners in the team each shared their own perspective of the patient and discussed the case. This forum enabled the team to share views from their professional discipline – medical, nursing, social work, therapy, and in some cases Old Age Psychiatry.

Findings from assessments were shared alongside general reports of how the patient was currently functioning on the ward. These accounts also appeared to be supplemented by anecdotal stories passed on from relatives and/or events observed, or been told about by the nursing staff. Senior nursing staff were present during MDT meetings and shared information about how the patient generally presented and functioned daily on the ward. Many of these anecdotal events positioned the patients negatively and focused on deficits (Sabat, 2001). However, senior medics in particular were observed not always to take anecdotal evidence at face value, and questioned or dismissed such information. For example, at one MDT meeting, the consultant told the OT that she didn't care how many cupboards the patient left open during a home visit, but she did care about gas being left on. In another MDT meeting both the consultant and the registrar asked senior nurses to clarify their meaning of inappropriate behaviour.

It was felt by the ward manager that the patient would need EMI care because of wandering and inappropriate behaviour. The registrar kind of questioned this and he said "when is the patient wandering?" and "what sort of inappropriate behaviour?", so kind of probing and I've seen the registrar do this before. He doesn't take it on face value that there's inappropriate behaviour ...

Fieldnotes: MDT meeting 220609

Such reports sometimes resulted in medics requesting more factual and objective accounts, and in this instance a 'behaviour chart' was advised as a means of objectively quantifying such events and subsequent accounts.

The meeting involved the process of summarising all accounts – some of which became documented in the patient's records. The events were drawn together and discussed. At the consultant-led MDT meeting, the senior medic summarised the salient facts of the case and made a decision about the management of the patient (and their family).

Reflecting on the dialogue observed during these exchanges, it became apparent that facts and information were often subject to a series of filters before being presented to the MDT for further discussion.

So, often these conversations about patients are information from a relative and it might not even be conveyed face to face, it might be conveyed via the telephone. So that's coming from the patient's relative from the phone, into the MDT via a physiotherapist. So there's a lot of chains where this information's getting past on, there's scope for interpretation. I just thought this was quite interesting.

Reflective notes: 171108

Although this filtering process may have altered the narrative, these were often still considered more plausible than that provided by the person with dementia. Relatives were most often providers of this information, and accounts from community practitioners were sought if available, particularly if family were not present, or as in Mrs Friar's case, the team had concerns about the relatives' ability to give a fair account of the patient. Some accounts provided by others presented the patient in a defective and dysfunctional way. Such information influenced the perceptions which practitioners had about patients.

To be honest with you from the information that I had originally gathered from the initial contact with Mrs Friar I thought it was going to be pretty poor, I thought I was going to walk into something where you think 'eeh my god, how have you people been managing?' So I think I probably did go in with maybe an expectation that it was going to be very complex and a lot of risks involved. And maybe in the back of my mind I was thinking do I

need to get an outside social worker, a community social worker for the husband if it was as bad as was fed back to us? I think probably what's happened somebody has gone out and panicked (laughs), which does happen. I don't know how they were on that day. But it was better than I expected I think.

Interview: OT 01AsH-2010

In this example, it is clear that had the community practitioner's account been taken at face value and not further explored, a negative account of Mrs Friar would have endured. However, the OT commented that her findings were very different from that of the other practitioners. In this case, the account from the community OT preceded the accounts given by the MDT, as the patient was assessed just days before admission. The account of the assessment presented Mrs Friar and her husband negatively, and in a telephone conversation with the ward OT, the community practitioner used value-laden language – describing the home as a “madhouse” and “circus” and “malignantly positioning” the patient and her family (Sabat, 2001). The OT shared this at the MDT meeting. At another MDT the junior medic described the family as “weird”. The ward manager recounted unusual behaviours displayed by Mr Friar on the ward. Their son and daughter were both reported to have learning difficulties (it was actually just the son) and the team expressed concerns that both Mr Friar and their son were incapable of providing the team with information as to whether Mrs Friar's confusion had increased or whether this is the norm. The consultant suggested contacting the patient's GP for collateral history.

The initial account provided by the community OT seemed to be a powerful and authoritative narrative, which resonated with what the team had observed of the patient and her family on the ward. The account raised numerous concerns which highlighted deviance from social norms (Becker, 1963). However, a contrasting account observed by the ward OT during the home visit provided a plausible counter argument and presented a positive narrative about Mrs Friar's home life. As I was invited by the OT to attend the home visit, I had a rare opportunity to personally witness the difference of observing someone in their own environment, and compare this with what I had observed of the patient on the ward and the narrative shared in MDT meetings.

My reflections on the day of the visit was that it was really interesting to get a bit of insight into a home visit to see what actually happens, rather than just read about it on paper and it was very interesting to see the handover from the previous OT and how this could have really potentially influenced this patient's discharge; how it had been described as a 'madhouse' and everyone had behavioural and some sort of special needs in the household. But what was observed was a different way to how things have been described really. It was very different from what I had expected, I'd expected chaos and kind of a disordered environment, untidy but what I observed was a very clean and tidy house. It was warm, there was a lot of modern appliances, the husband and wife supported each other and the son supported them too.

Reflective notes 141008

I found it enlightening to observe the patient in their normal social context. Like the OT, I was surprised at how differently Mrs Friar and her family seemed in their own home. Even in the context of being assessed, the Friars' seemed to manage well and Mrs Friar seemed happy. Interestingly, the narrative of the community OT was not queried or contested, but it only came to light that the initial account was perhaps the over-reaction of a junior professional, or that Mrs Friar's confusion had improved over time through a subsequent home assessment with the ward OT. The role of home visit assessments will be more fully explored in section 6.4.5.

Similar to Mrs Friar's case, for Mrs Carter, community practitioner accounts were also considered useful by the MDT in gaining further understanding of how the patient managed at home prior to admission.

...this patient phoned her daughter 350 times, they didn't give a time period. Her-daughter-in-law visits every day and this particular patient chases home care away, [...]. The patient is due to have a home visit and she's from sheltered accommodation ...(Mrs Carter) was described as having lots of Old Age Psychiatry documentation about her on record and I think was Old Age Psychiatry in the community... There was a bit of a query about whether this patient was medically sorted yet ... and there's

definitely a query about this patient's level of capacity according to the discussion and the patient was referred to as having no insight into the particular level of care that was required and no insight into her condition.

Fieldnotes: MDT meeting 080908

Records from the liaison psychiatry team provided additional background information and were regarded as an authoritative account about the patient which would inform their judgement. This is illustrative of more formal channels of information-sharing which impact on judgements of mental capacity. However, in addition, staff were observed sharing information and discussing patients in more informal circumstances such as at the nursing station, passing on the ward, and during breaks. Such interactions can also influence complex clinical decision making (Iedema, 2007b; Long *et al.*, 2007), but would not be documented whereas discussions in MDT meetings and ward rounds were recorded in the patients' records.

6.3.3 Written narratives – medical records

As shown in Mrs Carter's case, the medical team often considered written accounts produced by others, including community practitioners, as an important source of information to assist in making sense of the current presentation of the patient. However, the MDT and others on the ward frequently contributed to an extensive new patient narrative, which became documented in the patient's medical records.

Returning to Mrs Friar's "circus" and "madhouse" and her "scary" and "weird" family, such descriptors were verbally shared between colleagues, but were not recorded in the patient's medical records. In another MDT meeting, Mrs Salter was described as "barking mad" by the consultant. This term was directly applied in relation to Mrs Salter's mental capacity "...does not, repeat does not have capacity!" Such value-laden and pejorative terms were not recorded, however, labels with negative connotations such as "poor historian" (inability to present a coherent narrative around reasons for admission) and "ACOPIA" (unable to cope with activities of daily living) were routinely documented in the medical records of the patients with dementia in this study, further emphasising deficits in their physical and cognitive abilities. Such negative labels had potential for people with dementia to be

identified negatively by others and stigmatised according to their condition (Goffman, 1968), disenfranchised from capable people able to participate in decision making.

The term poor historian was used in the records of some participants to describe their inability to provide appropriate facts – usually around reason for admission. This label is debated in the literature as having pejorative meanings (O’Keeffe, 2011) and whether it functions in alerting practitioners to problems which can be addressed (Tiemstra, 2009). The debatable legitimacy of the medical-sounding label “ACOPIA” (Kee and Rippingale, 2009; McVean, 2009) was written in medical records to describe some patients who were thought not to be coping prior to admission. It has been queried whether such negative labels would be applied in person and not just used in medical records (Davis and Zajac, 2005), however, I observed Mrs Salter being described by this label to her daughter in a discharge planning meeting. Such negative and defectological descriptions of patients (Sabat, 2001) were commonly used and shared between practitioners, contributing to a narrative of loss of ability. Although verbal descriptions were ambiguous, written labels became part of the ‘official’ patient narrative.

In contrast to the hidden narratives shared in the MDT, the medical records provided a very visible and enduring narrative of the patient. Typically, the medical notes embodied the ‘official’ patient narrative and through a “process of factualization” this becomes the legitimate medically-endorsed version of the person with dementia (Gubrium, 1986). The narratives were controlled by institutional factors (Gubrium and Holstein, 2008) such as the embedded practice of structuring and format of the notes. This written narrative produced by practitioners developed over the course of their admission. Salient facts were summarised and recorded and numerous authors contributed. Patients arrived on the ward with written documentation from the Accident & Emergency department or a transferring ward/hospital. A summary of key information about the patient’s presenting medical conditions was provided, however social and behavioural issues were also included. Some patients were already defined at this stage as confused or unable to cope. Confusion and/or cognitive impairment had been screened for, using assessment tools such as the Abbreviated Mental Score (AMS), which consists of 10 questions for practitioners to use as a quick screen for confusion and is most used in hospital settings (Hodkinson, 1972).

Analysis of the medical records of the 29 patients in this research showed that the notes typically included information about the circumstances of their admission, presenting medical complaint, past medical history, social history, assessments, interactions with patients during ward rounds, discussions from MDT meetings, discussions with family and with other services, and referrals to services. For the majority of patients there were also records from previous hospital admissions or treatments. Practitioners were selective in terms of the events recorded and the level of detail and description varied. Some of the documents were structured, such as initial assessment proforma which requested specific details, generally however, the content and format of the information were constructed by the individual practitioner. Some events such as ward rounds were recorded consistently and routinely whereas other events were recorded on an ad-hoc basis and captured episodes such as falls, wandering or other unusual behaviours exhibited by the patient. As such, negative episodes or problems were recorded, emphasising the physical and mental deficits of the person with dementia (Kitwood, 1997).

Although the account was produced by practitioners, sometimes the patient's comments were recorded verbatim, to illustrate a particular point. Rather than giving the patient a voice, such comments often reproduced confused or negative responses, and included information used in connection with judgements on mental capacity. In the example below, the liaison nurse used quotations to highlight the inaccurate responses given by Mrs Gardiner.

Mrs Gardiner had no recollection of home assessment, adamantly denying having been "across the doors all week", she tells me "lives here" and enjoys the support and the company, she denies any problems or risks (including stairs) and therefore cannot weigh them in balance, believe them or retain the information, should this lady move into twenty-four hour care I feel her needs would best be met in social care with CMHT support

Medical records: Mrs Gardiner 120309, liaison psychiatry assessment

In addition to directly quoting patients' inaccurate responses, anecdotal accounts of patients also often emphasised negative behaviours, potentially "malignantly positioning" (Sabat, 2001) the patient and leading to judgements of incompetence. Nursing staff were observed

to have more regular direct contact with the patients than other members of the MDT through routine tasks such as assistance with self-care and general medical assessments, but also through more informal interactions which occurred as part of everyday life on the ward. As such, nurses often reported anecdotes about the patients on the ward, and sometimes noted these in medical records.

Through the ward round, MDT meeting and medical records, the narrative of the person with dementia becomes medically-driven and focused due to the admission. The person experiences a form of biographical disruption (Bury, 1982) which refers to the disruption experienced by people who have a chronic health condition and how this changes their lives, self-perception and perceptions of others based on the illness. In this context, the change is caused by the hospitalisation rather than the medical condition itself as they become a patient with dementia, rather than a person living in the community with memory problems or dementia, therefore the present narrative of the patient becomes dominated by the medical context.

6.3.4 Back to the future

The present patient narrative was influenced by the views of the MDT and their status as a medical patient on a hospital ward. However, narratives about the future returned again to the functionality of the patient in the community. Future narratives were less relevant to mental capacity judgements and more pertinent to informing best-interest decisions. However, the narrative which patients and families presented, based on events prior to admission coupled with the present narrative of how the patient functioned in the hospital environment, clearly influenced views on the patient's expected future capabilities. What was important in capacity judgements was whether the patient understood their past and current situation and how this impacted on events post-discharge. In the example below, the OT described Mrs Carter's reaction to her home visit.

And she was happy and we brought her back and 'oh, I've had a nice time out' and then we settled her down on the ward, then we went back sort of an hour later and she didn't even know she'd been out....But I think all things considered and I obviously write a detailed report when I come back. It was just felt that even with the wandering, with the lack of insight, with functionally not managing even down to toileting herself properly, keeping

herself clean, and hydrated and her diet with the diabetes, it was just felt that she'd had quite a substantial care package going in and it still wasn't meeting her needs. So all I did was highlight those risks and pass the report onto the social worker.

Interview: OT-01BsD-1709

In this example, the past, present and future aspects of Mrs Carter's home life are brought together. Through the assessment, the practitioner was confident that the details which Mrs Carter provided about her ability to cope at home was not evidenced in the home visit. Furthermore, it supported the account of Mrs Carter's daughter. Drawing on these narratives, the OT produced her own account in a report to the MDT which influenced the judgement of a lack of capacity and the future outcome of Mrs Carter's discharge plans.

6.4 Specialist assessment

Building on the exploration of the subjective nature of the multiple narrative accounts which practitioners were required to interpret to inform judgements on mental capacity, this section focuses on the process of specialist assessment as a means to practitioners achieving a more objective view of patients' mental capacity. This relates back to the research question of addressing which sources of information practitioners drew on to make capacity judgements, and which narratives were regarded as most credible and why.

Specialist assessments were observed to be used in addition to specific mental capacity assessments as a means of addressing uncertainty in establishing mental capacity. These assessments provided visible evidence of specific testing and assessment upon which to base decision around mental capacity. I return to the cases of Mrs Friar and Mrs Carter to elucidate how certain assessments played an important role in substantiating narratives and how this impacted on capacity and subsequent discharge decisions.

6.4.1 Defining specialist assessment

Based on observations, I define specialist assessment in this setting as non-routine, additional assessments, which were requested by practitioners to explore further specific areas of uncertainty. The purpose of specialist assessment was to provide objective evidence of observable phenomena and to establish a set of 'facts'. This was observed to be

a key process in informing decisions about mental capacity in relation to discharge decisions. In particular, such assessments provided 'evidence' which could be compared with the accounts of patients, their families and members of the MDT, and aid practitioner clarification of uncertainties around patients' physical and cognitive function, directly influencing capacity judgements as well as discharge decisions.

As part of the discharge planning process, specialist assessments were specifically requested by the consultant during MDT meetings. Social work assessments were common, and initiated when relatives or patients informed the MDT that they or their relative had difficulty coping prior to admission. In such cases a referral to the social work team and occupational therapist was often considered necessary. The social worker described the process of receiving an assessment request and the process which followed.

So...from receiving the referral I have two days to complete an assessment ... not saying that I would complete an assessment in two days because obviously if you know if they're not medically stable, you know that that's not possible. So from the very start I would you know start gathering the information for the assessment basically speaking to family, carers, friends and address myself to the person in question and the gathering information from medical records...

Interview: Social worker 01AsK-0511

The social worker reported engaging with all parties concerned rather than focusing only on the patient, and how this informed the rest of the assessment.

6.4.2 Accounts versus assessments

Practitioners completing assessments were reliant on the quality of information provided by the patient, their relatives and other members of the ward team to provide information against which to benchmark their assessments. In addition, the MDT considered information from specialist assessments completed prior to admission, as well as assessments ordered during the patient's current admission. During interview, the OT

described how she became involved with Mrs Carter, and the information she had access to from other services to help “verify” Mrs Carter’s home situation.

I was referred her from case conference. We received the referral and prioritised her as high with the information that they gave; we do like a data collection from her notes. So what we found was that she was actually known previously to the (Old Age Psychiatry) team, in particular obviously the consultant but also the OT had been out and done an assessment, so I had his reports as well so that was a lot of information I had about how she was managing previously from a professional point of view. But then we also... because Mrs Carter had such poor memory and to understand an insight into how she functioned at home we felt we needed to get some sort of back up or verification of what she was telling us from family.

Interview: OT 01BsD-1709

The OT was not confident in Mrs Carter’s account of how she managed at home, and the reports from the old age psychiatry team provided factual information gathered through community-based assessment prior to the admission which influenced the OT’s perceptions and actions.

Access to such information and prior knowledge of the patient could be beneficial for practitioners and patients. Some patients including Mrs Carter, Mrs Friar, and Mrs Woodward-Jones had been recently assessed in the community by other services such as Old Age Psychiatry and social work. In the case of Mrs Woodward-Jones, the patient was well-known to the Old Age Psychiatry service. They had frequent and recent contact with the patient prior to admission and were aware of a complex situation in which Mrs Woodward-Jones was supported by her friends. Knowing Mrs Woodward-Jones influenced the judgement about her mental capacity during her admission as they had an understanding of how she had previously presented in the community and how this had changed.

Although prior knowledge and background information could be useful, this could also potentially disadvantage patients and limit access to assessment. For example, Mrs Tanner did not have a home visit as this assessment had been carried out during a recent admission

on a different ward. This written report was accessed via the medical records and was not considered necessary to be repeated. Furthermore, sharing knowledge from previous assessments could negatively position the patient as in the case of Mrs Friar. However, in that case the MDT appreciated the value of reassessing the patient's function in her home to provide a more factual view of how the patient coped at home.

The assessment process was observed to be sequential, with various stages of assessment dependent on the patient's ability to participate and whether practitioners felt that any queries or concerns about the patients' capabilities had been addressed. For example, practitioners would initially have a 'chat' with patients before deciding on the appropriate assessments. Any specialist assessments were conducted before mental capacity was formally assessed, and seemed to directly influence the capacity assessment. For example reports from the home visit assessment and old age psychiatry were used when the MDT discussed mental capacity in relation to residence. The example below from the patient's records illustrates the sequence of events.

(Date) MDT meeting 11:50. Known to (Old Age Psychiatry), home visit was poor, mental health has deteriorated. Carers three times a day, does not let them in, lacks capacity. Plan is a planning meeting for residential care.

Medical records: Mrs Carter 120908

The extract also alludes to the role of assessment by old age psychiatry and the home visit assessment in informing capacity judgements in relation to residence decisions, which will be further discussed in section 6.4.5.

6.4.3 Cognitive tests and assessment

When trying to understand the cognitive capabilities of patients with dementia, practitioners routinely looked to assessment tools to try and clarify the extent of impairment in brain function. In comparison with judgements practitioners made on their direct interactions with patients and accounts shared by families, cognitive assessment tools enabled concerns around cognitive function to be quantified. Tests provide standardised questions, yield a score and have cut-off points which indicate the severity of cognitive decline. Such scores provide a legitimate way for patients to be categorised and defined in relation to pre-specified categories ranging from mild to severe cognitive impairment.

The Code of Practice recognises the commonplace use of such assessments and Section 4.50 states that medical or psychometric tests such as those used to assess cognitive skills may be helpful tools in assessing a person's capacity to make particular decisions, but the relevant legal test of capacity must still be fulfilled. These assessments alone should not be used to determine mental capacity in relation to a specific decision.

The Mini Mental State Examination (MMSE) (Folstein *et al.*, 1975) was observed to be the principal cognitive test used on the acute wards. Table 1 presents an overview of the MMSE scores for participants, and indicates where multiple assessments were undertaken. The table shows that all but one patient (Mr Miner) was not cognitively tested whilst an inpatient. MMSE scores were used to define a baseline of cognitive functioning, and to detect changes in cognition (explained in section 2.3), which were then discussed in MDT meetings. The scores allowed patients to be categorised as having either mild, moderate or severe impairment. NHS England provides guidance on thresholds which indicate cognitive impairment. A score above 26 indicates no cognitive impairment, 20-26 as mild, 10-20 as moderate, and less than 10 as severe impairment (Barrett and Burns, 2014). It emerged early in the process of conducting fieldwork that MMSE scores were routinely sought for patients with dementia, and formed an important part of capacity narratives.

...just looking through some of the general notes that I made via the code of practice and just reflecting on some of the things I've seen over the last couple of weeks. I was thinking about in terms of decisions of capacity, something I observed on the ward, in terms of assessment capacity is that a MMSE often seems to be used and MMSE scores are often taken into account when capacity is being discussed.

Reflective notes: 080708

In a specific example, an exchange was observed during the discharge planning meeting for Mrs Tanner in which the OT refers to mid-range MMSE scores indicating a lack of decision-making capacity, rather than indicating moderate stage cognitive decline.

The nurse reported that the patient had a MMSE score of 8 and that this was to be redone. The daughter queried what was meant by a MMSE and the OT spent quite a lot of time describing what the MMSE score was, he

explained that a cut off score of 14 or 15 would probably indicate that someone wouldn't have capacity to make decisions about going home themselves.

Discharge planning meeting observations: Mrs Tanner

This contrasts with the perspectives of many of the practitioners who, during interview, stressed that MMSE scores cannot be used as a proxy for mental capacity but should only be used as a guide.

...and I think sometimes going back to the MMSE, people assume if you've got a MMSE of 7 you're not going to be able to make a capacity decision and like I said before that's not what the MMSE is really there for.

Interview: Registrar 01BsM-0611

The quotes above and below illustrate a degree of subjectivity around assumptions about cut-off scores and thresholds when relating cognitive assessment scores to capacity assessments. However, in keeping with the provisions of the MCA, current guidance from the National Institute for Health and Clinical Excellence (NICE) states that MMSE scores alone should not be used to determine cognitive status (National Collaborating Centre for Mental Health, 2016).

So I think it's almost a question of a case of MMSE score say 14 therefore doesn't have capacity and it's justI feel there's a real over-reliance in the use of MMSEs to guide some decisions when it's rather inappropriate and again a bit like capacity, it fluctuates a MMSE as well, so I have definitely seen that though, not so much here....

Interview: Consultant Psychiatrist 01CsP-2711

Both quotes further illustrate that this relationship is flawed. However some staff explicitly alluded to MMSE scores as a key factor when making a judgement on mental capacity. In the example below the physiotherapist stated the usefulness of the MMSE directly in relation to the patient's cognitive ability and mental capacity.

...oh I think they're quite the mini mental state, they're very, you know helpful especially when you're judging the patient's capacity because you

know how well they're doing, how, what's the score rate and I mean it reflects upon the you know work to how much ability they have got, what's the extent of the forgetfulness is there really. So they're very helpful MMSEs

Interview: Physiotherapist 02sF-2005

This illustrates a clear example of misinterpretation of the MCA which has potential to over influence capacity narratives disadvantage the person with dementia through an over-reliance on cognitive assessment tools which measure specific aspects of cognitive functioning – but not decision-making ability.

Mrs Friar and Mrs Carter both had their cognition assessed only once during the admission. Mrs Friar scored a mid-range score of 15, indicating moderate cognitive impairment. However, Mrs Carter's score of 9 was indicative of severe cognitive decline, and advanced dementia. Neither of these scores seemed to reflect MDT observations of how the patients presented on the ward. Mrs Friar was considered by the MDT to be significantly impaired, but her family were not concerned. In contrast, although the team did not initially consider Mrs Carter to have significant cognitive impairment, the score seemed to confirm the concerns raised by the OT and the stories given by her daughter.

Although the MMSE was considered a key mechanism for determining cognitive function, different from other specialist assessment, I observed a wide range of practitioners undertake the assessment within the hospital setting. The task was often delegated to junior and trainee staff such as student doctors and nurses, ward nurses and healthcare assistants. MMSE assessments conducted by Old Age Psychiatry, were usually undertaken by the liaison nurse. Furthermore, the assessments were usually carried out in the public space of the wards, sometimes with more than one practitioner present. This standard and objective assessment which was regarded by practitioners as the key mechanism for yielding critical information about an individual's cognitive abilities was often not conducted in a systematic manner, but the implications of the scores clearly influenced capacity judgements.

Only one other cognitive assessment tool was observed to be used. At Site 2, The Middlesex Elderly Assessment of Mental State (MEAMS) (Golding, 1989) was used to assess the cognition of Mr Collier and Mrs Shearer. In these cases, the MMSE was not considered sensitive enough to capture Mr Collier and Mrs Shearer's cognitive deficits effectively. The MEAMS assessment is designed for use with older people to detect gross impairment of specific cognitive skills, differentiating between functional illness and organic cognitive impairment by assessing ten areas of cognitive functioning: orientation; memory; new learning; naming; comprehension; arithmetic; visio-spatial skills; perception; fluency; and motor perseveration. In comparison, the MMSE only tests for cognitive decline in five areas.

Over-reliance on cognitive test scores presents a rather narrow snapshot of cognitive function and this assessment does not allow for judgment of cognition in a normal social context or reflect usual social cues and interactions in which people with dementia may benefit. Testing fragments the functions rather than recognising that functions are more often used simultaneously. Furthermore, 'testing' separate elements of cognitive function should not be extrapolated to judge how people will function in everyday activities and do not reflect the complex combinations of cognitive functions required to interact socially, as formal assessments do not include testing of fundamental aspects of human nature such as empathy and self-worth (Sabat, 2001). Therefore, although this objective measure played an important role in practitioner understanding of cognitive function, it must not dominate capacity narratives nor be interpreted as a proxy for mental capacity to ensure that mental capacity is explored more broadly than cognitive function.

6.4.4 Old Age Psychiatry assessment

Old Age Psychiatry were not always part of the ward MDT, and commonly only visited the ward only in response to specific requests for assessment. Despite this, input was observed to be common, although not routine for patients with dementia. Old Age Psychiatry assessed specific issues such as, mood, behaviour, cognition or a medical regimen. The patient could be assessed by the nurse or consultant on single visit, or over a series of episodes depending on the nature of the issue.

Two thirds of all of the participants in this research had input from Old Age Psychiatry. Requests were commonly made in cases where it was particularly difficult to establish

whether patients had or lacked mental capacity regarding decisions about place of residence on discharge. However, in some cases input was in connection with managing other aspects of mental health rather than specifically seeking support on judgements relating to mental capacity. There was an expectation that practitioners from this specialism could resolve uncertainty about mental capacity in relation to residence decisions.

... we sometimes struggle with and I think when it's not clear that's when we ask for involvement of the (Old Age Psychiatry) team to come and you know help us just for a second opinion and I know they don't really like doing that because their ideas about capacity are that we know them best...cause we've been looking after people for longer and asking them to come in and do a snapshot of their capacity. But I think sometimes it's always good to get a second opinion when it's unclear.

Interview: Consultant 01AsO-2111

The consultant described being aware that Old Age Psychiatry consider the MDT providing the patient's care as best-placed to assess capacity, but that a 'second opinion' was useful. Practitioners from Old Age Psychiatry acknowledged their role in contentious cases but largely regarded their role as informative and the team providing care over the course of the admission would have better knowledge of the individual and therefore their judgement would be more appropriate.

...my first reaction would be that it wouldn't be my core role so I'd need to know why it was felt appropriate to get an old age psychiatrist to come and assess capacity. So we've been through a spate of referrals like that when the Mental Capacity Act first went live, usually initiated by social workers asking the medical team to get an assessment of capacity by the old age psychiatrist. And we took quite a firm line, saying that the person who should assess capacity should be the decision maker and that our role would be very much as second or third opinion in difficult and contentious cases and that's accepted by the medical or certainly the care of the elderly consultant fraternity and that's very much the way we're used if we're being asked purely about capacity.

Interview: Consultant Psychiatrist 01CsR-2711

The liaison nurse outlined her role in assisting the MDT in resolving uncertainties around mental capacity, requesting assessment by the consultant only in the most complex cases.

INT I'd say for me personally... when I know that there are some questions surrounding someone's discharge and their capacity, what I would do is very much just add my own contribution, any pointers, anything I have picked up during my assessment which might be helpful for the multi-disciplinary team to decide on capacity. Only thereon and above that if the team are then still finding that difficult I'd maybe get one of the consultants involved when it's... particularly for ward A at (Site 2)

MP What does your assessment involve?

INT I do a mental state examination , MMSE, the depression score, it, we've got assessment tools for delirium, for eating disorders, for like a variety of things [right] that we feel are necessary to do and at the end of it we'll, we'll have an impression and a plan that the impression might not be regarding capacity.

Interview: Psychiatry Liaison Nurse 02sI-0106

Old Age Psychiatry were more commonly observed to be involved if the patient was known to the service prior to admission. Returning to the case of Mrs Carter illustrates how the team were involved in assisting the MDT in establishing whether the patient had mental capacity to make her own decisions regarding residence.

In the five months prior to her admission, Mrs Carter had regular input from a CPN (Community Psychiatric Nurse) linked to the Old Age Psychiatry team and had also been assessed by the consultant psychiatrist and OT. This was to monitor her behaviours and cognitive decline resulting from dementia. Early on in the admission the MDT noted the involvement of the community team and discussed the case with a liaison nurse to obtain background information on the patient. Although the consultant appeared reasonably confident that Mrs Carter lacked sufficient capacity to make a decision about going home or into care, the liaison nurse was involved in exploring this further with Mrs Carter. The team

agreed with Mrs Carter's daughter that it would be in her mother's best interests to move from her sheltered accommodation flat to a residential care home.

In comparison with this seemingly quite straightforward judgement about mental capacity for Mrs Carter, there was no involvement from the service in arriving at the capacity judgement for Mrs Friar. Mrs Friar was one of the minority cases of patients with borderline mental capacity who was not assessed by Old Age Psychiatry. She was not under the care of community psychiatric services and there was no discussion about involvement from the liaison team, despite initial concerns that this case would be complex regarding ascertaining mental capacity. On examining this case, it would appear that the successful home visit (described in detail in the next section) clarified uncertainties about both the patient's mental capacity and discharge home, so that further assessment of Mrs Friar's mental capacity had not been required. If, however the home visit had been unsuccessful, it could be suggested that further input may have been considered necessary to clarify the situation.

6.4.5 Home visit assessment

The majority of specialist assessments for this particular patient group were observed to be conducted on the ward or within the hospital environment. This included some occupational therapy assessments, such as washing and dressing assessments and the kitchen assessment which was carried out off the ward and in a part of the hospital with specialist equipment.

The home visit was the only assessment in which the patient was examined outside of the hospital environment. Patients were assessed in their own home by the occupational therapist. This enabled practitioners to gauge how patients functioned within their normal social context of familiar surroundings, routines and relationships. It made their actions and behaviours at home very visible to practitioners, helping practitioners to establish the norms of for the individual in terms of their interactions and behaviour during the assessment. This specialist assessment appeared to be a fundamental process of obtaining 'concrete evidence' of how a patient functioned in their home environment. Although it was obvious that assessing how patients manage at home will influence discharge decisions, the home visit assessment was observed to influence directly judgements as to whether patients had the capacity to make their own decisions about returning home.

Only eleven of the 29 patients in this study (Including Mrs Friar and Mrs Carter) had home visit assessments. These were considered by the MDT to be amongst the most difficult cases of determining mental capacity in relation to place of residence. The home visit assessment emerged as a critical specialist assessment in the process of providing factual evidence influencing judgements as to whether the patient had or lacked mental capacity to make a decision regarding their place of residence on discharge.

Table 2. Home visit assessments by patient

Patient	Capacity judgement	Capacity outcome	Destination
Mr Mills	Borderline	Capacity	Home
Mr Walker	Capacity	Capacity	Home
Mrs Carter	Borderline	Lacked capacity	Care home
Mrs Baker	Borderline	Lacked capacity	Home
Mrs Friar	Borderline	Capacity	Home
Mrs Gardiner	Borderline	Capacity	Home
Mrs MacVicar	Borderline	Capacity	Care home
Mrs Shearer	Capacity	Capacity	Home
Mr Collier	Borderline	Lacked capacity	Care home
Mr Miner	Borderline	Capacity	Home
Mr Ryder	Lacked capacity	Lacked capacity	Care home

Again the cases of Mrs Carter and Mrs Friar are compared to provide examples of the assessment leading to different outcomes, highlighting the importance of this assessment in clarifying uncertainties around mental capacity and discharge and how it influenced outcomes for the patient and their relatives.

Practitioners expressed the benefits of the home visit assessment in terms of gaining a perspective of patients within a familiar environment, compared with the ward.

Because you're making an assessment of a patient in an unfamiliar environment and you're being told by the people who know the patient better that they do better at home but you don't have any objective evidence that you can't see it yourself and that sometimes is more difficult and in those patients again you still do the formal assessment of capacity if

you think that that's indicated but then you rely a lot more heavily on the family and on the OT to go and do a home visit perhaps, see the patient in their own environment and the input from the social worker if the social worker's known them before as to how they were managing in the past.

Interview: Registrar 01BsM-0611

Here, the registrar compared how such assessments provide “objective evidence” about the patients’ abilities, rather than more subjective accounts from families. The registrar explained how they relied on this information to inform judgements on mental capacity regarding residence.

A series of ward-based assessments were completed by the OT prior to undertaking a home visit. Firstly, the OT discussed the patient’s home with them, then tested activities of daily living such as washing and dressing on the ward. The OT judged the appropriateness of a range of assessments based on patient’s physical and mental capabilities. For example Mrs Mason did not require a home visit as she was able to demonstrate her ability to carry out tasks independently in the kitchen area. However, in contrast, a kitchen assessment was considered inappropriate for Mrs Tanner due to reduced levels of functioning.

The OT describes how she initially assessed Mrs Friar on the ward, but that provided insufficient clarity about how the patient might manage at home.

...we had to do a home visit because of the social elements, as to whether or not they were coping at home and to assess her function in her own environment. I mean like basic skills like her washing and dressing and being able to sequence an activity was fine, she could manage that on the ward, no problem. I assessed her doing that. It was just very like unclear as to how they were coping before she came into hospital. So we did a home visit.

Interview: OT 01AsH-2010

The therapist emphasised the importance of Mrs Friar’s social context and ability to cope rather than her ability to carry out routine practical tasks. Although patients’ physical functionality could be assessed on the ward, an evaluation of the patients’ social environment could often not be made, in particular if the social situation was unclear.

Typically, home visits were arranged by the MDT when patients were considered medically fit for discharge, but concerns had been raised about the patients' ability to cope at home. These concerns stemmed either from a changes in the patient's functional or cognitive abilities which had led to their admission or had occurred whilst an inpatient, or more often, concerns raised by others that the patient had already been struggling to cope prior to the admission.

In the cases of Mrs Friar and Mrs Carter, the MDT were aware of significant concerns around how they had managed at home prior to their hospital admission. As discussed earlier in the chapter, an account from a community OT in particular influenced the MDT's understanding of Mrs Friar's inability to manage at home, whereas Mrs Carter's daughter had informed the MDT that her mother was struggling to cope in her sheltered accommodation flat.

In Mrs Friar's case, there were multiple concerns uncovered in a recent community assessment prior to admission although the team expressed the view that the family must have been managing to an extent. The team also thought that community practitioners could clarify the situation. However, in Mrs Carter's case, it was her daughter who alerted practitioners to her mother's problems at home.

...she was living like in sheltered accommodation but she was, as I said she wasn't looking after herself, she wasn't eating, she was sleeping, well she sleeps a lot there, she was sleeping most of the day and then she was walking along the corridors and she was frightened

[...]

our (name of son and daughter in law) and (name of older son) my older son used to go every night and see how she was, (name of son and daughter in law) were doing her shopping, and I mean they were like doing her meals but she wasn't eating her meals, they were making sandwiches for her, mind my daughter in law was doing all her washing because she was starting to smell and that, and she wasn't my Mam, clothes were dirty.

Interview: Mrs Carter's daughter 091208

In both cases, the accounts were dominated by claims of dysfunctional households, with the patients engaging in risky behaviours as a result of their cognitive deficits. The purpose of the home visit was therefore to assess the physical environment and obtain observable,

first-hand evidence of how the patient managed routine daily functions within their own home. The layout and condition of the home were also examined. Details were obtained about physical aspects of the patient's home such as accommodation type, tenure and layout, type including whether there were stairs and adaptations to the property such as handrails.

The patient went upstairs and it was noted how the patient negotiated the stairs. The student nurse had to count the stairs on the way up. The patient seemed to negotiate the stairs easily, went into the patient's bedroom and there was two single beds in there. [...] The OT measured the heights of the beds and asked the patient to get onto the bed to see how she mobilised. She also asked where the telephone was and the patient said this was next to the bed and the OT asked who she would ring if there was an emergency. She said she would call 999.

Fieldnotes: Mrs Friar's home visit 141008

In addition, upkeep of the home and signs of poor maintenance such as a lack of hygiene, cleanliness and tidiness were noted to signify whether the patient had been coping prior to the admission.

...he came in because he was physically unwell. There's no question about a social breakdown but he won't change his clothes, his clothes are filthy, they've got food down them, he eats mostly pies, he drinks a lot of beer or whisky or whatever it is he drinks and when the occupational therapist went out, you know it was plain he'd been incontinent and all the furniture and the carpet was threadbare and you stuck to it and all the rest of it. Well clearly all that is undesirable but he's been living like that forever and you know, I don't know what is the right point to intervene to say that, that lifestyle is not acceptable.

Interview: Consultant 01BsQ-1212

The consultant commented on the subjective nature of judgements around coping. This highlights the scope for negative judgements on the home environment to influence opinions about the patient's ability to cope and their subsequent insight into their abilities.

This was clear in the examples when Mr Collier was considered to lack capacity, primarily based on his reluctance to engage with professionals around his 'squalid' home environment.

... I get that you have to have measures in place so that people can, you know, if they have capacity they make that choice, and I understand that people have different, you know, what I class as tidy might not be what somebody else classes as tidy or whatever, but there must be like a cut-off point where he just clearly isn't coping at home. I mean his personal hygiene and stuff was poor when he came in. I think you can tell it's not great even on the ward and at home, you know, when he's got sheets that haven't ever maybe been cleaned, ever, for potentially six years or something like that, then that's kind of that's nobody's level of cleanliness, even third world countries and things like would struggle toDo you know it's not pleasant and when you can't physically get round the house and stuff because there's so much dirt and clutter and things then I question whether people...because he has sight problems and stuff as well, I don't know if he realises how bad things have got for him but you ask him and he goes, "Oh my daughter does the cleaning", and clearly nobody does the cleaning because there hasn't ever been any cleaning done in that house for a considerable length of time.

Interview: OT 02sC-1305

Here the OT explicitly linked what she observed during the patient's assessment and his response to her concerns and his capacity to make decisions to return to this environment. During home visit assessments, patients were specifically asked questions about the support they received at home, and what families or services did to assist the patient with their activities of daily living. Therapists asked the patient to perform routine tasks to see how they managed daily activities such as negotiating the stairs or making a cup of tea. Patients were also asked abstract questions relating to their safety such as who they would call in an emergency and how.

The OT asked the patient to show her how she used the cooker and she proceeded to explain the bits of the cooker and to show her how she'd

clean it and explained the grill. The OT clarified and asked the patient to turn on the hob and she said she didn't know. But her husband was there straight away and he helped her to light the gas hob but he has a tremor and he had some difficulty with this. [...] She spoke about how her son and husband do the cooking and the husband explained in quite a bit of detail how he does the potatoes and steams the veg on top to be healthy.

Observations: Mrs Friar's home visit 141008

This observation demonstrates that although Mrs Friar was unable to perform the task which the OT set, the norm was for Mrs Friar and her husband tackle tasks as a team with the support of their son, reflecting their usual relationship within the home. Rather than focus on the fact that Mrs Friar failed to complete certain tasks and needed help, this OT recognised the supportive network of the family and how this worked well for this patient and her family. This is an example of good practice which emphasises the importance of enabling people with dementia to demonstrate their capabilities, which although may require support, facilitate retaining autonomy and independence.

Although practitioners considered home visit assessments to have many benefits, the timing of such assessments were not always optimal in terms of assessing patients appropriately. If assessed too early in their admission, patients may not be medically and cognitively stable. Conversely, some patients remained in hospital several weeks after their home assessment, with potential for needs to change. For example Mrs Baker had suffered an acute infection, but the assessment went ahead resulting in a distressing experience for the patient and her family.

...that social worker had decided to send her home for a visit, a home visit, when she was in (Site 1) and but she was poorly, and her legs were bad [...] Mam was...she just wasn't well at all and she got herself upset because she was at the....her legs were bad, she had something wrong with her legs at that time and she could hardly walk and when she come home and she couldn't do the things, they were pushing her saying you know, "Can you make a cup of tea? Can you get on the bed?", and she couldn't. If they had left it for another week and then brought her home, and I spoke to the

nurses about it when I got home and they said "I know" she says "I think we shouldn't have really let her go home"...

Interview: Mrs Baker's daughter 110209

In this example, the patient was not given a fair chance to demonstrate her capabilities in her own home. The assessment only served to highlight what Mrs Baker was unable to do, which was distressing for the patient and her family. As well as disadvantaging the patient, this also had resource implications as the assessment had to be repeated to gain an accurate picture of Mrs Baker's physical and cognitive abilities whilst at home.

... The initial home visit was not particularly successful, partly because she was down with I think it was cellulitis or a urine infection, a further urine infection so therefore, it was felt that it was not an optimal time for her to have the visit. So she had a further home visit later on when she was completely medically stable and they did identify certain issues as risks on the home visit.

Interview: Consultant 01BsE-1610

Although practitioners considered the home visit assessment valuable, both they, and family recognised limitations, in that one single visit home for a short time is not enough, and that assessing someone in their house does not reflect that 'home' is just one aspect of living in the wider community. One junior medic described home as a 'very big place', explaining that 'home' is not just about the house, but the whole neighbourhood environment. Someone may be able to make a cup of tea but may have trouble if they go out and about. The OT explained that a half hour assessment provided a better picture than ward based assessments, but still only provided a "snapshot" of the patient.

...they [home visits] give you a bit insight and how somebody is orientated around the house and stuff like that. So they're important, but again you're not going to tell from a half an hour in a house with us all around how somebody is going to function when they get back home because when you leave them and stuff like that they'll do whatever they want to do, so it can give you an idea but it'll not give you like 100%...

Interview: OT 02sC-1305

Whether this 'snapshot' revealed a successful performance, or failure to perform adequately clearly influenced capacity judgements. The junior doctor below described how if patients failed to perform well, and persisted in requests to return home, this was then likely to result in a decision that the patient lacked mental capacity to make their own decision.

... a lot of these patients they actually cannot process the information that you've given them so you're not actually coming to a fruitful conclusion. Sometimes a patient that's really demented will say to you 'I really want to go home' and you know we give them a choice, you know we'd give them a choice, you know we'd send them on a home visit and they'll go, and they'll fail the home visit and that's an indication that actually yeah, we know they don't have capacity and we've given them a chance to go and prove them self in their home environment... and if they've failed a home visit then it's not a safe place to send them to.

Interview: Junior Doctor 01BsN-2011

Failure to appreciate the meaning of home and inability to perform generally were taken as evidence that the patient lacked capacity to make this decision and a best-interest decision would be made, whereas the OT below referred to capacity in a more narrow sense, relating to the specifics of the assessment.

I have to think about it in terms of like the smaller, breaking it down into whether or not she has the capacity to understand that [Mrs Friar] would be unsafe using the cooker and the fire. Now at the time I don't think that she would have had this capacity to understand that because she was quite evasive you know when we were around the gas cooker, she was trying to rush it and then we tried to stop her and say 'that would be unsafe if you did this and that'. She was just unwilling to engage in that conversation and I think that's probably like a sign that she probably doesn't fully understand the risks and consequences. [...] So with regards to capacity about understanding like risks I don't think that she did show she had an understanding and could communicate them risks. Thinking about the bigger picture about the capacity to go home, to make the decision with regards to going home, again I think, I don't know to be honest with you,

she was able to engage in discussions about how the visit went but she wasn't very clear about it. So I think because of her memory she probably doesn't have capacity but she could clearly see that she wanted to go home. So I think she maybe didn't have capacity based on her understanding of the risks and being able to like communicate them back to you.

Interview: OT 01AsH-2010

Although Mrs Friar did not have capacity to appreciate specific risks around home safety, the OT was less clear about whether this indicated that the patient was unable actually to make a capacitous decision about returning home. The decision became about the risks of discharge rather than the issue of mental capacity, and the OT felt that the assessment fulfilled that purpose.

6.5 Chapter summary

Practitioners were faced with making sense of a multiplicity of narratives when deciding whether a person with dementia had sufficient mental capacity to make a decision about where to live on discharge from hospital. The findings support that accounts of people with dementia were commonly doubted by practitioners when narratives appeared implausible, triggering concerns about mental capacity (Twining, 2008), particularly when compared with the assumed more reliable narratives sought from others, such as family and community practitioners.

Although past narratives were important, whilst an inpatient, a new narrative was constructed about the patient, by a host of practitioners, and from a range of disciplines. This work commonly occurred behind the scenes and was invisible (Goffman, 1971) to patients and their families. This backstage teamwork impacts on the frontstage presentation of the patient (Ellingson, 2005) as the narrative, as documented in medical records, became the most authentic account of the patient, and embodied the 'official' medical narrative of the patient (Gubrium, 1986). This was the authoritative narrative on which decisions about mental capacity were based. Therefore, people with dementia often had limited opportunities to directly contribute to their narrative which was constructed about their

mental capacity (Sabat and Harré, 1992) creating a lack of narrative agency (Baldwin and Bradford Dementia Group, 2008).

Although multiple perspectives about the patient informed judgements on mental capacity, they provided insufficient 'evidence' upon which to base decisions. Therefore, in many cases, there was a need for those subjective and unobservable accounts to be rendered more objective and factual through specialist assessment. Specialist assessment provided a more visible way for practitioners to evidence their decision-making process around mental capacity. Mrs Friar's case typifies both the privileging of practitioner accounts over the person with dementia, and also the value of assessment. The community practitioner's negative account predominated the MDT's perceptions, and this narrative was regarded as the most reliable. Mrs Friar and her family were negatively positioned (Sabat and Harre, 1992; Sabat, 2001) through the narrative that no-one in the family would be able to provide an accurate version of events at home. This prompted concerns about her decision-making capacity regarding place of residence. However, further investigation through the home visit revealed a more positive account of the patient. This example evidences good practice within the MDT which enabled Mrs Friar to present herself more positively, and resulted in her going home in accordance with her wishes. Understanding of the narrative of the person with dementia was entrenched in broader cultural practices of communication with people with dementia. This example reinforces the importance of positive, person centred communication through enabling the person with dementia to present their perspective in a meaningful way (Downs and Collins, 2015).

In Mrs Carter's case, the mismatch between the patient and her daughter's version of events around coping at home was the main trigger for the concerns of the MDT. Again, good practice was revealed, and had her account been accepted, and left unexplored by the MDT, she may have returned home, perhaps to unsuitable living arrangements. This reinforces the need for practitioners to ensure that all accounts are explored fully and that the person with dementia's account may need careful interpretation, with recognition that their version of events may not be deliberately distorted, but may reflect their understanding of their world. (Sabat, 2001).

To meet the provisions of the MCA, the two-stage test of mental capacity which focuses on current decision-making ability may shift the emphasis away from judgements about the accuracy of complex narratives to an approach which appreciates current cognitive functionality. However, complicated multi-authored narratives required resource-intensive investigation, with considerable input and assessment by the MDT and often requiring an extended inpatient admission. Adequate exploration and assessment are necessary to ensure that patients with dementia are given the best chance of retaining autonomy and independence.

The home visit was a particularly powerful assessment – rendering the patients home environment more visible to practitioners – which was instrumental to the discharge outcome. However, home visits and Old Age Psychiatry assessments indicated whether someone would be able to function physically and mentally in the community, and current levels of cognitive function but not necessarily whether they were cognitively capable of making a capacitous decision about going home. Whilst these assessments formed an important part of judgements on mental capacity, the purpose of these assessments must be clear – they may influence judgements on capacity – but they must not be substituted for the legal test of capacity.

Although specialist assessment provided a means of clarifying unresolved narratives around mental capacity, in the most complex mental capacity judgements, uncertainties and practitioners considered these decisions particularly challenging. These further complexities in mental capacity judgements for people with dementia in this context are explored in the next chapter.

Chapter 7. Complex cases and enacting binary notions of mental capacity

7.1 Introduction

The previous chapters considered interpretative approaches to capacity assessment and how the accounts of others shape and substantiate judgements on mental capacity in relation to place of residence on discharge. In this chapter, I explore the third aspect of enactment of the MCA in this context. I focus on the research question of how binary notions of mental capacity fit with the reality of practice when making judgements on mental capacity, and how this impacts on people with dementia and their involvement in making critical decisions about where they live. I address the third objective of this research by drawing on some of the most complex capacity judgements in detail, to illustrate how they were managed in practice through strategies adopted by medical practitioners, to conform to the binary distinction between capacity and incapacity required by the MCA.

First, I relate the most complex judgements to the concept of 'borderline' mental capacity. I then examine the main discourses identified which practitioners used to reconceptualise people with dementia from borderline mental capacity, to fit with the binary legal framework of the MCA. The chapter concludes by exploring who makes the definitive decision about mental capacity in relation to place of residence on discharge from hospital. I draw on a broad range of patient cases to illustrate the many factors which can contribute to complex judgements of capacity by making comparisons between patient cases with shared similar characteristics but for whom a different capacity outcome was reached.

7.1.1 Defining borderline mental capacity

To understand the context of judgements when it was uncertain whether patients had or lacked mental capacity to make their own decisions about going home, it is useful to explore what was understood about patients who were considered to be 'borderline' in terms of decision making. In both legal and clinical practice, capacity is rarely conceptualised as fully present or lacking, but on a continuum, which only becomes a binary concept at the point of decision making (Owen *et al.*, 2009a). This 'grey area' of capacity (Kapp, 2002) is recognised in the literature as marginal competence (MacCourt and Tuokko, 2010) or borderline

(Herring, 2008; Herring, 2009), and also in the MCA Code of Practice in reference to cases where there is doubt about capacity (Section 4.48).

Practitioners in this research conceptualised the capacity of patients to make their own decisions regarding residence as either 'borderline' or 'clear-cut'. These were common phrases which practitioners across a range of disciplines used to describe mental capacity status. Practitioners categorised patients as such during interviews and were observed to describe patients in this way in their interactions with each other, for example when discussing cases in MDT meetings. This often then also became documented in the patient's medical records.

The consultant wanted to know where home was and what home was. It was described as being a bungalow and the patient was described as having no care package. The plan was to one, have a further home visit, two, have a planning meeting, and it was discussed that this patient probably lacks insight into how she can cope. But it was felt that a new home visit would clarify this and this patient had to be given the benefit of the doubt. The patient was described as having borderline capacity which needed to be rechecked. The feeling at the moment was that on balance the patient lacks capacity.

Fieldnotes: MDT 37 2200908

This exchange observed during an MDT meeting illustrates that practitioners understood that patients could not remain as borderline and this was a transient status which would require further consideration. The broad range of factors which need to be carefully explored and balanced in such complex cases are apparent, as is the work practitioners must engage in to make sure the right outcome is achieved for the patient.

Whereas borderline cases were characterised by uncertainty and sometimes disagreement as to whether the patient had or lacked capacity, in comparison, practitioners regarded clear-cut cases as uncontested and straightforward. In addition, the capacity of borderline patients was often considered to fluctuate – at times the MDT judged the patient as having capacity, but on other occasions they were thought to lack capacity. Practitioners used three main discourses to reposition patients from a liminal status of borderline mental

capacity to a capacity status defined by the binary outcome of capacity or incapacity, imposed by the legal framework of the MCA.

Practitioners were familiar with complex cases of mental capacity. One consultant estimated that about a third of patients could be categorised into each group: clear-cut capacity, borderline capacity and clear-cut incapacity. However, of the 29 patients included in this research, 20 were considered to have 'borderline' capacity status. This was how the patients were defined and described by the MDT, around the time of discussing discharge plans. Only nine cases were considered to be 'clear-cut' judgements, either possessing or lacking the requisite capacity to undertake their own discharge decisions. Figure 5 demonstrates initial judgements on capacity, with borderline cases occupying the overlapping area. Figure 6 depicts the final capacity decision, which was fairly evenly distributed. Cases originally considered 'clear-cut' and with no change in capacity status are depicted using black text. Cases in white text are those who moved from their borderline position.

Figure 5: All patients by capacity status – lacking, borderline and with capacity

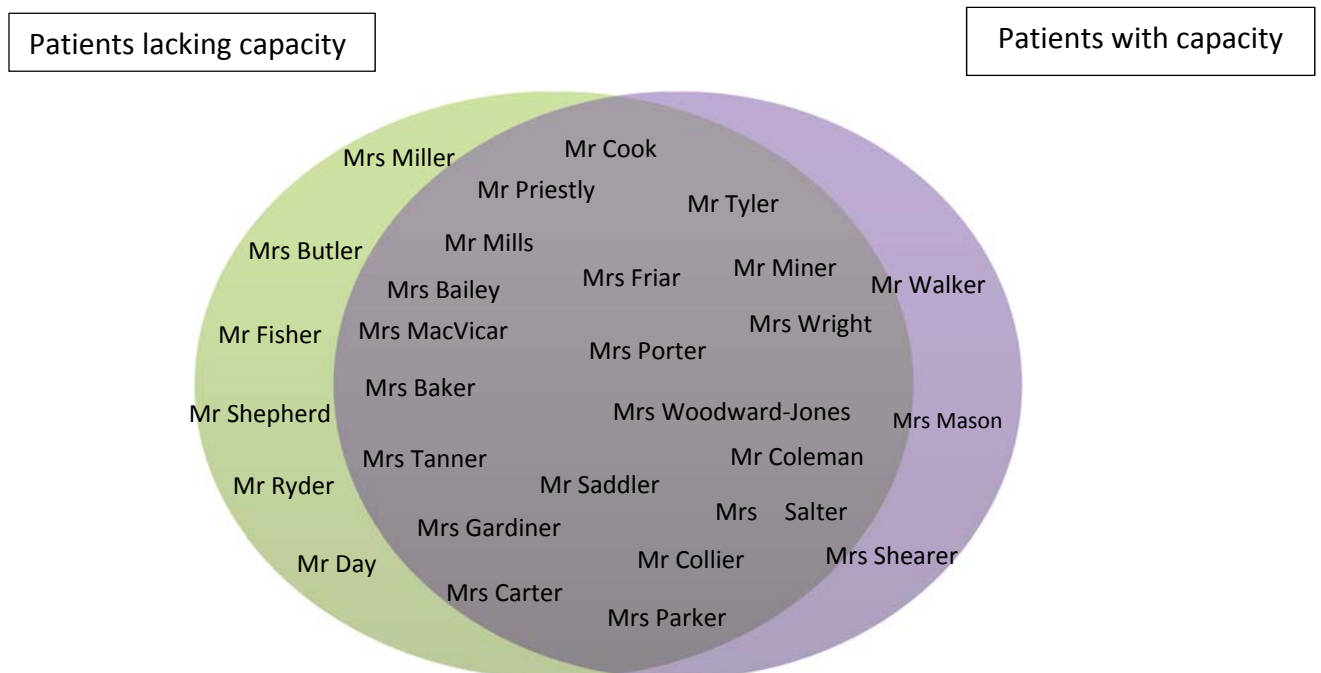
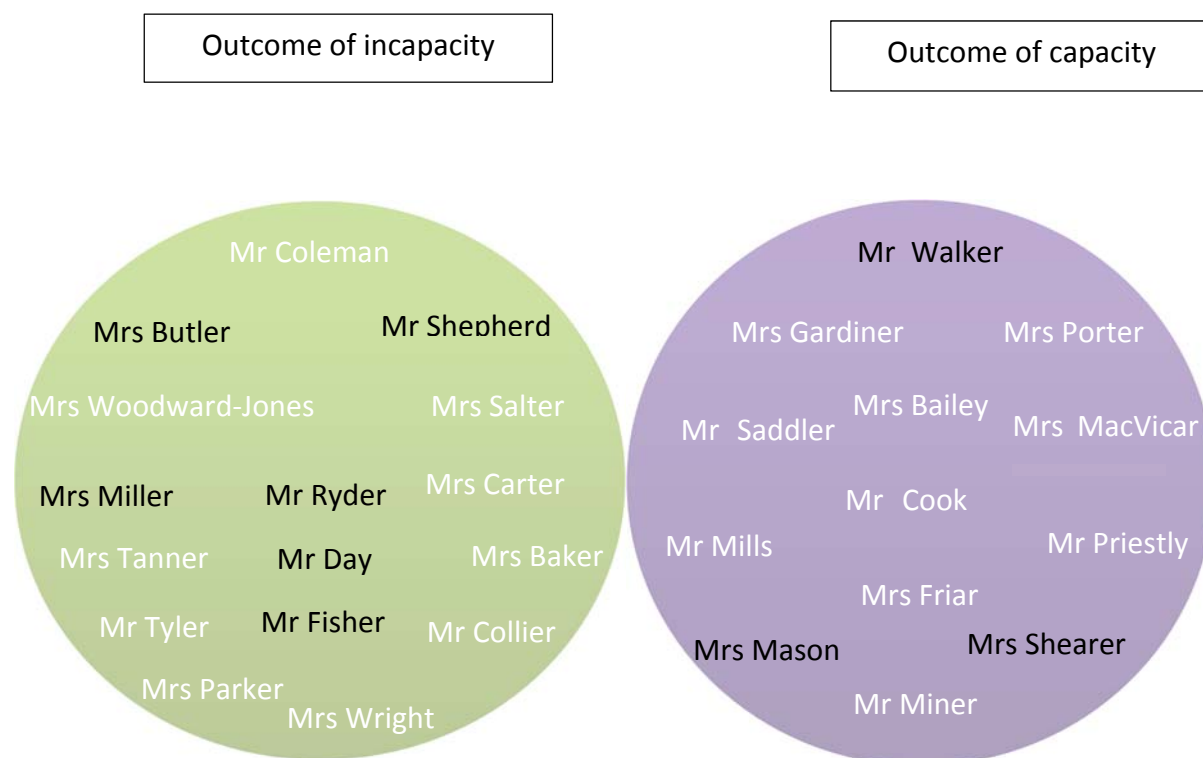


Figure 6: Capacity outcome for all patients



7.2. From borderline to binary outcomes

Analysis of capacity judgements of all 29 cases indicated that patients were categorised according to three main discourses: medical; behavioural; and cognitive, to enable practitioners to re-position patients from the status of borderline mental capacity to either having or lacking capacity. These categorisations were not mutually exclusive, and most cases featured some elements of each but were categorised according to the dominant narrative determining each capacity and subsequent discharge decision.

Six of the 20 patient cases with 'borderline' mental capacity are presented to highlight the three dominant discourses which were observed to influence their capacity judgements. These cases were regarded by practitioners as particularly challenging. Comparing and contrasting cases illustrates the challenges facing practitioners in applying binary distinctions of mental capacity, and the dominant discourses which shaped these judgements on capacity and discharge outcomes. For each construct a comparison is made between two 'borderline' patients – one of whom was finally judged to have capacity to undertake this decision – and the other lacking mental capacity and requiring a best interest decision on

their behalf. Examples from the other 14 borderline cases demonstrate commonalities and unique cases. Further contrast is illustrated using the cases of 'clear-cut' mental capacity.

7.2.1 Medical discourses influencing mental capacity judgements

A variety of medical factors were observed to influence capacity judgements. A third of all cases showed predominant medical issues, of whom the majority had borderline capacity status, and the majority of those were ultimately considered to have the requisite mental capacity to make their own decision about going home. Analysis of these cases revealed that events such as sudden deterioration or improvement in physical or mental health, accidents, and medical complications occurring during the admission shaped judgements and assisted practitioners in reaching a definitive judgement on capacity relating to hospital discharge.

Getting better?

The experiences of Mrs Gardiner and Mrs Baker emphasise the role of changing medical status and how crossing boundaries between 'good' and 'ill' physical and mental health impacted on such decisions. Both patients were considered by the MDT to be very much on the borderline of having capacity to undertake their own decision regarding residence. Due to this uncertainty, much time, resource and consideration were invested in ascertaining the mental capacity of both patients. The MDT undertook multiple capacity assessments and specialist input was sought from liaison Old Age Psychiatry teams. In both cases, much of the uncertainty was characterised by their clinical state of fluctuating cognition which medical professionals considered attributable to recurrent urinary tract infections (UTIs), leading to mental confusion, delirium and physical fatigue. Mrs Baker had a complex medical history of co-morbidities and further medical complications whilst an inpatient. Indeed it was her chronic medical state that had led to her admission. In contrast, Mrs Gardiner had a far less complicated medical background, and her admission was the result of a fall causing a fractured femur. Mrs Gardiner had a previous diagnosis of dementia, Mrs Baker did not – this was only assessed whilst an inpatient, indicating that a diagnosis of dementia was not instrumental in informing the capacity judgement in these cases.

The registrar explained during an interview that they were waiting for Mrs Gardiner's acute confusion to resolve. Although at that time he doubted she had capacity to make a decision,

the emphasis was on the acute nature of her illness and how this was affecting her cognitive state.

...it [capacity] certainly needs to be revisited because ... the ward round this morning showed that you know, she didn't have any, you know, she wouldn't have capacity. She thought her parents were helping her, sort of living around the corner from her and quite clearly was in a different state of mind to when that assessment was done in February. She's had acute illnesses and we need to make sure that we treat and let any sort of delirium settle so we've got a true picture of what she's going to be like; make sure that we revisit the situation on numerous occasions; give her more time, get an idea if this is just fluctuating and we've caught her on a bad morning rather than actually [...] as you know it's not the same circumstances, she's come back into hospital for a reason, with falls, increased confusion and has been treated for a UTI, so we need to make sure that that all settles and her baseline hasn't actually changed.

Interview: Registrar 02sH-2705

In contrast to Mrs Gardiner's acute medical issues, the consultant described Mrs Baker's chronic physical condition as affecting her mental state. Whilst acknowledging the influence of her acute conditions, her lack of understanding about management of chronic medical conditions was key to reaching a judgement that Mrs Baker lacked capacity to make a decision about returning home in accordance with her wishes.

...she was a lady who was readmitted after a recent discharge from one of the community hospitals. She had come in with a urine infection and she had renal failure on top of her urine infection. She also had what we call urinary retention, [...] so therefore, we had to: number 1, catheterise her, get her bladder to empty um completely relieve the pressure on the kidney and also treat her urine infection. Coinciding with all this urinary problems she had what we call delirium i.e., increased confusion. We suspect she has had a bad run of cognitive impairment for some time and that has not been sort of formally diagnosed as dementia. [...] She also developed some other medical problems of cellulitis in the leg which required a further course of

antibiotics. So once the cellulitis was resolved, once the urine infection was resolved, once she stayed on the catheter and she was tolerating the catheter and her blood markers of infection and kidney function were back to baselines, we started working on discharge planning.

Interview: Consultant 01BsE-1610

The interviews with the registrar and consultant highlight clear uncertainties around the mental capacity of both patients relating to their medical conditions. The clinicians found both patients sound in judgement on some days but not others, causing considerable difficulty in reaching a judgement of capacity and incapacity. Although senior medics interpreted their interactions with the patients to indicate fluctuating capacity, interestingly, cognitive test results did not greatly fluctuate in either case. Mrs Baker's test scores slightly increased within the moderate-score range, and Mrs Gardiner's showed slight changes within the mild cognitive impairment range.

Both patients were keen to return to their homes, an outcome supported by their respective friends (Mrs Gardiner) and family (Mrs Baker). However, Mrs Gardiner was open to the suggestion of a residential placement whereas Mrs Baker was steadfast in her wishes to go home. Ultimately both patients were discharged home in accordance with their wishes. Mrs Gardiner was considered capable of making her own decision, however a best-interest decision was reached for Mrs Baker, who was judged to lack sufficient insight into her current care needs. Significantly, of the 29 cases, this was the only best-interest decision in which the patient returned home.

Comparative cases

The experiences of Mr Mills and Mr Cook provide contrast with those of Mrs Gardiner and Mrs Baker. Despite initial concerns around capacity, both patients who had previous diagnoses of dementia, were considered to make rapid physical and mental improvements due to treatment and resolving delirium. The uncertainty around their capacity status was quickly dispelled and both patients were deemed capable of making their own decision to return home, whereas cognitive and medical uncertainty endured for Mrs Gardiner and Mrs Baker. Conversely, whilst for Mr Coleman the uncertainty was quickly resolved, there were negative consequences for Mr Coleman, whose physical and mental health rapidly deteriorated owing to pneumonia, whilst still an inpatient. Although initially unsure whether

Mr Coleman could make the decision to return home as he and his wife wished, the MDT decided that the patient's marked physical and mental deterioration indicated a lack of capacity and that a best-interest decision of discharge into nursing care was the best outcome for Mr Coleman and his family.

In all of the above cases, a biomedical understanding of dementia (Lyman, 1989; Bond, 1992) was applied to making sense of mental capacity, as the impact of other medical conditions on capacity, and the on clinical management underpinned decision making. This reflects traditional medical models of decision making, which prioritises medical knowledge held by practitioners (Lupton, 2012) and may undervalue other important aspects of decision making such as the preferences, wishes and choices of the patient and their family.

7.2.2 Behavioural discourses influencing mental capacity judgements

Patients' behaviour, both prior to admission and on the ward, emerged as a key factor influencing capacity judgements. Behaviours deemed 'irrational' or 'odd' were often interpreted as a sign of cognitive deficiency and impaired judgement. Behaviours often seemed secondary to other dominant narratives, but nevertheless remained a strong theme. Only four cases were categorised as their behavioural status being instrumental to the capacity decision. Two cases were clear-cut (Mrs Mason having, and Mr Shepherd lacking capacity); and two borderline – resulting in contrasting capacity outcomes described below. Mrs Friar and Mr Collier represent complex borderline cases positioned within a behavioural context to arrive at a binary capacity outcome.

'Unusual' behaviour on the ward and at home

Although both Mrs Friar and Mr Collier were considered borderline in terms of mental capacity, initial judgements were somewhat reversed over the course of the admission. In both cases, a home visit assessment was integral in clarifying the behaviours of the patient at home, which impacted on judgements on capacity and the subsequent discharge outcome.

Initial perceptions of Mrs Friar were that the behaviours of her and her family were 'odd' both prior to admission and during her inpatient stay. As described in the previous chapter, a report of events occurring just days before admission from a community occupational

therapist which was shared with the MDT, portrayed a picture of chaos. The conduct of the patient's family whilst on the ward was also perceived negatively. Mrs Friar's mid-range MMSE test scores indicated a fair degree of cognitive impairment. The MDT feared that no one in the family would be capable of undertaking a decision about discharge. However a home visit assessment with the MDT's occupational therapist revealed how the family functioned well as a unit and supported each other in a well-ordered environment. Despite original concerns, mental capacity was not formally assessed, no discharge planning meeting was held and the patient returned home in accordance with her and her family's wishes. The OT who carried out a home visit with Mrs Friar described how the information from the community OT about Mrs and Mr Friar's behaviours had influenced her perceptions about the patient and her family prior to meeting them.

INT:... one of the Community Occupational Assessment Officers, they're like assistants, she had a referral to go out and see Mrs Friar and when she got to the house she just said she really panicked, "I don't know how these are coping" and I think Mrs Friar was running up and down the stairs and the OT assistant, she was unable to engage her in any meaningful conversation.[...] The husband, she said he was strange I think is how she described him, wasn't sure if he was also confused and just alarm bells were ringing so she contacted the GP, the GP went out to see Mrs Friar and consequently got her admitted to hospital. So obviously I had that prior information before I went to see Mrs Friar. [...] I had the background information from the OAO who had gone out and it was very difficult to clarify how they were managing with the husband because I think the best way to describe him would probably be like eccentric (laugh) and everything was fine, everything was fine, they were a good team.

Interview: OT 01AsH-2010

However, the OT concluded that although Mr Friar was "eccentric", and Mrs Friar's behaviours were strange prior to her admission, during the home visit assessment, she had observed the family (including their adult son, who had learning difficulties) working well together at home. The successful home visit removed initial perceptions of social

breakdown and the doubts expressed by the MDT that none of the family would have mental capacity to decide on place of residence.

In contrast, although the MDT had some doubts about Mr Collier's capacity to make decisions about going home, these were minor. Most of the MDT surmised that he would have capacity to make the decision to return home – albeit to a house that was described as in a state of “squalor” by the team. Over several weeks, various members of the team tried to engage with the patient, who remained elusive about plans despite being keen to return home. Mr Collier's uncertain capacity status was revisited regularly during his admission by many of the MDT and referral for specific assessment by liaison psychiatry. Cognitive assessments and test scores indicated little impairment and the patient refused regular re-testing after attaining full marks, stating that the tests were “daft”. Mr Collier's lack of compliance with such assessments was noted, and the team felt that the cognitive tests were not uncovering his impairment. Ultimately, Mr Collier's lack of engagement and perceived lack of insight into the condition of his home and care needs were taken as evidence of incapacity to decide to return home and Mr Collier was discharged to residential care in his best interests.

The social worker described how Mr Collier's behaviours prior to admission were risky. Furthermore, his dismissive behaviour towards the MDT's concerns about such risk were the main cause of uncertainty regarding the patient's mental capacity to decide to return home.

He was admitted following the fall, as I say the home visit raised serious doubts about his ability to be returned to the home environment as it stood, it was very dirty, very unkempt, carpets were worn, torn, no aids and adaptations. Um trying to engage Mr Collier is very difficult because we have, do have questions about his capacity. He's always been, as described by his family, he's always been quite a loner, will just take to his bed basically, lie and smoke cigarettes, which is a behaviour without the cigarettes that he has exhibited in here really.

Interview: Social worker 02sJ-0206

In Mr Collier's case, judgements about his behaviours influenced the decision about his mental capacity most. Again, when compared with other cases of patients with borderline mental capacity, dementia diagnosis did not seem to influence perceptions around

behaviours and judgements on capacity. Mrs Friar had a prior diagnosis of dementia, whereas Mr Collier was suspected to have some cognitive impairment, although marginal, according to objective assessments.

Comparative cases

In contrast, the cases of Mrs Mason and Mr Shepherd were both considered to be 'clear-cut' capacity judgements. Both patients tended to display rather extreme forms of behaviour during their inpatient stay. Hospital security were called to intervene when Mrs Mason became upset during the night, however her behaviour settled quickly once her diabetic symptoms were controlled. An informal assessment of capacity during a routine consultant-led ward round revealed that Mrs Mason was more than capable of making the decision to return home. In comparison, Mr Shepherd's regular loud shouting and demanding the attention of the nursing staff was considered disruptive to the ward. Rather than resolving, this behaviour increased and persisted after all obvious medical complications had subsided. The team unanimously felt that his behaviour would be best managed in EMI (Elderly Mental Infirm) care, and his family were involved in a best-interest decision. Both cases were considered straightforward in terms of a capacity judgement by the team. Both had involvement from liaison psychiatry teams relating to their behavioural issues, but not specific to capacity judgements. Neither had a formalised capacity assessment and neither had home visits.

The key differences between the 'clear-cut' and borderline cases perhaps highlight that the subtle, less extreme behaviours blur boundaries around behaviour and subsequent capacity judgements. Scrutinising the behaviours of patients with borderline mental capacity enabled practitioners to be able to position the patient as either having or lacking capacity based on the person with dementia's understanding of their behaviours and whether they comprehended the consequences of their behaviours and ability to act on these (Sabat and Harre, 1992). Behaviours which were considered to deviate from cultural norms of patient behaviour in the hospital setting (Scheff, 1971) were considered to signify a lack of mental capacity. However, these cultural assumptions are based on ideas of behaviours of a 'normal' patient rather than the behaviours of a person with dementia (Miesen, 2004). Furthermore, these behaviours was considered 'symptomatic' of dementia, rather than

attributed to individual expression of self, or how practice can impact on behaviour (Sabat, 2001); impacting negatively on judgements of mental capacity.

7.2.3 Cognitive discourses influencing mental capacity judgements

Cognitive impairment was the third discourse which significantly influenced binary outcomes of mental capacity. Patients' cognitive status were determined by a combination of practitioners' interpretive judgements on patients' insight and understanding of their social world, and objective assessments such as cognitive tests and computerised tomography (CT) scans. Supporting services such as Old Age Psychiatry were routinely called upon for additional assessment where there was lack of clarity around cognitive status. Half of all cases in the study were categorised by a dominant cognitive discourse, of whom two-thirds were judged to have borderline capacity. With one exception – Mrs Shearer, who had clear-cut capacity – all of these patients had a prior diagnosis of dementia, which seemed to influence judgements. The majority of these cases were considered to lack capacity to undertake discharge decisions and a best-interest decision was considered appropriate to determine place of residence on discharge.

Cognitive changes

Mrs Porter and Mrs Woodward-Jones were two patients whose cognitive status was most influential in determining their final capacity status. Although both patients had mid-range cognitive test scores, Mrs Woodward-Jones' cognition was subject to far more scrutiny. She had an established history with the Community Mental Health Team (CMHT) who engaged in psychiatry liaison with the ward teams. She had a diagnosis of dementia, and neighbours and relatives had reported a series of events in which the patient had 'wandered' at night. Admitted for a suspected fall at home, she had few signs of physical injury, however the ward staff found her behaviour something of a challenge. She was frightened, sometimes challenging, and often overly affectionate. The MDT were very unsure as to how to best manage the patient's needs, which seemed largely related to her cognitive condition rather than her physical health. After seeking advice from the liaison psychiatry team the patient was transferred to a specialist cognitive impairment ward. On this ward, the patient's cognitive function was re-assessed multiple times. The MDT were uncertain over the patient's ability to make her own discharge decision. Further complicating matters, the patient was open to the possibility of residential care although she wished to return home,

and could see merits in both. In addition, her relatives supported a move to residential care, and the team were concerned whether the patient was “suggestible” to their wishes, rather than pursuing her own. Discharge planning meetings were held and the MDT revisited the patient’s capacity over time, which remained unclear and caused a degree of conflicting opinion about her capacity within the team. Ultimately, after a formal assessment of mental capacity by the consultant specifically relating to the issues of discharge, Mrs Woodward-Jones was judged to lack capacity and was discharged into residential care in accordance with her, and her relative’s wishes.

The liaison nurse described the patient’s prior involvement with psychiatry services and her transfer to a specialist dementia ward so that full assessment of Mrs Woodward-Jones’ cognitive state could be undertaken.

INT ...The community nurse that came to visit Mrs Woodward-Jones on the ward, whilst [consultant] was having a ward round so we actually had a discussion and then came and fed that back to [consultant] who was delighted that she would be going to a different ward to get the proper assessment.

MP: So what sort of things did you...?

INT: We went over what we knew about her, what the staff thought...what we knew about her from the past, what the staff on the ward had found whilst she’s been here, what I’d witnessed while I’d been here and (CPN) who had previous knowledge of the lady came in and did another quick um ... assessment of her mental state and her capacity and orientation and she found that she was more confused here and she was presenting, not as well as she had done at home.

Interview: Liaison Psychiatry Nurse 02sl-0106

Mrs Woodward-Jones’ mental state prior to admission was compared with her cognition on the ward and was noted to have declined. The consultant’s approval of the full cognitive and psychiatric assessment indicates that the main issue was the patient’s cognitive status

which was to be fully assessed by specialists in cognitive decline who could explore mental capacity in relation to place of residence in more depth.

Similarly, Mrs Porter was also admitted to hospital during an episode of 'wandering'. She was found in the street by the police late at night and had become unwell. Early in the admission, her family informed staff that they were concerned about the patient's safety at home. During the admission, the MDT found it difficult to engage with the patient, and requested support from the liaison psychiatric team. There were concerns over the patient's mood and general cognitive state. The patient was thought to have long-standing psychiatric issues and was considered reserved in nature, with a degree of cognitive impairment. Her family verified this. A consultant psychiatrist assessment of Mrs Porter noted her character and the progressive cognitive decline of the patient, illustrating the emphasis on her cognitive state with regard to making decisions about residence.

[...] She reports mild recent low mood. Worse in the morning but no other biological symptoms and no depression or depressive cognitions. Her affect is reactive. She may have mild to moderate depressive episodes but I don't think she's severely depressed. I wonder if much of her timidity and confidence reflects personality. [...]. She has probable mild cognitive impairment in clear consciousness and I note from the account of years of progressive decline today she scores 20/30 on the MMSE and her decreased confidence when she didn't attempt some questions. So I think this is probably an underestimate. [...]. I note plan of patient's discharge to a residential home near her husband. I'll review her there post-discharge. Aim to meet up with the family at this stage to get more collateral history.

Medical records: Mrs Porter 30108, old Age psychiatry Consultant review

The consultant was asked to review Mrs Porter's mood and cognition rather than to explicitly clarify uncertainty around mental capacity. Unlike Mrs Woodward-Jones, it is rather unclear how the decision regarding capacity was reached, and whether Mrs Porter was indeed assessed as having or lacking capacity to make her own decision about place of residence on discharge. I was present at the discharge planning meeting, and observed that the patient's son felt that his mother should leave her sheltered accommodation flat and

move into the same residential home as his father. The patient was not present, and this indicated that a best-interest decision was reached by the MDT and the patient's son. Furthermore there was no record of the process of capacity judgement in this case. I observed no discussions about mental capacity at MDT meetings, and nothing was specifically recorded in the patient's records about assessment of capacity relating to discharge. It could be assumed that the MDT and psychiatric team decision was informed by the principles of the MCA, whereby an assumption of capacity should prevail unless there are clear circumstances for doubting this. However doubts and concerns by the MDT were centred around the patient's cognitive status, and her ability to make decisions. The consultant and liaison psychiatrist gave a differential diagnosis of cognitive impairment (mild). In addition, nothing was documented about the patient's wishes and preferences relating to discharge – only the views of her family.

Comparative cases

Similarly to Mrs Porter, in the cases of Mr Miner and Mr Priestly concerns about capacity were implicit and although discussed at MDT meetings, not clearly documented in patients' records. Formal capacity assessment was not evident, however both patients were considered to have capacity and returned home in accordance with their wishes.

For several other patients for whom cognitive issues were dominant, the decisions about capacity were less equivocal than the cases of Mrs Woodward-Jones and Mrs Porter, but on the whole the audit trail was better documented. However, as noted in section 5.2.3, evidence of formal assessment of capacity was often lacking, especially in the cases that were clear-cut judgements.

Focusing on the cognitive deficits of people with dementia may position people negatively through failing to acknowledge their skills and abilities which remain intact (Sabat and Harre, 1992). This may further lead to assumptions about decision-making ability, resulting in people with dementia being excluded from the process as their expressed views and preferences are undervalued or misinterpreted. Medical emphasis on cognitive problems such as lack of insight was also perceived to indicate a lack of mental capacity, which increases the chance of a loss of rights for people with dementia (Bond *et al.*, 2002), including decision-making rights afforded through the MCA.

7.3 Who makes capacity decisions?

Having considered how practitioners made sense of and enacted binary notions of mental capacity in equivocal cases, I move on to consider which practitioners enacted this definitive judgement on mental capacity and how this impacted on the discharge decision. I consider the role of the senior medics and the multi-disciplinary team to illustrate who decides whether the person with dementia has or lacks capacity to make their own decision regarding place of residence. This opens up discussion of whether the appropriate professional assumes decision-making responsibility to enable the person with dementia to have access to fair assessment, and are enabled to retain independence and autonomy in decision making in keeping with the provisions of the MCA.

The Code of Practice (4.40) states that although multi-disciplinary teams can be involved in the assessment of capacity for treatment or examination, ultimately it is the role of the professional responsible for the treatment of the patient who must ensure that capacity is assessed. This becomes rather ambiguous in relation to hospital discharge which is not a treatment, and therefore open to interpretation as to who is best-placed to assess mental capacity. The findings affirm that consultants predominately undertook such assessments, rather than social care professionals. Interpreting examples of experiences captured in this research enables a challenge to traditional models of medical decision making, in relation to mental capacity.

7.3.1 Senior medics and decision making

It emerged early in the research process that the MDT engaged in discussion about mental capacity, but it was unclear whether this was a process of joint decision making.

Based on my observations to date so far, (pause) all capacity decisions tend to be discussed in the MDT but decisions do seem to be made by the consultants and sometimes are made on the basis of not what's just discussed at the MDT but sometimes just through questions asked during the ward rounds. So maybe it's a combination of those things, but even at the MDT I do feel that it's the consultant who seems to have the final say...

Reflective notes: 240708

Although the MDT was involved in the decision-making process, the majority of practitioners ultimately presumed that the consultant would and should assess capacity to make decisions regarding place of residence on discharge from hospital. This was contingent on negotiated communication (Ellingson, 2005) around mental capacity. Many practitioners (including the consultants themselves) expected the consultant to take this responsibility, pointing to traditional power relations in the medical hierarchy (Lupton, 2012).

...So I would say, team decision would probably orientate where we go with regards to capacity but I would say at the end of the day as with most things in hospitals the buck stops with the consultant, so they make the shout. (MP: And do you think that's the right...?) ... I think it should be, I mean at the end of the day, usually one person has to make the decisions and traditionally it's been the consultant...

Interview: Junior Doctor 02sD-1505

Consultants accepted this was part of their role, with the support of the MDT and sometimes with input from psychiatry, but that they had the ultimate responsibility for deciding if the patient had or lacked capacity relating to place of residence.

...it ought to be a team decision. There's no rule that it has to be made by a specific person. I think that very often the team looks to the consultant to make the final decision and document that.

Interview: Consultant 01BsQ-1212

However consultants also expressed the magnitude of this responsibility. A Consultant at Site 1, stated “*Who are we to play God with peoples' lives?*” This signifies a shift away from traditional medical models of care and decision making (Burcher, 2014) in which ‘Doctor knows best’ attitudes, which were once accepted as commonplace have been challenged (Stone, 2015) and a move towards more inclusive approaches to decision making enshrined by the MCA.

7.3.2 Other practitioners and decision making

As the research progressed, new cases emerged which suggested that practitioners other than consultants could play a key role in the assessment of mental capacity. This challenged what I had already observed, with the consultant as decision maker.

...various key members of staff pointed out three cases where there are complications with relation to capacity, where the patient has memory problems and where there are going to be some interesting decisions about discharge, one of which involves an IMCA decision [Mrs Parker] ...that was one of the key cases I was hoping to recruit from this next site. Another case there's a kind of strong mismatch between what the patient wants and what the patient's son wants [not recruited]. There's another case, a third case, [Mrs Gardiner] which is a case whereby there's a strong mismatch within the MDT, so I think that's a really important one to have because I don't think that's a sort of case I came across at the last site and this one, this particular case is where the social worker for the case is dominating in terms of what they think the right decision is for this patient, the social worker is seen as the decision maker, the consultant is backing that up saying leave it to the social worker but there was a disagreement from the whole rest of the MDT as for the plan of action for this case.

Reflective notes: 090309

Although the MDT played an important role in negotiating mental capacity through discussion, the consultant headed up the team and was therefore became the decision maker. The majority of practitioners agreed that the consultant should decide if the patient had capacity to make decisions about their residence. However, a minority of healthcare professionals, primarily from Old Age Psychiatry, suggested that social workers should make the capacity judgement. Mainly, practitioners regarded senior members of the medical team as best placed to assess mental capacity. However, once the patient was medically stable, the decision was no longer about treatment and it might be suggested that decisions concerning residence are therefore social issues. A complicating factor appeared to be the management of ongoing, chronic medical conditions which required further care and

treatment in the community. So although the acute medical issues were resolved, some residence decisions retained clinical elements.

Comparison of cases with other practitioners centrally involved in the decision-making process illustrates the different values which non-medical practitioners can bring to bear influence on assessment of capacity for people with dementia. Mrs Parker was the only patient who had her capacity assessed by an Independent Mental Capacity Advocate (IMCA). IMCAs are Independent Mental Capacity Advocates who provide legal safeguards in relation to the MCA and assist unsupported people who lack capacity to make decisions. Mrs Parker had no relatives or friends to advocate on her behalf. Although the role of the IMCA is to determine the best interests of a patient rather than assess mental capacity, in this case the IMCA did assess Mrs Parker's capacity in relation to her ability to decide whether to return home or go into nursing care. This arose as the social worker on the ward was unable to assess the patient, as the available social worker was male, and the MDT understood that Mrs Parker was fearful of men, and on this basis, input was sought from the IMCA. This illustrates good practice through a person-centred approach, with the recognition of, and meeting individual needs and preferences of the person with dementia (Kitwood, 1997), in an attempt to maximise Mrs Parker's ability to communicate her wishes.

The consultant had already completed the assessment and the IMCA re-assessed this whilst advocating for the patient. The IMCA arrived at the same decision as the consultant, that the patient lacked mental capacity to make her own decision about going home and agreed with the MDT that a best interest decision of a discharge into 24-hour care was the most appropriate. Some of the MDT queried whether the IMCA would mount a challenge to the consultant or just agree with the consultant, however during an interview, the IMCA expressed this as a central part of their role, and they were more inclined to presume capacity than medics.

We are often involved in discussing and challenging capacity assessments. If we may... this is part of the job in a sense because we might feel that the person's got more capacity than the medical staff feel that they have [right]. It's usually that way rather than the other way.

Interview: 02sP-0807

The IMCA experientially recognised that medical assumptions about dementia and mental capacity had potential to disadvantage the person with dementia (Lyman, 1989; Bond, 1992). However, non-medics often perceived their role as supportive, and that capacity decisions relating to place of residence should be made by others in the team.

In particular, therapists pointed to their lack of authority to make this decision. During an interview, one of the OTs at Site 1 described how they were “not allowed” to assess capacity, but “do this informally as part of their functional assessments”. However, after MCA training, an OT raised the point at a MDT/Handover meeting on Ward A, Site 1 that anyone can be the assessor and decision maker of mental capacity. The physiotherapist at Site 2 stated that she was not qualified to make such decisions. “I don’t think I’m qualified to make any decision on a patient’s capacity. I can make a perception of what I think they’re like.” The MCA does not define who should or should not assess capacity, but states that different people will be involved in assessing capacity dependent on the decision at that time, and emphasises the importance of the assessor’s appropriate skills (Section 4.38 – 4.43). Therefore, whether medical and clinical skills are necessary to make decisions about place of residence on discharge from hospital can be legitimately challenged.

7.4 Chapter summary

This chapter explored how practitioners interpret and enacted binary notions of mental capacity required by the MCA, when considering whether people with dementia can make decisions about place of residence on discharge from hospital. Critically exploring how the binary conceptions are applied in practice, the findings challenge the appropriateness of this dichotomous view of mental capacity, by demonstrating that people with dementia frequently could not be easily defined as either having or lacking capacity to make this decision. Patients with uncertain mental capacity were initially classified as ‘borderline’, however, practitioners needed to extensively evaluate and reclassify their status to meet with the provisions of the Act. The legal requirement to categorise decision making in a dichotomous way created challenges for practitioners who struggled to place people with dementia into narrow categorisations of mental capacity. They therefore used conceptual strategies to categorise patients based on medical, behavioural and cognitive discourses which were often associated with personal deficits rather than decision-making ability.

Given the importance of such decisions concerning autonomy, freedom, agency and choice it might be suggested that binary distinctions between capacity and incapacity inhibit practitioners in upholding the rights of vulnerable people in this setting. Forcing patients with dementia to fit with binary notions of capacity and incapacity by conceptualising capacity in cognitive terms (Owen *et al.*, 2009a) risks obscuring the position of people with dementia by an over-reliance on traditional medical based approaches to decision making and focusing on behavioural and cognitive deficits of dementia (Sabat, 2001). More structured and inclusive models of decision making may support the involvement of the person with dementia in such key decisions.

Although the MDT played an important role in contributing to work through the complexities of 'fitting' borderline patients with the dichotomous capacity status required by the Act, in the majority of cases, senior medics ultimately made judgement about whether the person with dementia could make their own decision about place of residence on discharge from hospital. Although members of the team and other practitioners could make a significant contribution to the capacity judgement through discussions in which the capacity status of the person with dementia was negotiated (Ellingson, 2005), traditional medical models of decision making (Lupton, 2012) were applied.

In this medical environment, the consultant has a long established tradition of being in a position of power, acting as the decision maker, occupying the most senior role with responsibility for the wellbeing of patients (Freidson, 1975; Coombs and Ersser, 2004; Lupton, 2012). However although traditional doctor-patient roles have been contested in relation to decisions in other contexts such as treatment decisions (Kaba and Sooriakumaran, 2007) this does not seem to extend to residence decisions for people with dementia. Due to the largely social nature of these decisions, the findings support that non-medical practitioners such as social workers should be given equal consideration in determining the best person to undertake capacity assessments relating to discharge for people with dementia.

Chapter 8. The involvement of patients and their relatives in decision making and discharge outcomes.

8.1 Introduction

The previous three chapters explored the interlinked aspects of interpretive work of mental capacity judgements, comparing narratives with assessment, and addressing binary notions of mental capacity in the enactment of the MCA when making hospital discharge decisions for people with dementia. To address the final area of enactment of the MCA, and the fourth objective of this research, I examine the involvement of people with dementia once the capacity decision was made. I explore whether and why people with dementia were included in, or excluded from, making the decision about where they would live. I focus on the experiences of patients who required a best interest decision to be made on their behalf, as they were deemed to lack mental capacity to make their own decision about place of residence on discharge from hospital. Best interest decision making is set out in section 3.2 of the MCA, which practitioners must follow when a person is assessed as lacking in capacity to make a specific decision. Those who had capacity, had the right to, and made their own decision. Over half of the participants in this research were judged to lack capacity to make their own decisions about place of residence on discharge from hospital.

The experiences observed for these 16 patient cases are drawn upon to illustrate: if and how patients were involved in decision making; followed by the involvement of family; and finally, the discharge outcome is explored, addressing whether this met the best interests of the person with dementia, and from the perspective of whom. Two patient cases are explored in particular detail – Mrs Baker, who was discharged home, and Mr Coleman who was discharged to nursing care. This contrasts a positive best interest decision and resultant discharge outcome, with a more negative experience (as defined by relatives). These cases are further compared to the 14 other best interest cases to highlight differences and commonalities in processes and outcomes.

8.1.1 Tensions between autonomy and beneficence in best interests

The desire to protect people with dementia from harm versus recognition of the necessity to facilitate autonomy in the context of hospital discharge (Strang *et al.*, 1998; O'Keeffe, 2001; Brindle and Holmes, 2005; Stewart *et al.*, 2005) in accordance with the MCA, emerged from

the data as a key tension, which underpinned the difficulties practitioners faced in the process of making best-interest decisions in relation to place of residence. During an interview, a senior medic summarised this tension and described the will to uphold the wishes and preferences of individuals and balancing this with the desire to protect vulnerable people.

Best interest in our frail elderly group is um, number 1 is taking their wishes into consideration. Number 2 is are their wishes realistic and number 3 is what are the risks involved and also yeah, protecting their health and wellbeing and trying to find an environment and a place where their health and wellbeing is maintained, they're not vulnerable so reduce vulnerability ... and respecting their wishes I think.

Interview: Consultant 01BsE-1610

This quote illustrates the factors under consideration in best interests, and the moral and professional wish to protect patients from physical harm by ensuring the patient was discharged to the most appropriate environment. These tensions between autonomy and non-maleficence are explored in this chapter to understand whether this is an approach influenced by paternalism and reflects commonly accepted medical models of decisions making which are applied to decisions of residence, or approaches which encourage and uphold the rights of people with dementia.

One of the core values fundamental to the MCA is to maximise the ability of vulnerable people to make decisions, or participate in the decision-making process as far as they are able to do so (Department for Constitutional Affairs, 2007). The emphasis is on empowering people and retaining autonomy through inclusion. Traditionally, people with dementia have been assumed to be incapable of making their own decisions and others have taken decisions on their behalf, leading to disempowerment (Hall, 2009). Prior to the introduction of the MCA, practitioners were not legally required to involve patients in such decisions (Bartlett, 2008), although this would have been considered good practice.

However, there is increasing recognition that people who have historically been excluded from decision making can be enabled to make their own decisions, and if not, to at least

contribute towards the process, which is reflected in these changes to legislation (Bartlett, 2008). Although a person has been assessed as lacking capacity to make a specific decision, the MCA stresses the importance of involving the person in working out their best interests. Paragraphs 5.21 – 5.24 of the Code of Practice state that every effort should be made to encourage and enable the person who lacks capacity to take part in making the decision. Furthermore, their past and present wishes and feelings, beliefs and values should be taken into account (paragraphs 5.37–5.48), and all relevant circumstances should be considered, which the person would take into account if they were making the decision (Section 5.13).

I was therefore interested in exploring if patients with dementia were included in decisions about place of residence on discharge from hospital, if all patients were included or if some were excluded, and furthermore how they are involved or denied participation. This involved seeking the views of all participant groups on involvement in the discharge decision and observing how decisions were made in practice. Considering the challenges of exploring patients' wishes and preferences and barriers to patient involvement enables a critical approach to evaluate involvement.

8.2 Patient involvement

Exploring the patient's wishes was considered the first stage in making a best-interest decision. Practitioners recognised the importance of exploring the wishes, values and preferences of patients in relation to place of residence on discharge, however the findings suggest that this was not always translated into practice. One senior medic explained that irrespective of capacity, meeting the best interests of the patient required exploring their views and trying to achieve the right discharge outcome for the patient.

It would depend on the circumstances, there's obviously emergency medical situations and making those best-interest decisions would go on the clinical team there and then. There's you know housing and different things like that aren't so much best... well there in best interest and in making those decisions it's important to get an idea of what the patient would want, what the patient does want, whether they've got capacity or not it's still important to try and fulfil their needs and you know expectations to an extent or to whatever is reasonable, and get an idea of

the family circumstances and if there's no family or if there's no advocacy for the patient's ideas then you know there is the IMCA, the Independent Mental Capacity officer's a sort of group that can help as well.

Interview: Registrar 02sH-2705

However, although practitioners were clear in their intentions to explore the wishes of the person with dementia, there was often a lack of evidence that patients had been included in the decision-making process. In the case of Mr Coleman, I observed the consultant exploring his wishes and preferences for discharge as part of the ward round. However, the only evidence of wishes for discharge recorded in his medical notes were those of his wife, sought by the OT.

12.30 S) – telephone conversation to Mrs Coleman, clarified that she wants patient home, agreed to carry out site visit re option of downstairs living, plan is site visit on (Date) plan is reassessment of bed transfers.

Medical records: Mr Coleman 031208

Although nothing was recorded in medical records about Mr Coleman's wishes, a conversation I had with his social worker indicated that the team were aware of the wishes of both the patient and his wife.

Just before I went along to have a chat with the patient, I bumped into the patient's social worker [...] I asked the social worker if the patient knew (the discharge outcome) and she kind of waited a while and she had a think about it and then she wasn't sure. She said that she knows the patient wants to go home and she knows the patient's wife wants him to go home but that there's some issues in terms of the patient's skin and that the patient needs to be turned every so often so that he doesn't get pressure ulcers.

Observations: 021208

This may reflect assumptions that patients will always wish to go home, and that only exceptions to this are noteworthy, and considered contrary to social norms and routine practice. However, concordance with the MCA requires that such discussions must take

place and must be documented to evidence that the wishes and preferences of vulnerable people have been sought and respected when possible.

Considering if, and how, the views and preferences of people with dementia were sought, it became clear that it was often difficult to gauge to what extent patients were actually involved in working out their best-interests. Having observed the interaction between Mr Tyler and the consultant, in which it was disclosed to the patient that his family disagreed with his wishes to return home and could no longer support him, it was unclear whether both Mr Tyler's family and the MDT had excluded him from taking part in this important decision about his future, or whether his diminishing cognitive abilities meant that he had forgotten earlier conversations.

I felt really sorry for the patient, I felt that he just looked so sad when the consultant was asking him all these questions and he just looked like he was looking around at everyone for an explanation as to why they were talking about these risks. He just seemed really surprised when it was put to him that his family couldn't help him out and it just kind of made me wonder whether the patient has actually discussed this with his family or whether his family shared these concerns with him and have even put it to the patient that they might not be able to support him. It looked like it was new information to the patient but it may not be, his family may have mentioned this to him before, he may not remember it, he may not want to acknowledge that his family can't support him or he's not as able as he once was. So it's really difficult to get to the bottom of and to understand what's going on in the situation but I just felt so bad for the patient and the patient had later on that day, told me how he was feeling so down and my heart really kind of went out to this patient at that time.

Reflective notes: 080609

What was clear from observing this interaction was that the situation seemed new to Mr Tyler, and this caused him pain and upset. If he had been made previously aware of these changes in circumstance, he had not retained or understood this information. It was unclear whether this new situation had been explained, as this was undocumented. His wishes around this changed context seemed under-explored. If his wishes had been sought, his

family and the team could not uphold these, and their decision that Mr Tyler should be discharged into care was carried out.

Exploring the preferences, wishes and values of patients with dementia could prove challenging for practitioners. Much of this was bound up with problems in communication with people with dementia, and practitioner perceptions about the wishes of the person with dementia and whether these accorded with their views of a realistic discharge outcome, informed by cognitive deficits. Mrs Baker wished to return to live in her bungalow with the support of her family. The consultant described Mrs Baker as clearly being able to articulate her wish, and to express this consistently, which strongly influenced her best-interest decision.

I think on balance, on a few occasions it came across that Mrs Baker doesn't have capacity and lacked insight into her difficulties, yeah. But she was consistent that she wanted to return home. That being the case, so we know her previous wish that she wants to return home and getting her back home was not a big challenge, there were only a few issues which we had to address and although, on balance, we felt she lacked capacity and insight, we decided to respect her wish and give her another chance to return home. So that was probably in her best interest I felt, at that stage, for her to be in her own environment as long as possible with her supporter.

Interview: Consultant 01BsE-1610

Although Mrs Baker was judged as lacking capacity, she was able to make her wishes known to the team. She clearly voiced her preferences when specifically asked during ward rounds. Mrs Baker made her wishes plain to a number of parties involved in the decision-making process. The consultant and medical team discussed Mrs Baker's wishes with her during the ward round. The OT and social worker were also aware of Mrs Baker's desire to return home. This was then documented in her medical records.

Ward round with [Consultant] [...] Patient keen to go home, feels daughter's very supportive and will help her manage. Not willing to consider alternative care and says 'no way'. NB; cognitive impairment MMSE less than or equivalent to 15 out of 30 at present. Home assessment

visit with OT did not go well, thinks there won't be any potential problems re. going home; not sure why can't. Impression; medically ready for discharge, lacks insight of the problems, not sure if has mental capacity, needs a full assessment. Plan: await planning meeting, discussion with MDT, consider repeat home visit, may need formal capacity assessment.

Medical records: Mrs Baker 011008

Documenting the patient's wishes ensured that all practitioners involved were aware of her desire to return home irrespective of the capacity decision, demonstrating good practice in sharing key information about the person's wishes. During an interview and conversations with Mrs Baker, she expressed going home as a natural and normal decision, which needed no consideration at all. She had been admitted from home and would return home. Mrs Baker's family were well aware of their mother's wishes and felt that they should honour these as far as possible. Mrs Baker's wishes were further explored in a discharge planning meeting with the social worker and her family. However, the decision had already been reached by the MDT and Mrs Baker's family, that a return home would be feasible, if the patient would accept the proposed care package. Also, the ongoing support of Mrs Baker's family seemed more critical than the patient's strong wishes.

In contrast, Mrs Wright was another patients who despite lacking capacity was clear in her wishes to return home. I observed Mrs Wright spontaneously expressing her wishes to nursing staff and these were documented in her records. However, despite her understood wish to go home, Mrs Wright was discharged into residential care. Like Mrs Baker, she also lived alone, but her daughter felt unable to continue to provide support to her mother at home and felt a placement in care would be best. This further demonstrates the influence of family support over patients' wishes and preferences.

Mrs Baker was one of the exceptional cases of patients who were present at their discharge planning meeting/case conference. Furthermore, she was the only patient involved in this process who was deemed to lack capacity to make their own decision, but returned home as she wished. Although the MDT team had included Mrs Baker in the process, during interviews with her family, they described her involvement as "tokenistic" with negative short-term and long lasting repercussions.

INT: ...we're all sitting here, it's like the X-Factor. There's four of us sitting there and they wheel her in [to the planning meeting] and you're saying to her 'this is what we decided on your behalf'. Now she was as good as gold – I think you MP were the last to leave – as soon as you went out the door she went absolutely ballistic. [...] She said, 'thanks very much!' She says, 'family; you make me sick the lot of you and was in temper and she walked through the door and we got (son's name), the brother, he's the favourite you know, we says, 'you see to her'. 'Open that bloody door' she said...and he said 'mam' he says, 'I can't, you're in the way'. 'Open the door or you will go through it!' And she stormed off to her bed...So we went in to try and talk her round. 'Just get away the lot of you, family, yous are a load of rubbish'

[Later in the interview]

INT: if you look at it from her point of view, we're all there...this is a woman who's been independent all her life, she has this few months of illness, she comes in and we're all deciding what's going to happen to her. We knew, and we told the social worker but it was completely disregarded.

Interview: Mrs Baker's daughter 131008

Mrs Baker had been denied the opportunity to act as an autonomous citizen through participation in decision making (Birt *et al.*, 2017). This also affected family relationships. On interview three months post-discharge, Mrs Baker's daughter described how several weeks later, their relationship was still negatively affected by the process, and her mother was often convinced that her family were making plans for her care behind her back.

...she didn't trust anybody after that [planning] meeting. She didn't trust anybody. If you were ...you know because [you] had to go into the bedroom to use the phone in there or the kitchen...because she had the television that loud so if anybody rang you used to take the phone in and she'd say, "What are you talking about? Come in here, come in here!" she just never trusted you.

Follow-up Interview: Mrs Baker's daughter 110209

Despite the desired discharge outcome being reached for Mrs Baker and her family, her family rejected the claim that their mother was really involved in the decision-making process. As their mother was included only at the end of the meeting, once the decision had already been made, they did not consider this to be meaningful participation. Furthermore, they had found this limited involvement unhelpful and damaging. This poses questions about earlier involvement of the patient in the decision-making process, and involving patients more fully. In Mrs Baker's case this may have been beneficial for all parties, and a much more positive experience for the patient and her family. Enabling Mrs Baker to make her own autonomous contribution to the meeting would have ensured her wishes and rights were recognised and respected (Boyle, 2014).

Although Mrs Baker's family clearly felt that their mother should have been included in the decision-making process, (albeit more fully involved), in other cases relatives expressed concerns about involving the patient. These concerns were primarily about the ability to be open and honest with practitioners in the presence of the person with dementia. Mrs Wright's daughter did not wish for her mother to be present at the planning meeting. She was concerned that her mother would intentionally cover up many of the problems she had been struggling to manage prior to admission.

...the daughter expressed to me she didn't want the patient to be there as she felt that she couldn't be as open if her mother was in the room and also that her mother might not give a true account of events but would say that she was managing absolutely fine and would be able to communicate that she was but that this in fact wasn't true.

Fieldnotes: Planning meeting for Mrs Wright 250708

During the planning meeting, Mrs Wright's daughter willingly disclosed many details about a strained relationship with her mother over the last 30 years.

She said that her mother had a nasty side and although she presents as a kind of sweet elderly lady that she there's a side to her that nobody really sees.

Fieldnotes: Planning meeting for Mrs Wright 250708

Mrs Wright's daughter also commented that she knew her mother would hate her for putting her in a home and that her home was her pride and joy, however the social worker did not seem to question whether Mrs Wright's daughter was indeed acting in her mother's best interests or her own. Family play an important role in preserving the rights of people with dementia (Kontos *et al.*, 2017) and in this case, her daughter had not supported her citizenship. In contrast, Mrs Tanner's daughter excluded her mother from the planning meeting but described different reasons.

...the daughter was a little upset at the very beginning, she didn't want her mam to be present in the meeting even though the social worker was encouraging this, she said that she didn't feel she could be as open about her mother if her mother was present, particularly about things like personal care, and she said that this is because her mam would be embarrassed and then that would make her embarrassed.

Fieldnotes: Planning meeting Mrs Tanner 290708

Although this was well-intentioned, her daughter's actions were still exclusory. These examples illustrate that sufficiently involving people with dementia in the planning process was dependent on the attitudes of practitioners but also contingent on the support of family. Comparing cases of inclusion and exclusion from the decision-making process illustrates that families play a pivotal role in upholding the wishes of the person with dementia and enabling or preventing the involvement of the person with dementia as citizens (Kontos *et al.*, 2017). In this study, LPA for health and welfare was not in place for any of the participants, therefore in enacting the MCA, practitioners were faced with balancing the wishes of patients and their families, in ascertaining what was in the patients' best interests. This raises the question of whether practitioners should prioritise the perspective of family over the person who lacks capacity, which may compromise patient involvement. This involves a complex set of commonly accepted social relations, in which families often take over decision making from people with dementia. This commonly happens over an extended period of time as the decision-making ability of the person with dementia is thought to decline as dementia becomes more advanced, and shared decision making transitions into substituted judgement (Samsi and Manthorpe, 2013). Although joint decision making is often embedded in family relationships and can be perceived as the

desire to protect their relative, this may limit the rights and autonomy of the person with dementia.

8.2.1 Challenges of exploring patients' wishes and preferences

Although Mrs Baker provides a clear example of someone who was steadfast in her wishes and able to communicate these to practitioners and family, other patients were less able to express their wishes. Some patients were less vocal or certain of their wishes, and by comparison were judged ambivalent, or open to suggestions about their discharge. For example Mrs Tanner agreed to a care placement as suggested by the MDT. She was happy for her daughter to decide where she would live, and in interview stated that she trusted her daughter to make that judgement on her behalf. Although vocal and consistent in his wishes to return home, Mr Collier was considered particularly ambivalent about practical arrangements for living at home, highlighting tensions between acknowledging the wishes of patients and enacting these through the decision-making processes of best interests. A consultant psychiatrist described the difficulties in trying to elicit the personal preferences of the person with dementia who lacks capacity.

One of the things that you're trying to balance, and I think it's a difficult act, if you're trying to get a best-interest decision, you are being asked to consider their current wishes and if their current wishes are emphatic and loud then I think inevitably and possibly, to some extent, correctly, they carry a bit more weight than the person who is ambivalent, you know, will sort of, in an offhand way, mention that they would rather go home but doesn't seem that bothered really. So I think ... a good best-interest assessment would take that into some account but clearly, we have to be careful that people who are emphatic but quiet don't get overlooked

Interview: Consultant Old Age Psychiatrist 01CsR-2711

Interpreting the current wishes and preferences of patients with dementia was often regarded as complicated, leaving practitioners unsure of how past wishes corresponded to the present. For example, Mrs Miller's nephew and the MDT felt that the patient expressed herself as though she was living in the 1950s. She mistook the junior doctor for her brother; talked of her deceased mother as though she were alive and sometimes thought her

nephew (in his 60's), was a young boy. She also thought her husband was alive despite being a widow for many years. She was unsure about where she lived prior to admission and why she was in hospital. Although difficult in terms of establishing the patient's perspective, resultant best interest decisions in such cases were considered straightforward by practitioners and the wishes of the family became central. In Mrs Miller's case, both the team and her nephew agreed that a care placement was now necessary to best meet the patient's needs. The team were confident that her nephew's motives were genuine and her nephew felt that his aunt would have agreed.

As I say I get quite emotional about it but I know it's for the best; I know this is where she's...where she's got to go and if she was in here sitting now, with all her faculties, she'd be agreeing with me.

Interview: Mrs Miller's nephew 280708

...she can only hold the information while we're having the conversation, she can't use it afterwards but I asked her once if this was all right and explained and she said yes she wanted to be looked after and she'd forgotten me and she'd forgotten we'd talked about it but when I went back we went through the same process, yes she wanted to be looked after and she trusted her nephew to sort it for her.

Interview: Social Worker 01AsA-0508

In this case, Mrs Miller struggled to express her current wishes in a way which could be understood in terms of place of residence by the MDT or her nephew.

Problems with speech and language also presented practitioners with difficulties in ascertaining the patients' wishes and preferences. Mr Fisher was an example of a patient who had severely limited speech, and despite specialist involvement of the speech and language therapy (SALT) team, the MDT seemed reliant on his wife to represent his wishes. Similarly Mrs Parker was considered difficult to engage with due to communication problems resulting from Parkinson's disease. Mrs Parker often engaged with practitioners through nodding or single-word responses only, leading to the involvement of IMCA services to explore her wishes and preferences.

Although personal preferences were sought, they often seemed to be outweighed by meeting the practicalities of the discharge, for example, the provision of care and support, and whether relatives and or social services could meet these medical needs. Although attempts were usually made to explore the perspective of the patient, their preferences and wishes appeared secondary to what the MDT considered the right discharge outcome. The psychological needs of the patient were considered important; however safety and the prevention of risk appear to be the main concerns regarding the patient's welfare. Whilst Section 5.38 of the Code recognises that wishes, feelings, values and beliefs will influence best-interest decisions, it also states that the final decision must be in the persons' best interests. Establishing these often required the involvement of others.

8.3 Family involvement

When practitioners encountered difficulties exploring the wishes of patients with dementia, relatives were expected by practitioners to represent and act on behalf of patients who lacked capacity to make their own decisions regarding residence on discharge. Thus practitioners involved relatives to advocate on behalf of the patient. In this section I examine the extent of family involvement and how conflicting concerns between the person with dementia, family and practitioners were addressed.

Family were involved in the majority of the 16 best-interest decisions observed in this research. This was usually direct involvement but in some cases their wishes were expressed via practitioners. Three cases – Mrs Woodward-Jones, Mrs Gardiner and Mrs Parker – had no family to help ascertain their best interests. Both Mrs Woodward-Jones and Mrs Gardiner had close friends who were directly involved in trying to work out their best interests. However, Mrs Parker was 'unbefriended' and an IMCA worked with the patient, a family friend (who was happy to provide information but could not provide support and did not want decision-making responsibilities), a careworker and the MDT to establish her best interests. This is in keeping with the MCA, and in cases when there is no relative willing or able to act as an advocate on behalf of the person, the Code of Practice recommends that an IMCA should be available to represent the person's best interests (Section 5.50).

However, for the majority of patients who lacked capacity to make their own decision about place of residence, it was family involvement which was key to securing their best interests.

The Code of Practice recognises the important role families can play in establishing the best interests of the person who lacks capacity, recognising their role as someone who can represent people who lack capacity and should be consulted with (Section 5.49) to work out what they think would be in the person's best-interests and as information providers on the person's wishes and feelings, beliefs and values (Section 5.53).

8.3.1 Judgements on relatives as advocates

The MDT made judgements as to whether they considered relatives to be upholding the patient's best interests and not only serving their own personal interests. I observed this as an interpretive and evaluative process, based on assumptions around the relationship between the patient and their family. Practitioners expressed personal judgements about families and, in general, most relatives were assumed to have the best interests of the patient at heart, reflecting traditional social values of the role of family. The assumption that families wanted what was best for the person was evident, even in cases when the MDT considered this to be detrimental to the patient's relatives.

There were a minority of best interest cases in which the MDT were unclear or suspicious of the preferences and wishes of relatives such as Mrs Woodward-Jones, Mr Shearer and Mr Dyer, which in the main seemed to stem from disagreement between the MDT and the relatives about the most appropriate course of discharge for the patient. In an interview, the ward manager commented on the subjective nature of assessing whether families are upholding the best interests of the patient, describing Mrs Fisher's intentions for her husband.

...She [his wife] is next of kin and the patient's advocate would seem appropriate. At no point did we feel as though she had anything other than his best interests at heart, but how do you measure that?

MP: How did you measure it?

INT: Subjectively.

MP: And what do you mean by that?

INT: its assumption really isn't it? ... I mean she's already got his money so she wasn't going to benefit from that ... if she'd had the physical abilities and she'd been able to cope with incontinence I think she would have had him home [...] But it is it's assumption at the end of the day. How do you measure love? She adored this man but I can't tell you how I measured that either, it was just I saw the way she interacted with him and the questions she asked and her whole approach and you know? You can't measure it. Unless you can get us a love-o-meter.

Interview: Ward Manager 01AsF-2210

The ward manager referred to Mrs Fisher as her husband's "advocate", however she highlighted the vulnerable position of Mrs Fisher and her physical limitations of being able to care for her husband at home. The MDT were confident that Mrs Fisher's wishes to take her husband home reflected those of her husband but felt that this outcome would be in neither of their best interests. However, the appropriateness of relatives to act as advocates and safeguard patients was often difficult for families, who felt poorly equipped to challenge the views and decisions of healthcare professionals about the medical 'facts' of the discharge decision (Emmett *et al.*, 2014).

8.3.2 Planning meetings and family involvement

Although details about the patient and their home circumstances were often sought informally, planning meetings or case conferences were the main forum in which relatives could directly participate in discharge decision making in the patient's best interests. Although not described as a 'best interests' meeting, these enabled health and social care professionals, multiple family members, and in a minority of cases the patient too, to share their preferences and expectations and discuss plans for the patient post-discharge. The purpose of these meetings was to address the needs of the patient with dementia and identify any challenges or risks and how these might be addressed through family support or paid care. Section 5.49 of the Code of Practice states that best-interest decision makers have a duty of care to consult other people who are close to the person with dementia where practical and appropriate, in order to work out the best interests of the person who lacks capacity. However, although the Code recommends such case conferences for settling

disputes (Section 5.68), there is little practical guidance on how practitioners should best engage with relatives.

Comparing observations conducted in discharge planning meetings with MDT meetings indicated that, the MDT had already agreed what they considered to be in the patient's best interests prior to the meeting. Rather than meeting with families and patients to agree a plan through joint decision making, the MDT were seeking agreement – primarily from the relatives – with their discharge plan. Again, this work was conducted behind the scenes and communicative practices were invisible to relatives (Goffman, 1971; Ellingson, 2005). Whilst some families welcomed the opportunity to clarify plans, others perceived this as a negative process. Case conferences were not held in all cases. For example the social worker noted in the medical records why a meeting was unnecessary to establish the wishes of Mr Coleman and his wife, noting the family's agreement to a nursing care placement.

(Date) social worker – PCT nurse assessment completed, requires general nursing care, family are accepting that patient requires 24-hour care in a nursing home as patient requires turning every four hours through the night for skin integrity. Needs could have been managed through the day but not through the night. Mrs Coleman also acknowledged as much as she would not like her husband in a care home, she would struggle to meet heavy needs 24 hours. Planning meeting not required as all family agree and are now undertaking the process of looking for a suitable home, I will arrange funding for placement.

Medical records: Mr Coleman 021208

However, subsequent interviews with Mrs Coleman revealed that she felt unable to challenge the recommendations of the ward manager and social worker, indicating that her wishes had not been fully explored, and as such, she may have benefited from a formal case conference. Therefore, although practitioners did engage with relatives, this was only partial, and resulted in limited involvement in decision making for families, sometimes resulting in disempowerment of patients with dementia and relatives (O'Connor and Purves, 2009). Although engaging with relatives represents a shift away from traditional models of medical decision making and paternalistic approaches in which medics assumed authority

and power over others (Emanuel and Emanuel, 1992), relatives did not always agree with the proposed plans of the clinical team. Achieving agreement between patients, relatives and the MDT was not always straightforward, leading to conflict and sometimes challenges to the authoritative decision makers.

8.3.3 Conflicting concerns

Section 5.54 of the Code of Practice states that when determining best interests, everyone's views are equally important, even if there is disagreement. In a number of cases, practitioners were observed to disagree with the wishes and preferences expressed by relatives as to what would be in the patients', and their own best interests. The Code sets out potential areas of conflict (Sections 5.63 – 5.69) and states that in cases of dispute, the decision maker must find a way of balancing or deciding between conflicting views (Section 5.64), and that people who disagree should not be excluded from the decision-making process (Section 5.67).

Observations of MDT meetings highlighted that the team pre-empted whether there would be likely consensus or conflict before meeting with the family, based on prior interactions with families or through entries in the patient's medical records, which outlined the relatives' preferences and expectations. The team anticipated complex family dynamics in Mrs Baker's case due to the involvement of several siblings.

...the OT said that she had had the patient's son on the phone this morning regarding the planning meeting this afternoon, and there had been mixed messages from the patient's son regarding management of the patient at home. [...]. The Liaison Nurse mentioned that there are six sons and daughters involved and so many of them have got different opinions on the care of this patient. Various relatives were staying over to care for the patient, but this was now too much and she felt that now they had had a break and were able to step back, they think they can manage now because they have had that break but at the time, it was too much. [...] It was referred that there would probably be some family dynamics in the planning meeting and they weren't sure who was going to be attending.

Fieldnotes: MDT meeting 290908

Many of the concerns about conflicting opinions stemmed from anticipating that relatives would challenge the recommendations of the MDT. Such challenges were often considered to be caused by emotional responses of families around the practicalities of providing care and support for the patient on discharge. Practitioners acknowledged the role of relational and emotional factors, such as guilt, spousal roles, and family expectations, fearing this would result in sub-optimal patient care on discharge. In such cases, relatives were encouraged to re-examine their preferences, and to prioritise practical over emotional consequences of their wishes, imposing a paternalistic approach to the decision making process (Sjöstrand *et al.*, 2013). Examples include Mr Fisher and Mr Coleman's wives.

The deterioration of his physical health actually sort of brought that home to her that she couldn't deal with those things but what she did not want to say was that she wouldn't take him home because of the guilt and we just had to reinforce that if that's what she did want to do that we could support that but family and herself, I think they did know that in their hearts that she couldn't, that she was a lady that could not have coped with his incontinence. She was very particular about certain things and that element she found more than difficult. Had he been continent, I think he would have gone home. I think that swayed it for her and I think in some senses that's right and that she needed the support to say that's ok to feel that way, because she was his wife after all you know and this had been a very proud man ...

Interview: Ward manager 01AsF-2210

The ward manager explained how Mrs Fisher was "swayed" to agreement by the clear outlining of her husband's present needs and how the patient required 'permission' from the team to agree to a care placement. However, I observed the case conference in which Mrs Fisher attempted to challenge the MDT, but was quite strongly advised to think of the consequences to her husband and herself if the discharge did not work out. This was expressed through concerns about Mrs Fisher's own health and how she would manage should her health deteriorate and it was suggested to her that she would compromise the best care of her husband.

8.3.4 Challenging the MDT

Some of the difficulties relatives and patients faced in challenging the decision of the MDT lay in the presumption that doctors would not allow something to happen if they did not consider this appropriate for the patient, and the advice of the medical team was to be accepted rather than challenged. This reflects traditional paternalistic models of the doctor-patient relationship, deeply-rooted in social understanding of medics as powerful professionals whose judgement must not be questioned (Lupton, 2012). Although this approach has been challenged through theory and policy in recent decades (Kaba and Sooriakumaran, 2007), this may not be an accepted social norm, particularly for older generations (Glasby *et al.*, 2016) who may have experienced a culture of medicine pre-NHS, when doctor-patient contact was a private enterprise, often limited and dependent on personal resources.

During an interview with Mrs Coleman, she shared with me her feelings about accepting the views of the MDT that her husband should not return home and should be placed in a nursing home. She explained that she could never have forgiven herself if she had ignored the advice of the hospital staff and something had happened to her husband or herself when the team had outlined the risks of Mr Coleman returning home.

Well I had to see this social worker and different people because they think (Mr Coleman) is ready to come out of hospital, I was going to take the caring and someone was going to come in three times a day and then the sister turned round and said it wouldn't be possible because (Mr Coleman) has to be turned four times a night and she didn't think I would be capable of doing it, so then they turned round and said well the next option is a home, you know and that is the last option I wanted to make but what can you do these people know their jobs they know what they're doing, I mean if he falls and I fall well that's just asking for more trouble.

Interview: Mrs Coleman 031208

Mrs Coleman felt she could not ignore the advice of the team who “know what they are doing”. This could be interpreted as accepting good, professional advice. However, reluctant deference to the professional view, may reflect the difficult situation of relatives

who must undertake complex decisions about healthcare needs and place of residence (Livingston *et al.*, 2010).

In the majority of cases, relatives accepted the concerns raised by the MDT, however when challenges were mounted, these were often from adult children, rather than spouses (Samsi and Manthorpe, 2013). The families of Mrs Salter, Mr Shepherd and Mr Ryder attempted to challenge the professionals about the level of care required for the person with dementia. Mrs Salter's daughter felt she was inadequately equipped with the necessary information about the medical deterioration of her mother to make an informed decision on her behalf.

...But what didn't happen at that [discharge planning] meeting, which should have, was the discussion of the care issues, the care package that was inadequate and what wasn't put into the equation was, the actual...observations that other specialists had. [...] there were quite a few salient, massive points. If those had been put forward to me, beforehand, the nursing diagnosis would have been different and I'm concerned now that that diagnosis is wrong. That it is inadequate and as I said... when I was talking to the Registrar the last Tuesday when I was in, I said those important bits of information were missing and if I'd seen that, I wouldn't have been quite so stroppy, my daughter wouldn't have been so obstinate and it would have been a better procedure and now when I think about it

Interview: Mrs Salter's daughter 031108

Mrs Salter's daughter defended herself. Had practitioners shared key information about her mother, she felt she may have better understood her mother's needs and may have been more accepting of the MDT's perspective on meeting her mother's best interests. In Mr Shepherd's case, the dispute was centred on the appropriate place and level of residential care for the patient, rather than whether he would return home.

The social worker commented that patently the patient can't go back into the community and they can't go back to the way things were. He described how he feels that the family are fixated on the patient going into a nursing home which is just around the corner for the patient's family and that it's nearby for them and handy for them. But he feels that this decision has to be about the patient's best interests and also thinking about the

best interests of the other residents, he said that he didn't feel fair that the patient should be settled in nursing care which is dual registered residential nursing care and then would have to move in a week or two because of his nocturnal behaviour. He said that the nursing home didn't seem to have a level of an understanding of the patient's needs in terms of the patient's behaviour.

Fieldnotes: MDT meeting 110509

In this case, the wishes of the family were considered secondary to the needs of the patient, as their preferred place of care was thought to be about convenience rather than the type of care provided, which the team prioritised. The team also suggested that Mr Shepherd's needs may not be compatible with the needs of the other residents at the care home, highlighting another layer of complexity when working out the patient's best interests. However, it could be countered that Mr Shepherd's family may have been prioritising their father's social needs through regular contact and a more familiar local environment, rejecting paternalistic views and asserting themselves as having better knowledge of their father and his needs than the MDT (Nolan and Keady, 2001).

As well as conflict between the MDT and relatives, practitioners described cases in which several family members had conflicting preferences and wishes. In these cases establishing the patient's best interests was particularly complicated as all viewpoints had to be considered as well as the views of the patient and the MDT. In the case of Mr Ryder, not only did the MDT dispute that it would be in the patient's best interests to discharge the patient home, but Mr Ryder's sons disagreed about the care needs of their father. They differed in opinion about whether he should return home or move to a purpose-built family home in another part of the country with his other son. In addition, Mr Ryder's daughter-in-law did not attend the case conference, although she had herself described in an interview her "predicament" in which she knew Mr Ryder better than either of his sons as she spent lots of time with him and provided much of his support at home. The team discussed the differences of opinion between the brothers and their concerns about the best interests of the patient.

... there was some discussion about the two opposing perspectives of the brothers, one who seems more realistic, as they put it, about their father's

chance of getting home and the other son who thinks that his father will be fine once he manages at home. [...]. The ward manager and the occupational therapist said that the social home visit might have one or two effects or outcomes. The social worker felt that it would give the youngest son more hope of the patient being able to return home but the OT felt quite strongly that it would prove that the patient isn't able to cope within the home environment. The registrar discussed with the consultant that if the family were adamant about the patient going home, that this patient probably will get home but there was a possibility that this patient would have to be placed on the Vulnerable Adults Register. [...]. There'd been a case conference last week but they thought that it might be necessary to talk to the family again and present the family with a list of problems. They felt they needed to ring the GP. The registrar described how he was totally dubious about this discharge and can't see what else that they could do and if the patient's family wanted this, then that's what would happen. The ward manager said "we can stop it happening" and the OT also described it as being "so risky".

Fieldnotes: MDT meeting 220609

This detailed extract demonstrates that although the registrar felt that the team were powerless to act against the wishes of Mr Ryder's family, the ward manager suggested that they could prevent the risky discharge favoured by the family. In all three cases, dispute between the MDT and relatives was resolved when the families accepted the recommendations of the MDT and agreed to the professional perspective on meeting the best interests of the patient. This demonstrates how the balance of power remained with the MDT who felt equipped to take on the challenges of relatives and defend their plan, and the family were disempowered in the decision-making process (Emmett *et al.*, 2014).

8.3.5 Countering challenges and clinical risk

I observed that the management of clinical risk factors were presented as inarguable evidence that practitioners were acting in the best interests of patients. This provided a way of countering challenges mounted by family members about the appropriateness of discharge decisions. Decisions based on clinical factors seemed to assume priority over

more subjective aspects of safety and risk, including behaviour and could legitimately 'trump' the wishes of the person with dementia and their families.

Managing clinical uncertainty included the consideration of chronic and acute physical conditions as well as cognitive impairment and dementia. Returning to the case of Mr Coleman, this is one example which highlights the prominence of clinical risk management. Prior to admission, Mr and Mrs Coleman had been managing at home without input from any formal services. They had been considering a move into a sheltered accommodation flat but had not pursued this. They had both assumed that once Mr Coleman had recovered from his chest infection and hip fracture, he would return home to convalesce. However, clinical management overrode management of his mental wellbeing and the wishes of Mr Coleman and his wife. The medical care of the patient took precedence over the social aspects of the discharge and individual wishes and preferences (Bond, 1992). The MDT decided that 24-hour nursing care was the only feasible option in terms of maintaining Mr Coleman's physical health. The clinical requirement which most influenced the best-interest decision was that Mr Coleman now needed to be turned during the night which the team deemed too risky to be managed at home. If not managed appropriately, it was anticipated that Mr Coleman could develop pressure ulcers and Mrs Coleman could not safely manage the moving and handling of her husband.

Mrs Coleman remained uncertain about the clinical risks, which she did not feel had been explained to her.

I mean when we were sitting having the meeting in the hospital, there was a nursing sister and the somebody a social worker I think, lovely, talking away, "yeah we'll get him home Mrs Coleman" you know and "we'll get you this and we'll get you that" and I was over the moon, brilliant, and then the sister walked in, and I don't know her name, and she said, "You can't look after him", "Pardon?", "You can't look after him", I said "but why", "Well you know he's got short term", I says "Well I know that" he's had it for about three or four years now, I've coped "I know but he's got to be turned over three times through the night", "What?", "He can't turn himself over", so straight out of my hands then.

The emphasis was placed on the management of uncertainty in clinical risk (Clarke *et al.*, 2011). This legitimised the prioritisation of the medical perspective over the wishes and preferences of the person with dementia and their family in the pursuit of best interests.

8.4 Risk management and achieving the 'appropriate' discharge outcome

In this final section, I explore the context of risk reduction as another important contributory factor which influenced best interest decisions, impacting on whether patients' wishes and preferences were considered and realised. Exploring practitioner attitudes to risk and the success of the discharge outcome as perceived by the people with dementia and their families illustrates how the enactment of the MCA in this context may facilitate or limit upholding the preferences of people with dementia to return home in accordance with their wishes.

The fifth and final principle of the MCA states that before the decision is made, regard must be given to whether the purpose of the decision can be effectively achieved in a way that is least restrictive of the person's rights and freedoms (Section 1(6)). With respect to a change of residence, the Code of Practice states that the least restrictive option should be chosen (Section 6.8), but that the final outcome may not be what the person who lacks capacity wanted (Section 6.10). Section 6.13 of the Code states that placing a person in hospital or a care home may deprive a person of their liberty, and even if the placement was made in the person's best interests, this is no protection from liability. Deprivation of liberty is not specifically defined in the Code of Practice, leading to the later development of specific legislation (Ministry of Justice, 2008). However the Code highlights difficulties in ascertaining what amounts to restrictions or deprivation of liberty. The Act signposts to the European Court of Human Rights and factors contributing to deprivation of liberty. This list includes: the person would be prevented from leaving if they made a meaningful attempt to do so; a request by carers for the person to be discharged to their care was refused; the person was unable to maintain social contacts because of restrictions placed on access to other people; and the person lost autonomy because they were under continuous supervision and control.

Findings from this research suggest that the least restrictive discharge outcome may not have been achieved for all 16 patients who lacked mental capacity to make decisions about place of residence on discharge from hospital. That is to say, there were considered to be no other alternatives which would better promote their independence and freedom. The discharge outcome of the sixteen patients for whom a best interest decision was made are examined, paying attention to whether the outcome was deemed to be successful and did indeed meet the best interests of the patient with dementia.

8.4.1 Reducing risks

Although practitioners described meeting best interests as getting the patient to the appropriate place of discharge, this was observed as being a care placement in all but one case (Mrs Baker). Placement in care was considered the least risky option and the setting which would best protect patients from risk, providing maximum patient safety.

Reflecting on observations of the many MDT meetings which I attended, it became apparent that although considerable attention was given to the risks of a person with dementia returning home from hospital, there was little consideration given to the risks of a placement in care. Furthermore, the emphasis was placed on managing physical risk factors, rather than the threat to personal autonomy, independence and social relations.

It often seems to be a central point of discussion in MDT's, the risks of the patient returning home are often discussed but there never seems much attention to risks of a patient going into residential care and it just prompted me to think about what the risks are, who is deemed to be at risk and why? Is it a physical risk they're thinking about or is it mental risks, you know is wellbeing taken into consideration? Is it the risk to the patient themselves or a risk to family and it was just something that I don't think I've given much headroom to but it might be a theme that is quite important and how capacity decisions are reached maybe informally

Reflective notes: 010609

However, interviews with a range of practitioners revealed differences in attitudes. Practitioners from psychiatry liaison teams and social work appeared to be more accepting

of risks around returning home. The liaison nurses at Site 2 felt that practitioners were afraid to take risks and preferred to take the options which reduced risk or were considered less risky. This reflects a reluctance for practitioners to promote positive risk taking for people with dementia (Clarke *et al.*, 2011).

I think as well, as professionals we are all very, very frightened to take risks and the, the option that sort of reduces risk...If for example somebody's deciding about whether they can, whether to go to care or not, there's a huge sigh of relief when someone agrees to that because for all healthcare professionals involved that then means that person is safe. It doesn't necessarily mean that they're happy, or that they have a sense of wellbeing and I think there is a reluctance to opt for the wellbeing side...

Interview: Psychiatry Liaison Nurse 02sl-0106

The liaison nurse highlighted patient wellbeing was often sacrificed, grounded in professional fear of failing to protect patients from harm. The care home was perceived by practitioners as a safe environment, compared with home. The liaison nurse felt that practitioners should be encouraged to accept risk as part of everyday life, as long as it was well discussed and documented. In some cases the risks surrounding home discharge were considered too great to consider, resulting in a residential placement and the prioritisation of beneficence over autonomy.

Although the risks of discharge into care were observed to be underplayed in comparison with risks to returning home, follow-up interviews revealed that incidents still occurred in institutional care settings. For example, despite being discharged into care, Mrs Miller and Mr Coleman had further readmissions to hospital. This was particularly distressing for Mrs Coleman, as the rationale for placing her husband in care was to avoid risks to his health likely to result in further readmission. However, some practitioners acknowledged that risks could never be completely removed, even within the care environment.

You can't take the risks away, you can reduce them as much as you possibly can and you can advise but you certainly can't take them away. You can put somebody into 24-hour care and they're still going to fall, they're still going to have accidents and it's just making sure that you've done

everything that you feasibly can to reduce the risks in an appropriate way, without wrapping them up in cotton wool.

Interview: Psychiatry Liaison Nurse 01BsG-1510

Additionally, many practitioners felt that acute hospitals are a risk-averse environment, and as such, practitioners working in this setting were influenced by this ethos resulting in a risk-averse approach. Several practitioners described approaches to best-interest decisions as paternalistic.

I think in some other cases we're kind of, we maybe are a bit paternalistic sometimes in the less severely impaired patients and we make decisions on their behalf or in their best interests without specifically defining capacity decision in the notes.

Interview: Registrar 01BsM-0611

Some practitioners expressed tensions between seeking to protect patients from harm and being overprotective (Carrese, 2006). The ward sister at Site 2 referred to feeling overprotective of some patients based on the personal relationships she built up with patients over extended time on the rehabilitation ward. She acknowledged that some patients were going to be readmitted but that they had rights to go home if they had capacity. She seemed frustrated at the likelihood of readmission, "Well it's like we'll see when you come in with the other broken hip then!" Fear of inadequately preventing the patient from risk on discharge appeared to be the root of such paternalism. One consultant described the duty of care to protect patients from risk and harm – even though this may not be in accordance with the wishes of the patient or their relatives.

And I think you know the situations of best-interest decisions is made along with relatives. My understanding still is that ultimately ... we have the responsibility to make sure that the decision is... the right one and as safe as it can be and that discharging somebody to an unsafe environment when they don't have capacity even when the relative or next of kin wants that is the wrong thing to do, I still think it's the wrong thing to do. I may be challenged about that.

Interview: Consultant 01AsO-2711

This exemplifies a tendency towards prioritising non-maleficence over autonomy in determining best interests, which does not reflect the basic principles of the MCA. In contrast, some practitioners acknowledged that prioritising risk reduction was questionable and expressed the wish to be more accepting of risk but felt that they were constrained and encountered barriers through the risk-averse culture of the MDT. Such risk-aversion may be rooted in individual and institutional factors such as criticism of professional conduct and fear of litigation (Clarke *et al.*, 2011). In the extract below, the consultant debated which risks were acceptable and whether there was a difference in acceptability between relatives and healthcare professionals.

... that's where we often wrestle with issues of best interests and looking at safety and can we minimise the risks and what kind of risks are acceptable and what's acceptable to us and what's acceptable to the family and falls for example, a lot of people fall and you often can't prevent falls, you know you can do everything you can but there's still going to be a risk of falling. Is that something which means that somebody shouldn't be at home? Well probably not to be honest because they're going to fall in a residential home and you know people say right that's it, you know, they've got to be in care well is that necessarily the appropriate thing to do?...I think you know sometimes we discharge people, we accept there are risks, we minimise the risks, they fall again three weeks later, they get brought back in and people go, "well that's it then, you're not going home again" and that's not necessarily the right thing to do.

Interview: Consultant 01BsQ-1212

The debate relates to the appropriate management of risk, and in this example, questioning the commonly held assumption that care homes can best manage falls in this patient group. A 'one-strike' approach to managing risk and place of residence is also highlighted, indicating that practitioners might accept risks on one occasion but this was less likely to be accepted on readmission.

In Mr Collier's case, the MDT discussed the principal risks that they anticipated should Mr Collier return home. These centred around his actions within the environment and risks to others.

... he [consultant] asked the team what was the worst that could happen and the ward sister said that the worst that would happen was that he would burn himself to death in bed and that he was a fire risk. The consultant asked, "Burn himself to death? Or other people?" and it was described that it's an upstairs flat so he's potentially endangering other people. The OT said that on the home visit the patient said that he doesn't smoke in bed and she had felt that the stairs and falling down the stairs was the biggest risk if the patient was getting up to go to the toilet in the night. The social worker suggested to the team that a gate could be put in place and the physio said that she has a feeling that the patient might go over the top of it. And the consultant summarised that there were two big risks, the fire and falls.

Fieldnotes: MDT meeting 110509

In this instance, the protection of others was also discussed. Such aversion to risk is often based on an overestimation and fear of vivid, invisible risks which affect vulnerable and unknowing people in the broader community (Manthorpe, 2004), and in this case, risk of fire. This judgement was made on past events which influenced anticipation of risk on discharge. The OT presented a similar perspective.

I think there is loads of risks. I think he's going to go home, probably fall within 24 hours and come straight back in the hospital again, but if he says that he wants to go home, he understands the risks and what's going to happen then he ultimately does go back home again because that's his choice.

Interview: OT 02sC-1305

These judgements were made whilst the team considered Mr Collier to have the requisite mental capacity to make his own decisions about discharge, however the decision made in his best interests by the team to discharge him into residential care was considered to

ameliorate many of these risks, even if the decision did not accord with the patient's expressed wishes. This highlights the contested notion of risk between people with dementia, families and practitioners, and in this case, the prioritisation of the practitioners perspective over that of the person with dementia (Clarke *et al.*, 2010).

8.4.2 The appropriate place?

Although practitioners described best interest decisions as being about discharge to the most appropriate place, rather than automatically into institutional care, this was the most common outcome for patients with dementia who lacked capacity in this context. Fourteen patients were discharged into care (Mr Day died prior to discharge but the plan had been to discharge the patient into residential care). Only six of these patients were discharged into nursing care. Eight residents were discharged into residential care, suggesting that their care needs were socially, rather than medically driven.

Agreeing to a care placement in the patient's best interests was often difficult for relatives. In making a decision to place their relative in care, tensions were clear between being unable to uphold their relative's longstanding wishes and accepting the professional perspective that a care placement would meet the best interests of the patient with dementia.

...[she] hated the idea of going into a home because she said to me "never put me in a home or when I die I'll come back and haunt you"....really hated, hated the idea, so like now she just....isn't aware...and I don't tell her...and it eases my conscience.

Follow-up interview: Mrs Butler's daughter 060209

MP: and ... how did your husband feel about going into nursing care?

INT: He didn't want to...he hated it, you see him and I made a promise years ago that neither of us would put the other one in a home, right.

Follow-up interview: Mrs Coleman 160309

In both cases, the relatives knew that a care placement was not what the patient wanted, although Mrs Butler's daughter described how her mother didn't seem to know she hadn't returned home, whereas Mr Coleman was aware that he hadn't returned home to live with his wife. This demonstrates some of the difficulties facing families when making residence decisions on behalf of the person with dementia who lacks capacity (Livingston *et al.*, 2010).

Practitioners recognised the need for sensitivity in broaching the issue of a care placement with patients, reflecting their understanding that moving in to care did not usually reflect individual wishes and preferences. However one consultant remarked on the need for being clear with patients, suggesting that this information was often obscured.

So I thought that was really interesting that the consultant felt that they maybe aren't that explicit when they're exploring opinions of the patient and they do use terms like somewhere where you can get a bit more care and it just may not be very clear to patients that it's being put to them or suggested to them that one of the options is residential care, rather than returning to their original home.

Reflective notes: 080609

Whilst this is important for determining the best interests of the patient, this also has important implications for assessing capacity and ensuring that patients have the necessary information on which to base their residence decisions (Hughes *et al.*, 2013b).

Whilst understanding that placement was often a last resort for patients and families, practitioners across a range of disciplines tended to recommend placement in care, even in cases of uncertainty about the best outcome. This suggests that negative risks associated with institutionalisation and living in the community may not be considered equally (Zuckerman, 1987). The complexities of trying to work out Mrs Salter's best interests were described by the consultant during an interview.

... that was a complicated case where I'm not wholly comfortable that we did the right thing for her. So she was lady who had ... maybe [a] quadruple whammy of things that made it difficult to plan her discharge. English was not her first language, she spoke fluent English but there was always uncertainty about whether some subtleties were going missed in

her consultations because she didn't speak or English was not her first language and her first language was (Language 1) which none of us spoke so that wasn't very helpful. ...The second issue was that she had plainly been an eccentric lady and her eccentricities which I'm sure had been lifelong, were creating a problem for her carers later in life, where earlier they didn't and that's you know, we know that, how being eccentric doesn't mean you haven't got capacity and that people should be allowed to make eccentric decisions that we would personally not agree with but those eccentricities were becoming exaggerated into behaviours that we found challenging. The third thing was that she plainly had cognitive impairment. So she did have some memory loss and the fourth thing was that she then became paranoid so you know she had an additional mental illness or you know was obviously related to her dementia and perhaps indeed her previous personality but then she became paranoid. So she was extremely complicated. [...] So she was...that was very difficult. I don't think any of her, each of her problems if you like on their own would not have tipped her into going into residential care [...] and I think, the decision we made was in her best, clearly, clearly, you know we were looking at a best interest decision and clearly the fact that we made that decision meant we think or that was in her best-interests and I continue to think that was in her best interests...

Interview: Consultant 01BsQ-1212

This example illustrates that the consultant put the patient at the heart of the decision, considering many aspects of Mrs Salter's personality, background and health. However, despite reservations about placement, the MDT, headed by the consultant, made the best interest decision that a placement in residential care was in Mrs Salter's best interests.

Returning to Mrs Baker, this was a unique case in that she was the only person who was judged to lack capacity to make her own discharge decision, but returned home in accordance with her wishes. Furthermore, there was little disagreement and the patient, her family and the MDT considered this the right outcome. Although the patient had passed away at follow up, her daughter described two or three further admissions post-discharge.

However, Mrs Baker's daughter and son-in-law clearly expressed that each discharge home had been the best outcome for their mother, who each time, clearly expressed her wish to return home.

INT 1: we wanted her home

INT 2: ... when I'm talking about that meeting it wasn't that we didn't want her home...it was the way it was handled, and we wanted her home because that's what she wanted, it's all about her, but we knew we were on borrowed time...we knew we could only keep it up for so long and then she would deteriorate to the point where she couldn't come home anymore, but we knew that, and she maybe realised that herself, I don't know

Follow-up interview: Mrs Baker's daughter and son-in-law 110209

During an interview, the consultant was also confident that the right outcome was achieved for the patient and her family, as the discharge met the wishes of both. In contrast, Mrs Coleman had not wanted her husband to go into a nursing home, but felt obliged to act on the advice of the MDT and her step-children. During interviews at the time of discharge and at follow-up, she expressed the detrimental impact of the discharge into care for her husband.

...he was in the nursing home six weeks when he died and it was the most horrific six weeks that we've ever known. His memory started getting worse, his body started deteriorating, he wasn't recognising people you know and getting very irritable, irritated at for nothing, it wasn't him, it was like two people in the one body you know and I mean from going into that home as I say, ... 'til he died, I have never seen such a change in anyone; mentally and physically.

Follow-up interview: Mrs Coleman 160309

Mrs Coleman did not feel that the right outcome had been achieved for her husband and regretted accepting the advice of the MDT.

In perhaps the most complex case in this research, right up until Mr Collier left the ward, the MDT could not decide on the appropriate outcome. This conflict stemmed from the MDT perspective that a care home would be the safest place for Mr Collier to live, but that Mr Collier was explicit in his wishes to return home, but ambivalent in discussions about living in residential care.

The registrar reviewed the patient's notes and the medical notes stated that the patient did not have capacity. The registrar asked if the patient was adamant that he wouldn't go to a residential home and asked would he object to residential home. The registrar asked what the family's wishes were with respect to the discharge. The registrar suggested that if the family were in agreement with the placement of residential care. They could suggest to the patient that he has a trial in residential care, rather than a trial at home which the patient had suggested.... It was felt that they didn't need an IMCA if everyone was on board with the decision and the registrar checked this with the MDT. [Social worker] asked the MDT outright if they thought this decision was right and was in keeping with the patient's best interests. It was the physio who suggested the trial in a residential setting, saying that they could explain to him that it wasn't set in stone, that he could try it there and then go home if he didn't like it, rather than the reverse of having a trial at home, then maybe going to residential care. So I was quite surprised by the conversation. This patient was considered to have capacity and it was thought that the patient would get home. It was considered ... I'm pretty sure the registrar and the consultant had considered this patient to have capacity to make a decision at one point but there must have been some change in this situation. I know the OT had had doubts over time but I was quite surprised by the fact that the patient was considered not to have capacity to make this decision and that even though the patient didn't have capacity, is expressing a wish to go home but the MDT feel that this patient's best interests would be met in a residential setting.

Reflective notes: 220609

I was surprised by the reaction of the MDT and their thoughts on discharging Mr Collier in to residential care. Throughout the admission, I had observed that the team had grown to reluctantly accept the patient's unwise decision (as discussed in section 5.3.5) and expected that he would return home. The revised discharge plan hinged around the change in the capacity decision, and the clear focus on Mr Collier's reluctance to accept a placement in residential care. The judgement that Mr Collier lacked mental capacity meant that the team could now make a best interest decision, which reflected their professional judgement over the wishes of Mr Collier. However, although the social worker questioned whether this met the patient's best interests and seemed uncomfortable with this outcome, he was outnumbered by the rest of the team.

The decision remained contentious. Although the MDT felt that the right outcome had been reached for the patient, at follow-up, Mr Collier expressed his unhappiness and frustrations of living in residential care. This may have resulted from his perceived lack of involvement in the decision-making process. During an interview with Mr Collier at the time of discharge he described that the system didn't support his involvement in decision making.

MP: do you think it should be you who makes the decision?

INT: well you should have an input somewhere along the line. Don't you think so?

[...]

MP: and how would you like to have that input Mr Collier?

INT: well after all the facts have been discussed is that sort of ask you, sort of question like "and what do you feel about that, do you feel as though you're ready to do that or that or whatever", but as it is you don't get that you know

MP: and who do you think will make the decision about where you go?

INT: Who? The consultant probably.

Interview: Mr Collier 010609

During interview at follow-up, he further described how he felt 'tricked' by the social worker and doctors as he felt he had only agreed to a trial discharge, and he felt unable to challenge the outcome. I was unaware of any process to formally review the trial placement.

Furthermore he described feeling isolated, as the home was located at the opposite end of

the city to where he previously lived, and friends did not visit. He did not feel that he fitted in and the patients with dementia concerned him. I noticed during the interview that the patient could still be described as 'unkempt'. He sat alone in the smoking room and described how he spent a lot of time there. Mr Collier's questionable hygiene habits had been one of the drivers leading to a best-interest decision of placement, yet residential placement did not appear to have improved this on a personal level for the patient.

The interview was conducted in a downstairs smoking room, the healthcare assistant at the residential home said that Mr Collier was the only patient who used the room. He was in there already when I got there...When the patient was in hospital one of the reasons they felt he didn't have the insight into his living conditions and his personal care was because he was described as being unkempt, sometimes unclean but I noticed today that in my observations that even in residential care the patient could be described as quite unkempt. His nails were extremely dirty, I don't know if it was nicotine stains, I think it quite possibly was, his hair was a bit wild, he was clean shaven...there was a stain on his t-shirt so his clothes didn't look particularly clean and I think that was one of the kind of issues that was raised about there being a general air of his house being in a bit of a state and the patient being a bit unkempt. So obviously was there an expectation that the patient would be now more 'kempt', for want of a better word, if he lived in a residential setting whereas on observation today it didn't really look to be the case.

Reflective notes 021009: interview, three-month post discharge with Mr Collier

In contrast, at follow-up, several of the patients and their relatives felt that although the decision for their family member to be discharged into care had been difficult at the time, this had been the right outcome for the person with dementia and themselves. Mrs Salter and Mrs Miller expressed being settled in their new environment. In his own words, Mr Tyler summed up the outcome for himself and his family.

MP: ...and do you think it was the right decision for you to move here?

INT: Well I'm quite happy with it. I get on well, aye I'm quite happy here.

MP: What about your family, do they think it was the right choice for you to come here?

INT: Oh yes, aye, they're happy if I'm happy with it.

Follow-up interview: Mr Tyler 300909

Many of these best-interest decisions were considered appropriate by the participants and their relatives. The case of Mrs Baker is an example of the right outcome being achieved. However, the data provides clear examples of an unsatisfactory discharge outcome in the cases of Mr Coleman and Mr Collier. Furthermore, in Mr Collier's case, not only was the outcome unsatisfactory but the least restrictive outcome was not achieved.

8.5 Chapter summary

Including the person with dementia often posed significant challenges for practitioners, leading to limited involvement of people with dementia in making decisions about place of residence on discharge from hospital. Increased opportunities for involvement in such a consequential decision as place of residence would preserve the rights and agency of the person with dementia (Boyle, 2014). However, not only health and social care practitioners are influential in the inclusion or exclusion of people with dementia in making best-interest decisions. Family played a significant role, in securing the involvement of people with dementia in working out their best interests. This data highlights the importance of achieving full and inclusive involvement of people with dementia when making life-changing decisions, to ensure that people with dementia are given optimal opportunities to participate in significant decisions impacting on their lives, and included as agentic social citizens (Bartlett and O'Connor, 2007; Bartlett and O'Connor, 2010).

Whilst health and social care professionals invested considerable resource in discharge planning meetings and case conferences to engage with families around plans; family involvement was often limited to ascertaining values and wishes rather than involvement in the best-interest decision itself. Although practitioners often expressed that the family made best-interest decisions on behalf of the person with dementia, I observed that relatives contributed to, rather than made decisions. The MDT relied on the co-operation of families to support their proposed best-interest decision, and in cases of disagreement, the

discharge plan proposed by the MDT was most often realised over the wishes of patients or their families. The management of clinical risk was often used to successfully substantiate and counter challenges made by relatives. This suggests ethical challenges inherent in the enactment of the MCA and a paternalistic approach (Beauchamp and Childress, 2001; Sjöstrand *et al.*, 2013) to meeting the best interests of people with dementia, with tendencies towards traditional hierarchies of practitioner-patient relationships (Emanuel and Emanuel, 1992). Furthermore, such approaches do not facilitate meeting the provisions of the MCA in practice which supports a joint approach to decision making.

Tensions between ethical values of respect for patient autonomy and preserving patient welfare are particularly clear in discharge decisions for people with dementia (O'Keeffe, 2001). In best interest cases in this research, paternalism often manifested in a risk-averse approach and were observed to be at the heart of best interest decisions. Practitioners commonly opted for the discharge outcome which was considered least harmful to patients from a medical and physical perspective, sometimes at the expense of mental wellbeing. In the context of the acute hospital, an entrenched culture of paternalism (Lupton, 2012) was recognised, however practitioners from Old Age Psychiatry and social work were generally more accepting of risk. Favouring placement as a safer environment for patients with dementia for whom a best-interest decision was required was evidenced by only Mrs Baker returning home in accordance with her wishes. Although in many cases, placement in care was a satisfactory outcome, for others, the negative impact had life-changing consequences. As such, it may be suggested that those who are best placed to uphold the wishes and preferences of patients who lack capacity are only partially included in decisions about their welfare, reducing the likelihood that the preferences of the incapacitated persons will be upheld when determining best interests on place of residence on discharge from hospital.

Chapter 9. Discussion

This thesis provides a critical exploration of the legal framework provided by the MCA through exploring the interpretive work undertaken by practitioners, when making judgements on the mental capacity of people with dementia to make decisions about place of residence on discharge from hospital. It highlights the many challenges facing practitioners in the interpretation and implementation of the Act within the hospital setting. This emerges as a complex context in which decisions of significant magnitude are made about the abilities, wishes and rights of people with dementia. This research demonstrates the often complicated and resource-intensive interactions and relations which occurred between patients, families and health and social care practitioners to implement the Act. Despite the difficulties and complexities of assessing mental capacity, which assumes a dichotomous judgement about whether people with dementia can decide they will live on discharge from hospital, many examples of good practice were observed.

In meeting the aim and objectives of this research, I have critiqued the MCA from the perspective that the act is difficult for practitioners to enact in the context of hospital discharge and people with dementia. Central to this is the legal construct of capacity as a dichotomous concept which can be determined by a two-stage test (Objective 3). This data demonstrates that to enact the MCA in reality, the process of capacity assessment often involved a significant amount of interpretative work by practitioners, and mental capacity judgements in practice often remain largely based on these subjective interpretations (objectives 1 and 2). I have described how interpretative processes of judgements on capacity influence assessment, but that for many people with dementia, a distinct and separate assessment of mental capacity, as defined by the MCA, is not made in practice (Objective 1). I have also examined the range of information sources which practitioners draw upon to arrive at their judgement on capacity, and considered which types of narratives, and provided by whom are considered authentic, plausible and carry credence (Objective 2). The extent and opportunity for inclusion of the person with dementia in making the decision about whether to return home was explored (Objective 4) in connection with how wishes and beliefs about returning home from hospital become bound up with

judgements on their mental capacity to make this decision themselves, or whether someone makes this decision on their behalf.

Interpretation of these findings leads to consideration of three key areas:

1) Whether the assessment of mental capacity for people with dementia in the hospital environment is the most appropriate setting to enable full and fair assessment and optimal inclusion in residence decisions.

2) Whether the MCA offers an adequate model of decision making in this context, for both those implementing the Act and people with dementia.

3) Reflection on how social science perspectives and an ethnographic approach can be applied to better understand important decisions around mental capacity and residence; and how this work adds to existing research on the MCA in practice.

9.1 Implementation of the Mental Capacity Act in other contexts

In considering the implementation of the MCA specifically in the context of hospital discharge for people with dementia, it is useful to explore enactment of the Act in other settings. An important body of research has been conducted to review how the MCA is enacted by health and social care professionals when working with people with dementia in a range of community settings. Manthorpe et al interviewed specialist dementia nurses (Samsi *et al.*, 2012) and staff from organisations supporting people with dementia and their family carers (Manthorpe *et al.*, 2012) to gain an understanding of their views on usage of the act in community practice. This was followed up over the following two to four years later with local Adult Safeguarding Co-ordinators (Manthorpe *et al.*, 2013), dementia nurses (Manthorpe *et al.*, 2014) and care home staff (Manthorpe and Samsi, 2016), to explore changes in experiences and understanding of the Act and whether this had improved. Concerns remained around the quality of assessments conducted by other health and social care professionals, and uncertainty and a lack of clarity still existed around professional hierarchies and responsibilities of decision making (Manthorpe *et al.*, 2014). These are important issues which resonate with the findings from this research. Further research was conducted around understanding of new criminal offences created by the MCA (Manthorpe and Samsi, 2015). This work provides evidence to support how the Act has been understood and incorporated into practice, often with increased practitioner confidence over time, but

with an awareness that the Act continues not to be fully implemented, despite continued high regard of the principles of the Act.

This thesis addresses implementation of the Act specifically within the context of the acute hospital by medical practitioners, and decisions of residence, which presents different and particularly complicated challenges, as medical issues are brought to the fore as well as, social, legal and ethical issues. This adds to the work exploring value judgements and ethical tensions in decision making (Greener *et al.*, 2012; Hughes *et al.*, 2013b), and comparison of practice with legal standards (Emmett *et al.*, 2013a; Emmett *et al.*, 2014) in this context.

In addition to empirical research investigating the implementation and embeddedness of the Act in professional practice, this has also been investigated at a policy level. The House of Lords Select Committee published its findings in 2014 (House of Lords Select Committee on the Mental Capacity Act 2005, 2014). The purpose of the committee was to review the implementation of the MCA in practice. The committee sought evidence from leading experts in the field and also drew on research evidence to inform its findings. Hughes *et al* submitted written evidence to the Select Committee which was later cited in their report (Hughes *et al.*, 2013a). The key finding from the Select Committee was that although the principles of the Act were held in high regard, the Act was poorly understood and therefore poorly implemented in practice. A prevailing culture of paternalism in healthcare and risk-averse approaches of social workers were highlighted as the main barriers to implementation in the sector. This reinforces the message that there remains a need to better understand how the Act is implemented in practice.

9.2 Residence decisions and mental capacity – a social decision in a medical context.

In considering the influence of the acute medical setting on the enactment of the MCA, I address whether assessment of capacity for people with dementia in the hospital environment is the most appropriate setting to enable full and fair capacity assessment and optimal inclusion in residence decisions. This relates to two key findings from the research. First, that the necessary and resource-intensive exploratory, interpretative processes of arriving at judgements on mental capacity, were not systematically captured. This did not reflect the amount of work required by practitioners', who had no prior knowledge of the patient, to arrive at capacity judgements in this setting. Furthermore, ambiguity as to

whether capacity had been assessed in accordance with the provisions of the MCA were created though lack of documentation of the basis for the capacity judgement. Second, although narratives from multiple stakeholders influenced capacity judgements and best-interest decisions, in this context, the narratives of medical practitioners were considered more authoritative and often prioritised over those of the people with dementia and their families. Therefore the social dimensions of the issues of mental capacity in relation to place of residence may become overshadowed by the medical context.

The findings highlighted examples of practitioners in the acute hospital environment struggling to prioritise protection over individual choice. This introduces debate as to whether decisions about mental capacity, best interests and place of residence, which take place in the acute medical environment are overly influenced by the medical context, and 'medicalised' in a similar way to that which dementia itself has been (Lyman, 1989; Bond, 1992). Clear tensions occurred in the implementation of the MCA in the hospital setting between the legal criteria, clinical practice and the social nature of residence. The findings suggest that tensions stem from the issue that decisions about place of residence, within a hospital setting, governed by a legal framework cannot be defined as purely, social, clinical, or legal. The findings also indicate that, in essence, residence decisions should be considered more closely aligned to social matters than a medical issue. Once any acute medical issues have been resolved, and if longstanding medical conditions can be managed in the community, as they had been prior to admission, then in such cases, the medical element of the decision making then becomes questionable. The decision is based more on factors to do with place of residence and social management rather than medical treatment and management. This raises questions around the legitimacy of medical professionals routinely making decisions about where a person lives, and how this impacts on capacity assessment.

Assessment of capacity is a legal decision enacted in a medical environment. However, the practitioners in this research rarely conceptualised assessment of capacity or best interests as a legal procedure but approached assessments in terms of acting within a duty of care towards their patients. In making an assessment about the person's mental capacity, in this circumstance, the hospital consultants were enacting the provisions of the law rather than providing opinion or evidence to support a legal decision made in a court of law. Although

there are no publicly available figures, the observation data suggested that only in rare cases, legal determination of capacity and best interest reach the Court of Protection. No examples of this were witnessed over the course of this research, which extended beyond the 29 cases to the many other patients who were present on the wards and are not included in the research. In addition, practitioners did not raise issues relating to these extreme cases and legal intervention.

Decisions relating to residence differ from other decisions, such as treatment decisions, which can be more clearly defined as medical in nature. The boundaries around treatment decisions are more easily defined by more predictable and contained risks (Zuckerman, 1987; Emmett *et al.*, 2013a). The clinician will be carrying out a procedure which requires medical knowledge to perform the procedure, and given that knowledge, they are best-qualified to inform patients, to make judgements around eligibility, necessity, acceptability, risk, and predict outcomes. When comparing clinical decisions with those concerned with place of residence, clinicians have knowledge about the physical and mental functional abilities of the *patient* with dementia, but their knowledge is limited about the home environment of the *person* with dementia. This encompasses knowledge the clinical team have on how the patient functioned prior to admission, how they are likely to function in the future, and whether they would be best served by returning home or being discharged into institutional care. Furthermore, the values and beliefs of the patient with dementia cannot be clinically determined in the same way that aspects of function can be assessed or tested (Sabat, 2001).

Perhaps at the heart of this complexity is that many of the issues regarding residence are not medical in nature, and therefore applying medical exploration, reasoning and decision making when trying to ascertain residential capacity is ethically troublesome. Referring back to the case of Mr Collier, there was relatively little attention given to Mr Collier's physical or medical condition and related care needs, but the concerns about his ability to manage in the community stemmed from the unkempt condition of his home and lack of appreciation of potentially risky behaviours such as smoking in bed. Although these concerns were not medical in nature, the senior medical team tested Mr Collier's capacity and ensured that the decision to discharge him into residential care was agreed. Also, despite the ward social worker conducting several 'informal' assessments of capacity and anticipating that Mr Collier

would have capacity to make his own decision to return home, it was the medical staff who had made the final judgement of incapacity and best interests, despite the predominantly social nature of the decision.

9.2.1 Clinicians as decision makers for a non-clinical decision?

As part of how the clinical context impacts on decisions relating to capacity and place of residence, practitioners working in this medical environment expressed clear tensions between being able to take a more person-centred approach to assessment of capacity and having more structured and standardised approaches to testing mental capacity. The Select Committee report stated that a paternalistic approach in healthcare settings is limiting the implementation of the Act, stating that a “A fundamental change of attitudes among professionals is needed in order to move from protection and paternalism to enablement and empowerment”(page 8) (House of Lords Select Committee on the Mental Capacity Act 2005, 2014). This research suggested that practitioners were often aware of the limitations of this paternalistic approach and wished to push these boundaries to enhance the freedoms and rights of people with dementia but felt constrained within the medical environment where paternalism was still felt to be deeply entrenched.

Practitioners engaged in a significant amount of work to inform their capacity judgements, This backstage (Goffman, 1971) or invisible work (Allen, 2014a), which occurred in the ward setting through interactions, assessments, and meetings with colleagues and with patients and their families, greatly influenced best-interest decisions and led practitioners to their perceptions of best interests which they presented to families for their approval. This suggests that good practice may happen, but goes undocumented and so remains hidden. In particular, this was evident with capacity assessments which were not commonly recorded in a consistent and transparent way. So although a great deal of consideration and effort was afforded to working out whether a person with dementia had the capacity to make their own decision about where to live on discharge from hospital, and enacting binary notions of capacity or incapacity, this work was not routinely well-evidenced. This meant that the time and commitment invested by the MDT was invisible and also resulted in ambiguity over processes and documentation, leaving health care professionals potentially vulnerable, if the capacity decision were to be legally challenged. This echoes with findings of the Select Committee report which highlighted that the process of formally conducting capacity

assessments was often not completed and not documented (House of Lords Select Committee on the Mental Capacity Act 2005, 2014).

The lack of evidence of formal assessment of mental capacity may stem from the process. Many practitioners felt that assessment should be conducted along the lines of having an informal conversation, rather than enacting capacity assessment as a test, as set out in the MCA. This was founded in beliefs that placing people in a test situation with regards to their personal freedom would serve only to disadvantage the person with dementia. On the one hand this appears appealing, removing fear and pressure for the person with dementia being tested. Sabat emphasises the importance of engaging in the process of natural conversation to assess cognition. This enables the person with dementia to use multiple brain functions and draw on contextual cues, which the 'tester' can interpret and respond to, rather than conducting tests which are based on standardised measurement of function in which cognitive function is broken-down into its sum parts, decontextualising meaning to individuals (Sabat, 2001). Furthermore, it is recognised that standardised cognitive tests have significant limitations which serve to disadvantage particular populations. For example cognitive tests do not take into account cultural sensitivities (Hohl *et al.*, 1999; Rait *et al.*, 2000a; Rait *et al.*, 2000b) and linguistic differences (Escobar *et al.*, 1986), and misclassification is more likely to occur, further disadvantaging people defined as from lower social classes and with lower educational attainment (Jagger *et al.*, 1992). The cut-off points which define impairment versus 'normality' may not be appropriate for all populations (Cullen *et al.*, 2005).

However, it could be argued that protecting people with dementia from the knowledge that they are being 'tested' could also represent an overprotective and paternalistic approach, reflecting traditional approaches to medical decision making and prioritising professional judgement as reported in the concerns of the Select Committee. This may also have potential to disadvantage the person with dementia for whom the purpose of the 'chat' is not clear, and who may not understand that they are being 'tested' and expected to fulfil certain criteria in order to 'pass' the test. In addition it may position the person with dementia as someone who is unable to engage with autonomous choice and further limit opportunities to exercise agency in critical personal decisions. More broadly, practitioners have been criticised for their limited recognition of the rights of vulnerable adults to make

their own decisions and a lack of awareness of their duty to assess capacity in advance of making decisions on behalf of the person (Boyle, 2011). Improved guidance for practitioners, which may facilitate assessment of mental capacity which meets with the provision of the MCA whilst giving the person with dementia the optimal opportunity to engage with the process (Hughes *et al.*, 2015), may be a useful approach for consideration.

The findings confirmed that in the acute medical setting, senior medical clinicians usually continued to take the role of assessor of capacity and determining best interests. There is, of course, a clear role for clinical judgement in the assessment of capacity and determining best interests in this context. Clinical judgement has traditionally been regarded as the 'gold standard' of capacity assessment (Moye and Marson, 2007), as already suggested, circumstances under judgement are not in themselves clinical but of a social nature. Practitioners cannot use standardised assessments to measure whether a husband loves his wife and wishes to care for her as he always has, and therefore practitioners are reliant on their professional judgement to consider the multi-faceted decision about place of residence on discharge for the person with dementia.

Assessment of capacity was most often performed by consultants and/or registrars, and usually conducted as part of routine medical ward rounds. There were conflicting views that the patient was "their patient" highlighting the duty of care and responsibilities of the medical team. This was placed in a normalised context of what usually happens, the historical context of what has traditionally happened (and assumed should continue), and reinforced through institutional practice and existing guidance on accountability and responsibilities for senior clinicians (General Medical Council, 2012; General Medical Council, 2014). However, clinicians also described how others within the team often had better knowledge of the patient than the consultant who had limited direct patient contact. Whilst a multi-disciplinary team approach was considered necessary, it was most appropriate for the consultant to assume the ultimate responsibility for the patient as they were in their care and they were the most senior practitioner in the team. Whilst this may reflect existing relationships and notions of trust within the MDT, this approach also reflects more traditional models of doctor-patient relationships and hierarchies of medical power (Freidson, 1975; Coombs and Ersser, 2004; Lupton, 2012; Gabe and Monaghan, 2013).

Although the MCA supports a shift of power to the most appropriate decision maker, this has complex deep-rooted power dynamic implications in a multi-disciplinary medical setting.

In addition, the findings also indicated that the acute hospital setting fosters a risk-averse culture, where a “protection imperative” prevails (House of Lords Select Committee on the Mental Capacity Act 2005, 2014). Therefore many practitioners agreed in principle with the ethos of the MCA, but struggled to enact the principles in practice and recognised this as a failing. Uncertainty around responsibility for decision making (Manthorpe *et al.*, 2014) and organisational and institutional fear of litigation (Clarke *et al.*, 2011) may contribute to persisting uncertainties around risk and residence decisions on discharge from hospital for people with dementia. The data suggested that placement in care continued to be viewed as the best way to reduce risks on discharge for patients with dementia, in particular for those who lacked capacity to make this decision themselves. This suggests that the ‘least restrictive’ options were not always achieved in practice.

In only a small number of cases in this research, social care practitioners such as social workers and Independent Mental Capacity Advocates (IMCAs) were significantly involved in carrying out mental capacity assessments and decisions, and determining best interests. This recognises the importance of involving others in the process, and suggests a good understanding of the principles of the Act. However, these assessments were commonly considered supplementary to those of the medical team who ultimately made decisions. This suggests that assessment of mental capacity in the hospital setting results in the medical perspective being privileged over the judgements of others and traditional medical models of decision making prevail in this context. The assumptions were that it was right that the senior clinician, usually the consultant, should take responsibility for such serious and complex decisions as capacity assessment and best interests in relation to deciding place of residence. This opens up space for discussions as to whether medical practitioners are the most appropriate people to explore capacity and best interests regarding place of residence or whether there is scope for practitioners from social care disciplines to have a more prominent role as decision maker, rather than advisor. This may extend to community-based practitioners who might have access to more information or better knowledge around the social circumstances of the person with dementia.

Recent research suggests social workers are considered to be the most appropriate assessors for decisions which are regarded as social in nature (Bogg, 2015). Social workers complete assessments for local authorities to determine individual care needs (Alzheimer's Society, 2015b; Gov.UK, 2016), and therefore will be most likely to undertake capacity assessments regarding a change in residence in the community. The literature suggests that community practitioners and community-based assessments of capacity and best interests for people with dementia place less emphasis on the medical factors and risks are defined more broadly (McDonald, 2010); taking into consideration social aspects such as vulnerability, which benefit from home-based assessments using tools which support assessment of capacity in relation to safe and independent living (Naik *et al.*, 2010). Community GP's may also have a role to play, and may have a longer established relationship with the person with dementia, providing some continuity through provisions such as having a named GP (British Medical Association, 2016). However, despite policy intentions to build relationship continuity, organisational and social factors mean this is not easily achieved in practice, and people often see whichever GP is available (Hill and Freeman, 2011). If circumstances do not allow for decisions about residence to be delayed until post-discharge and made in the community, a more structured approach to capacity assessment may help practitioners to meet the provisions of the MCA. Assessment specifically tailored to the decision of residence on discharge from hospital would provide practitioners with some clearer guidance on the information which might be considered relevant to the specific decision whilst allowing for the recognition of individual circumstances and values (Emmett *et al.*, 2013a; Hughes *et al.*, 2015).

9.3 Binary notions of mental capacity and patient involvement in decision making

Returning to the framework provided by the MCA, the third key finding from this research was that the Act was often difficult for practitioners in the medical environment to apply in practice, due to the requirement of practitioners to make judgements on mental capacity fit with the binary notion of capacity. In the context of residence decisions for people with dementia in the acute hospital setting, mental capacity was commonly equivocal. This links to the fourth key finding from this research; that judgements of incapacity impacted on the extent of involvement of people with dementia in making decisions about place of residence.

In this context, medical practitioners found it particularly challenging to implement binary notions of mental capacity to enact the legal requirements of the MCA. Imposing a binary framework onto a condition which is inherently complex and subject to the interpretation and interactions of others was problematic. The significance of the complexity caused by imposing binary conceptions of capacity on people with dementia opens up space to discuss whether the MCA offers an adequate model of decision making in this context, both for those implementing the Act and people with dementia. I therefore consider the adequacy of the MCA, and whether emphasis should be placed on how the law is interpreted and enacted in the medical environment, by considering alternative decision making models and approaches to capacity judgement. This opens discussion about whether changes to the Act itself would ensure the person with dementia and their rights as citizens remain at the forefront of judgements and decision making, or whether this may be achieved by how the current Act is interpreted and implemented in practice.

Representing traditional medical models of decision making, senior medics were expected by all (themselves included) to 'fall on the sword', and enact binary notions of capacity. However, assistance was often sought from medical specialists who were considered experts in the area of mental capacity, indicating uncertainty in the enactment of the Act. In this research it became apparent that within the hospital context, Old Age Psychiatrists were regarded as experts in the area of capacity assessment in relation to discharge decisions, and requesting their specialist input concords with the provisions of the Act. Psychiatrists are medics specialising in mental health conditions, therefore it is unsurprising that they were considered to be the expert decision makers in this context. However, although judgements made by consultants in Old Age Psychiatry were held to be the expert view, practitioners from this service professed that their knowledge for the Act could not be substituted for knowledge of the person, and therefore could not simply be 'parachuted in' to make capacity judgements.

Since data collection, anecdotal evidence from practitioners in this branch of medicine have suggested there has been movement away from Old Age Psychiatry providing expert input to providing a more facilitatory role to practitioners already managing individuals' care. However, there is a lack of research and guidance around this. This exposes tensions around the decision maker and their knowledge of the person as well as the Act itself. Although

practitioners from psychiatry more commonly regarded their role as advisory to the clinical team, rather than to act as assessors and decision makers, the clinical team did not always feel that they had sufficient knowledge or expertise to arrive at a dichotomous judgment. UK research notes capacity assessment in relation to placement issues as the most common reason for referral to such services in the acute hospital setting (Mujic *et al.*, 2009), highlighting that this is a complex issue and that this branch of medicine is commonly called upon to provide expert input.

This complexity of applying the principles of the MCA in practice revealed in this research suggests that although there are ways in which professional practice in the acute hospital setting could be reconsidered to ensure that the provisions of the MCA are enacted, fundamental aspects of the Act itself may create the main barriers to effective implementation. Positive functions of the Act in this context must be recognised. The Act can be described as a boundary object (Star and Griesemer, 1989), and can be useful in the clinical context for enabling clinical decision making (Allen, 2009; Allen, 2014b). In this context, the MCA creates a shared structure, through which mental capacity can be interpreted and enacted to reach a consensus view when there is uncertainty, by forming a clear boundary between capacity and incapacity. Furthermore boundary objects may act as a means to uncover the invisible working practices of practitioners, through highlighting the extent of cross-boundary interdisciplinary organisational work to enact decisions and deliver care in the hospital setting (Allen, 2014a).

However, whether the Act itself creates barriers also resonates with debate around whether the MCA provides an adequate model of decision making for people with dementia. Although the MCA attempts to provide flexible and supportive measures to ensure that appropriate decisions are made in the best interests of people who lack capacity, and with no more procedural difficulty than is required (Bartlett, 2008), this research highlights the particular difficulties of the inflexible concept of mental capacity. The binary divide or dichotomous judgements of capacity and incapacity which is currently required by the MCA has been highlighted as problematic, in particular for people in earlier stages of dementia and people who are considered borderline and variable in terms of their mental capacity (Nuffield Council on Bioethics, 2009; Richardson, 2012). Alternative conceptualisations of capacity supported by different approaches to decision making have resulted from a

response to changes in international law. This includes considering capacity in terms of a continuum of decision-making ability, ranging from fully autonomous through to requiring considerable input and support from others (Burch *et al.*, 2014). Supported decision making is suggested as an approach which may reduce discrimination for people with disabilities through protecting their rights to decision making, and in the context of dementia has been presented as a model which may 'bridge the gap' between times when the person with dementia is able to undertake their own decisions and reliant on a proxy to convey their wishes (Nuffield Council on Bioethics, 2009).

The model of supported decision making is enshrined in Article 12 of the UN Convention on Human Rights, the Convention on the Rights of Persons with Disabilities (CRPD). The Convention entered into force in 2008 and was ratified along with its optional protocol in the UK in 2009 (United Nations, 2006), soon after the implementation of the MCA in 2007. Along with over 150 other countries, the UK has committed to revising domestic legislation as necessary to comply with its provisions (Bartlett, 2012; Burch *et al.*, 2014). The CRPD reflects a major paradigm shift from medical models of mental capacity and decision-making ability to social models of understanding disability. Medical models of disability emphasise the passive nature of people with disability as recipients of healthcare with conditions which can be medically treated, leading to exclusion from decision making, resulting in marginalisation (Bartlett, 2012). This relates to the concept of "cognitive citizenship" in dementia, (Graham, 2004) which suggests compromised health care rights and provision, and therefore citizenship rights are determined (and limited) with reference to cognitive abilities and impairment. Although social welfare models acknowledge that long-term conditions are not always receptive to medical treatment, the focus remains on the limitations and deficiencies of individuals and exclusion from wider society (Bartlett, 2012). A more inclusive approach requires a shift from substituted decision making, moving from a status approach to a functional approach enabled through supported decision making (Devi *et al.*, 2011).

Central to the ethos of supported decision making is that individuals are provided with the necessary supports to make their own decisions based on their views and to communicate these, rather than delegate decision making to another person such as family or friends as in substituted decision-making. Legal power and decision-making autonomy is therefore

retained by the person, who may require representational support through elements of substituted decision making, and the person appoints the representative (Gooding, 2013). Such approaches to decision making are contingent on supportive and trusted family members (trusted by both the person with dementia and health and social care professionals) with whom the person with dementia is willing to share their confidential information (Nuffield Council on Bioethics, 2009). This may represent a more realistic view of autonomy, whereby decisions are made alongside, and with others, reflecting interdependency and involvement of others for advice and guidance from models of relational autonomy (Gooding, 2013; Burch *et al.*, 2014). However, as in cases identified in this research including Mr Collier, Mrs Wright Mrs Parker, Mrs Woodward Jones and Mr Tyler, and not all individuals have a supportive social network, and have potential to be further disadvantaged by reliance on others to jointly negotiate this process. In addition, the role of family as advocates to adequately uphold the wishes of the person with dementia in relation to discharge from hospital is debated (Emmett *et al.*, 2014).

Alternative approaches to binary notions of mental capacity, which incorporate elements of both supported and substituted decision making, may help to 'bridge the gap' by removing the divide between having and lacking capacity (Gooding, 2013; Burch *et al.*, 2014). A 'stepped approach' (Chartres and Brayley, 2010) shifts the focus from whether the person lacks capacity or not, to a status of no loss of legal capacity, emphasising that efforts should be directed to identify decision making impairments and provide appropriate support to enable people to exercise legal agency. A three-tiered approach, which is also based upon a spectrum of autonomous, supported, and facilitated decision making, rather than a loss of capacity (Bach and Kerzner, 2010; Richardson, 2012) can also ensure that people who would previously have been regarded as incapacitous, have their wishes and decisions legally recognised and respected. Proxy supported decision making which lies somewhere between substituted and supported decision making models is reliant on input and representation from trusted individuals with good knowledge of the person's wishes and life-view (Stone, 2015).

Given that two-thirds of the participants in this research were considered to have borderline mental capacity to make their own decisions about going home from hospital, supported decision making may represent an approach to provide scope for those with equivocal

mental capacity to have greater inclusion and autonomy in a decision which has such magnitude. The findings suggest that in order for this to be achieved in practice, patients with dementia and their families would need to be more fully and transparently included in the processes of decision making. The data highlighted that decision making was largely practitioner-led (specifically by medical professionals), and that involvement of families and people with dementia could be improved, avoiding perceptions of participation tokenistic (as in the case of Mrs Baker's involvement in the discharge planning meeting, in which she was only included in the meeting once the decision had been reached between the MDT and Mrs Baker's family): and as a means simply to endorse the professional view. However greater involvement may need to be supported by the investment of even more time and resource. The questions must also be asked whether introducing a potentially increasingly sophisticated models or 'ratings' of mental capacity would make clinical judgement easier for practitioners or further complicate the process of making judgements on mental capacity in the medical setting; and more importantly if this would be likely to result in fairer and more equitable assessment for people with dementia.

In addition to changes in practice, this also raises questions about whether the current provisions of the MCA could support approaches to joint decision making around such key issues in the lives of individuals. This continues to be a contested area (Bartlett, 2012; Richardson, 2012; Burch *et al.*, 2014; Stone, 2015), with the crux of the dilemma being that best interests in the MCA on the one hand is understood as an objective test, which reflects the views of what others consider to be in the best interests of the vulnerable person, or whether on the other hand it reflects respecting the past and present wishes and preferences of the person who lacks capacity. In addition adequate social policy which equates to access to social rights must also be in place to enable the MCA to be enacted to promote the citizenship and human rights of people with dementia (Boyle, 2008; Boyle, 2010).

It has been suggested that changes to the law and the MCA are perhaps less important than ways in which practitioners might be enabled to adapt their own practices to reflect the principles of social models of decision making (Richardson, 2012), given that the main premise of the MCA is to keep people involved in the decision-making process (Bartlett, 2012). Evidence suggests that NHS practitioners value opportunities to improve their

understanding of ethics and the law, and the chance for personal reflection on the moral nature of healthcare practice (Hagger and Woods, 2005). This research has identified that the Act itself may currently limit practice, and the complexity of implementation which practitioners routinely encounter is an important barrier to the involvement of people with dementia and their families in decisions relating to place of residence.

9.4 Social Science in interdisciplinary research

Having discussed the social nature of decisions made in a medical environment by clinicians as lead decision makers; and considered the adequacy of the decision making framework provided by the MCA, I now reflect on how social science perspectives were applied to better understand important decisions around mental capacity, best interests and residence decisions.

This research demonstrates that social science perspectives have a key role to play in interdisciplinary research. Social theory enhances understanding of the application of the MCA in relation to discharge from hospital for people with dementia (*Objective 1*), as it broadens the focus from a medico-legal context through acknowledging the influence of broader social relations which impact on these decisions. I reflect on my theoretical and methodological experiences as a social scientist to discuss the relevance of the discipline in interdisciplinary research.

9.4.1 Reflections on my theoretical and methodological position as observer

As an ethnographic researcher, it was my role to engage with participants in the hospital environment. This included the multi-disciplinary team and other staff, people with dementia as inpatients and their families and friends. My interactions with the participants within this social context enabled me to observe and discuss the enactment of the MCA with those directly affected. This social interactionist approach made it possible for me to present a range of experiences of capacity judgements and hospital discharge, through analysing and interpreting these myriad accounts, and representing these, influenced by social constructionist theories.

In my role as a social scientist researcher, I did not have the experience or insight of a practicing health or social care professional in the, 'realities' of enacting the MCA for people with dementia. However the lens of social science enabled a perspective through which to

observe, analyse and critique the Act, based on a broad range of views, knowledge and experiences. This knowledge of social science concepts and theory may also explain why my interpretation of the application of the Act sometimes differed with professional perspectives.

In this role, I was also required to enact the provisions of the MCA, and to some degree, experienced some of the same complexities as the people I was researching. I was also constrained by the binary concept of mental capacity, and at times, was uncertain about whether individuals with dementia had capacity to consent to participate in this project. I therefore had to make judgments based on my interpretation and application of the Act. However, the consequences of participating or not in this research, were likely to be far less significant than decisions regarding place of residence for individuals. Nevertheless, I also enacted the MCA in practice, which gave me a small amount of insight into the complex decisions facing practitioners and anxieties over ascribing people with the label of capacity or incapacity. Whilst making my own judgments on mental capacity were a necessity of research governance, of key importance was that people with dementia, including those who lacked capacity to consent to participate were enabled to participate. This was critical to gaining the perspective of people with all stages of dementia and ensured that their views, perceptions and experiences could contribute to the story of enactment of the MCA.

Emphasis on the social aspects of the enactment of the Act enabled me to situate this issue in the everyday lived experience of people with dementia. For example, positioning theory and notions of selfhood in dementia (Sabat and Harré, 1992) helped me to reflect on the social conditions of the context. This included considering how people with dementia are perceived by others whilst inpatients in comparison with perceptions of them living at home in the community prior to admission. As patients with a condition which required medical attention, new vulnerabilities and deficits were commonly identified and highlighted by others, impacting on their position as a capable decision maker. Applying social science concepts such as social gerontology, social citizenship and social constructionism to the findings shifts the emphasis of the location of people with dementia from being just patients, and patients with problems – older people with cognitive problems who have a long tradition of being discounted, overlooked and considered unable to make valid societal contributions – towards an understanding of valuable citizens with feelings, wishes and

rights which must be respected. An awareness of cultural norms and social practices established in medicine helped to understand the context in which the MCA was being enacted. Interpretivist approaches also contributed towards understanding the enactment of the MCA, not only as a process of decision making but to recognise the significance of the outcome and what that means to people with dementia and their families.

Theories on agency and citizenship enable debate on whether people with dementia can be empowered through the legislation of the MCA, if supported by others. This recognises both the importance of individuals with dementia as active human agents capable of making choices and decisions and acting upon these (Kontos, 2005; Kontos and Martin, 2013; Martin *et al.*, 2013), but also the necessity of society to understand that people with dementia are not just passive recipients of care but can be active social agents with rights which must be respected (Bartlett and O'Connor, 2010); and the role of healthcare service providers in ensuring against “cognitive citizenship” (Graham, 2004) in the care, treatment and management of patients with dementia, extending to judgements on mental capacity and decisions about place of residence.

Theories critiquing the medicalisation of dementia, in particular those which emphasise power relations embedded in medical culture (Coombs and Ersser, 2004; Lupton, 2012); negative consequences such as social control by medical professionals and a lack of understanding of the social causes of dementia (Bond, 1992); and medical decision making models which prohibit inclusion of people with disabilities in decision making due to medicalised conceptions of limitations caused by their condition (Bartlett, 2012), facilitate an understanding of the context influencing how practitioners interpret and make sense of the provisions of the Act. Such theories support the consideration of traditional institutional practices and relations in the hospital setting, and whether these are evolving, influenced by changes in law and broader societal attitudes to dementia.

Social constructionist theories of dementia presented in Chapter 4 which emphasise the importance of personhood and the influences of the actions of others on the experience of dementia in reframing dementia more positively (Sabat and Harré, 1992; Kitwood, 1997; Sabat, 2001; Kontos, 2005; Sabat, 2005; Hughes *et al.*, 2006; Hughes, 2011b; Kontos and Martin, 2013), were applied to explore the meaning of mental capacity. This critique

highlighted the significance of the dichotomous distinction between mental capacity and incapacity as set out in the MCA. This research shows that when interpreted and applied to decisions about place of residence on discharge for people with dementia, these constructs can be unhelpful and problematic. These narrow constructs of mental ability do not always enable practitioners to implement the Act in the way it was intended – to respect and uphold the wishes and rights of vulnerable individuals. A significant proportion of patients with dementia in this research could not be readily positioned as having or lacking capacity to make residence decisions, and in response, practitioners had to employ a range of complex and resource-intensive strategies to position patients within this binary framework. For example Mrs Woodward Jones required an inpatient stay on a specialist dementia ward with considerable input from Old Age Psychiatry to determine her decision making capacity; Mrs Baker required two home visit assessments; and several patients including Mrs Gardiner endured an extended stay on the ward whilst their decision making capacity was explored.

In addition to the methodological insights applied to the data, a realist ethnographic perspective (Hammersley, 1992) also uniquely shaped my relationship with the various healthcare teams throughout data collection. Theoretically, my position as researcher was to become an 'invisible' part of the team, and to remain as an impartial observer of events and gather information. This approach worked well, and enabled me to build relationships with key informants, including consultants, senior nursing staff and Occupational Therapists, and negotiate access to medical spaces where relevant decisions were made. These spaces were off limits to non-practitioners, accessed only by designated practitioners within the multi-disciplinary team. Although clearly setting out my observational stance, on occasion, the MDT (including consultants) looked to me to directly contribute to decisions on mental capacity – in particular, in complex cases. In these cases I reiterated my role as an observational researcher, who could not contribute to the decision-making process. Practitioners understood me to have expert knowledge of the MCA and its application in practice in this context. This may imply that despite expressed confidence in the Act and practice, senior practitioners acting as decision makers still welcomed 'expert' advice and guidance, suggesting uncertainty and lack of confidence in interpretation and enactment.

Despite declining to give case-specific advice, I may have influenced practice in a more subtle ways. Although I only made notes, and did not participate in conversations during key events such as MDT meetings, my presence appeared to have some impact on practice.

... she [ward manager] said again how much I've just been part of the team and I'd fitted in. She also made a very interesting comment, she said that she thinks that just my being there on the ward was useful and it made them think about what they were doing. This made me reflect - has the research alone influenced the behaviour and if so, whose behaviour has been influenced? Also, is this a positive thing or is it a negative that I've had an impact of being there, have I not kind of captured a true picture? So in research terms, have I altered the field that I've been working in but if I have altered it, will it have been for the better? If the result is that, I've made people more focussed on thinking more carefully about capacity decisions and discharge decisions then I think that's a positive thing. I can't think of a way it might have impacted detrimentally on a patient. Maybe other than for staff erring on the side caution and not discharging home but I really don't think that would be the case. If it's helped people being more reflective in their practice and pay more attention to capacity issues then I think that can only be a positive outcome really.

Reflective notes 201108

This exchange with the ward manager revealed that despite my objective of remaining impartial, my presence alone may have been sufficient enough to influence practice, and the presence of the researcher will always influence the field. This quote also validates methodological choices as it illustrates that the data collection methods were on the whole readily accepted by the hospital teams. Only one consultant was slightly suspicious and unnerved by my presence during MDT meetings and ward rounds. This consultant seemed concerned that I was critiquing his professional judgement, and semi-joked with me about ending up on an exposé TV documentary. During MDT meetings I was sometimes asked to “close my ears” particularly when having a conversation which was questionable whether it was in keeping with the Act, serving to demonstrate a clear understanding of the Act, but the struggle to enact this in practice. Whilst this may demonstrate elements of paternalistic

practice, in the main, the practitioners involved gave me full access to 'private' medical spaces, indicating confidence in their practice with 'nothing to hide'.

Whilst remaining as impartial as possible during data collection, engaging with and interpreting the data over several years, highlights many of the influences which I bring to the data as a social scientist. My wish to champion the rights of vulnerable older people inevitably means that through this research, I have selected and presented examples from the data to represent both positive and negative experiences of the enactment of the MCA in this context. This interpretation may therefore convey some agreement or disagreement with decisions on mental capacity judgements and discharge outcomes for people with dementia.

Whilst social science perspectives including social constructionism, grounded theory and ethnographic methods were used to collect and analyse this data, this research makes its own contribution to enhance interpretation of data using social science perspectives. Many of the findings which I present in this thesis are based on my observations of, and practitioner reflections on practitioner-patient relationships with people with dementia, and, in particular medical practitioners and doctors practicing in the acute hospital sector. Existing theories on doctor-patient relationships explore power relations between medical practitioners and patients in terms of decisions around management and care of illness. This is classically conceptualised in terms of four models, which incorporate paternalism and power resting with the practitioner as the decision maker, to a deliberative model in which the patients values are explored and the patient is supported to make their own choices (Emanuel and Emanuel, 1992). Although it is recognised that there has been a shift from paternalistic models of practice towards a more person-centred approach based on a model of shared decision making and recognising the validity of the perspective of the patient (Kaba and Sooriakumaran, 2007), this relationship remains inherently complex (Burcher, 2014). These models have tended to focus on interactions concerning the management of physical health, and assumptions that the patient is cognitively intact. When considering the experiences of the doctor-patient relationship specifically for people with dementia, the emphasis has often been around disclosure of the condition and the role of triadic relationships including family relatives (Fortinsky, 2001; Adams and Gardiner, 2005), and truth-telling, (Marzanski, 2000) and commonly in primary care and GP interactions with

people with dementia around disclosure on diagnosis (Downs *et al.*, 2002; Turner *et al.*, 2004; Downs *et al.*, 2006). Proctor considers power imbalances leading to exclusion from routine care decisions in interactions with doctors in day hospital (Proctor, 2001), however this research focuses on interactions specifically on the judgements of doctors on abilities of people with cognitive impairment and dementia to make important decisions. This is an area which is under-researched and a recent review of shared decision making in dementia indicated that there are no studies of involvement of people with dementia in decision making in the inpatient setting relating to medical decision making (Miller *et al.*, 2016). The findings presented in this thesis further develops theories on citizenship and dementia in two ways. First, it makes a strong case to underscore the importance of practitioners including people with dementia in decisions which significantly impact on their lives and well-being, irrespective of judgements on their mental capacity to make this decision themselves. This is highlighted through cases with a positive outcome such as Mrs Baker, who returned home in accordance with her wishes despite being judged to lack capacity to make this decision. However, it is also reinforced by exploring examples in which patients were not as fully included in the decision as they might have been, and examining the barriers resultant from the intricacies of the Act which make interpretation and implementation difficult for practitioners.

Secondly, this work adds to the literature which promotes maximising the meaningful involvement of persons with dementia in research (Murphy *et al.*, 2015). In particular, I emphasise the importance of the inclusion of people who lack capacity to participate in research, who have traditionally often been excluded from the research process. This has meant that their experiences have either remain untold or retold through the lens of another (family member, paid carer, health and social care professional or the researcher themselves in an observational role). Undoubtedly, the narratives of practitioners, families and my own interpretation of observations and interactions contributed to my understanding of the person with dementia, the social constructionist ethos underpinning this research helped me to understand that people with dementia may have their own way of communicating their interpretation of events and circumstances, and that these should not be ignored. The combination of ethnographic interviews and observations enabled me to collect information from people with early to advanced stages of dementia, and often in their own words. In our interactions this helped me to move away from making literal

inferences from our conversations, and to put the person with dementia at ease to encourage each individual that their experience was important and their story should be told from their perspective in their own words. Furthermore, social constructionist approaches to dementia also informed my application of grounded theory to interpret the data in the same way – that I should question and challenge my own assumptions about people with dementia when interpreting our interactions and reconstructing their narratives which form the narrative for this thesis.

9.5 Strengths and limitations

A review of the literature suggests that this research presents the only in-depth ethnographic study of the implementation of the MCA in practice, detailing the enactment of assessment of capacity and determination of best interests in relation to place of residence for people with dementia on discharge from hospital. Whilst these detailed findings acknowledge the complexities faced by practitioners, they go beyond this to recognise specific factors which make the enactment of the MCA particularly complex to implement in this context. This is achieved by describing practice and by highlighting what makes such decisions particularly challenging for the practitioners who must undertake such decisions as part of their routine practice.

The research was conducted between June 2008 and June 2009, eight months after the provisions of the MCA were implemented in clinical practice. Therefore the findings reflect a detailed insight into the realities of practice in a specific place at a specific time, and to particular people. This was a unique time and recorded early implementation of the Act, in a context where it was given considerable attention. However, given the timescale from data collection to completion of this thesis, it is fair to consider whether the findings of this research continue to resonate in a broader and current context. Current literature and policy findings would suggest that the findings remain relevant and that the enactment of the MCA for people with dementia remains complex with practitioners continuing to struggle to implement the Act in a way to best respect and enhance the rights of people with dementia to make their own decisions on important aspects of their lives.

Key messages from the House of Lords Select Committee report resonate with many of the findings from this research, suggesting that little has changed in practice since this research was conducted, and furthermore that the applicability extends beyond acute hospital settings in the North East of England. The report highlights widespread support for the Act and how it was described by practitioners in unusually enthusiastic terms, however this appreciation and understanding of the Act is not translated in practice. The report states that capacity assessments are often not conducted, and when carried out are often of poor quality. Supported decision making is not well-embedded in practice and prevailing cultures of risk-aversion and paternalism result in institutional obstruction to the concept of unwise decision-making. Clinical judgements or resource-led decision making dominate best-interest decisions, and the wishes, feelings and thoughts of the person who lacks capacity are not routinely prioritised (House of Lords Select Committee on the Mental Capacity Act 2005, 2014).

The legal landscape has now changed due to the implementation of Deprivation of Liberty Safeguards (DoLS), part of the MCA and applies only to people in hospitals or care homes, and only those with a mental disorder, who are judged to lack capacity regarding a specific decision. The safeguards should ensure that such vulnerable people are cared for in the least-restrictive way (Ministry of Justice, 2008). Older people with dementia are at greatest risk of requiring detention and are also at high risk of medical morbidity and movement between hospitals and care (Shah and Heginbotham, 2010). However, although the safeguards came in to effect on 1 April 2009 (Department of Health, 2010a), the impact on this research was minimal. A significant proportion of the data was collected prior to implementation and the topic of safeguards was rarely encountered in interviews or observations. However a Supreme Court ruling in 2014, defined the three-part acid test for defining deprivation of liberty for the purposes of Article 5 of the European Convention on Human Rights: if the person lacks capacity to consent to their care/treatment arrangements; are under continuous supervision and control; and are not free to leave. This changed the way the safeguards were implemented in that now all people who are judged to lack capacity and are considered to be at risk of a deprivation of their liberty in a secure setting require a DoLS assessment (Department of Health, 2015a). Given that over half of the patients in this research were judged to lack capacity, such patients would now receive a DoLS assessment and their best interests may be subject to greater scrutiny.

This research was conducted in Care of the Elderly wards – arguably areas of good practice – where in many cases, much time and effort was devoted to establishing mental capacity and determining best-interest decisions. The practitioners based on these wards expressed considerable awareness of the social, ethical and legal aspects of mental capacity and best interests. Experiences would be expected to be different in general medical wards or specialist wards such as cardiology or gastroenterology where practitioners are less likely to encounter older people with dementia, and likely to be more focused on acute treatment and care of a specific condition rather than multi-morbidity and social issues which are often part of the care of older people. It would also be reasonable to postulate that if the research had been conducted on specialist dementia care wards, the findings would be different again as it might be expected that practitioners in such wards would have a level of expertise and above-average grasp of the MCA and how this might be implemented in practice.

9.6 Summary

At the heart of the MCA, and this research, is the notion that the person whose capacity is under scrutiny should be given the fairest and best chance of retaining autonomy in decision making. Even if the judgement is that the person lacks capacity, their involvement in the process should still be central when possible. Through the lens of social science theory and method, this critique of the enactment of the MCA has enabled insight into why implementation of the Act is challenging for practitioners in the context of the acute hospital, when making decisions about capacity and place of residence for people with dementia. It also demonstrates the impact on people with dementia and their families. This in-depth study of enactment of the Act may lead to reflection of how the provisions of the Act can be best implemented to ensure that the person with dementia has the best possible chance of making their own decision about whether they go home on discharge from hospital.

Chapter 10. Conclusions

In addressing the aims and objectives of my research, I have explored the interpretive work in which practitioners engage, to make sense of, and enact the MCA when making judgements on the capacity of people with dementia to make decisions about place of residence on discharge from hospital. Findings from the in-depth ethnographic study of 29 patient cases and the analysis of the experiences of health and social care professionals, people with dementia and their families have been presented to capture a range of key perspectives on this enactment. Through the lens of social science, I have critiqued the Mental Capacity Act to demonstrate how practitioners interpret and implement the Act in the acute medical environment. This sheds light on the complex nature of social relations embedded in judgments about mental capacity, by describing the significant, but often hidden or invisible work required by health and social care practitioners to arrive at a judgement of capacity or incapacity; and the extent to which patients with dementia and their families are involved in the major decision of whether they will return home.

The focus of this work was to consider how mental capacity for people with dementia was socially interpreted and determined in the context of hospital discharge, from acute medical wards soon after the enactment of the MCA, highlighting the social nature of both illness and medical practice. The findings show that through the process of admission to hospital, the way people with dementia live their lives in the community becomes part of their medical narrative, and thus under the locus of the medical team. Consideration of the persons' social circumstances forms an important part of judgments on mental capacity. Furthermore, the decision about whether a person with dementia has capacity to make their own decision about returning home, was most commonly made by a hospital consultant. The consultant has historically been a respected figure, occupying a position of considerable authority, both in the hospital setting and more generally, in western culture. Challenging decisions made by esteemed and authoritative clinicians is perhaps particularly difficult for people with dementia and their relatives, who despite the provisions of the MCA, may be only partially included in important decisions about where they live. As such, whether a person with dementia has the mental capacity to make a decision about living at home became largely medically determined, despite the significant social nature of the decision.

In addition, judgements on mental capacity must conform with legal standards set out in the MCA. What is evident, is the complexity of many of the capacity and best-interest decisions explored through this research. Critique of the implementation of the MCA in medical practice in the context of residence decisions reveals that practitioners understood and appreciated the principles of the Act, but the rigidity of the legal framework, which requires a binary capacity outcome, made it difficult for practitioners to fully implement the MCA in relation to hospital discharge in the context of time and other resource constraints of hospital setting.

Whilst many examples of good practice were observed, the effort and resource invested by practitioners to try to apply the legal framework would imply that the principles are regarded as an important part of practice to protect and respect people with dementia. However, the enactment of the act in practice was often problematic. Primarily, this resulted from the necessity to ascribe people with a complex and changeable cognitive condition, and perhaps also with a complex set of social relations, to fit with a disambiguous notion of mental capacity. This presented a significant barrier to the implementation of the Act in this context and is particularly well-illustrated by the 20 borderline cases of mental capacity observed. The complex set of social relations occurring in this context, highlights that the practice of individual practitioners is mediated not only by the law, but also continues to be shaped and often constrained by deep-rooted institutional practice of medicine, and broader social perceptions of dementia.

10.1 The unique contribution of this thesis

This thesis presents findings which describe how the Mental Capacity Act is interpreted, understood and implemented with a focus on the importance of social meaning of the law and its enactment in the hospital setting. The paradigm of social science enabled the detailed description and close scrutiny of 29 individual journeys of people with dementia through the decision-making process - from pre-admission to the discharge outcome – capturing both the enactment of the MCA in practice and the implications of this for the person with dementia and their families.

With people with dementia, their families and health and social care practitioners, I explored what it means to categorise individuals with dementia as having or lacking capacity to make important decisions about place of residence on discharge from hospital. Mental capacity and involvement in decision making is situated in the broader social context of how dementia is understood, and how medical and cultural assumptions contribute to people with dementia being enabled or prevented from having agency, and having their wishes recognised and respected. This therefore addresses an important gap in the body of work around the MCA, which has emerged in the last 10 years. It provides a unique contribution in being the only study of the implementation of the MCA in practice which explores the multiple, detailed and rich perspectives of all stakeholders, through ethnography and social science. Importantly, the views of people with dementia and their family carers are presented, as well as the experiences of medical staff who must enact a legal framework pertaining to the largely social issue of hospital discharge.

This work emphasises the importance of understanding the complex social relations which occur in the hospital context, which are embedded in judgments about mental capacity. This is particularly highlighted through the examination of cases which were most challenging for practitioners and considering these alongside more straightforward cases.

10.2 Current relevance to practice

Although data collection was conducted almost 10 years ago, it remains the only evidence of how the MCA is implemented in practice within the context of hospital discharge for people with dementia, helping to close the gap in research and literature around the involvement of people with dementia in shared decision making in the inpatient setting (Miller *et al.*, 2016).

In the broader social context, despite policy and cultural changes, the social relations of dementia and ageing mean that people with dementia continue to remain on the margins of society, in particular in relation to autonomy and agency. Social science literature continues to recognise that despite the beginnings of societal change in attitudes towards dementia, a range of challenges still remain (Higgs and Jones, 2009; George and Whitehouse, 2010; Birt *et al.*, 2017; Higgs and Gilleard, 2017; McParland *et al.*, 2017).

Despite changes in cultural and societal understandings of dementia, negative perceptions of the condition still require further challenge. Biomedical approaches commonly continue to dominate understandings of dementia, with explicit focus on loss of function, deficiency and death. Moving away from a dichotomised approach to dementia as 'normal' and 'abnormal', to a more fluid conception of the condition, which recognises complexity and multiple and myriad experiences may continue to challenge the biomedical understandings of dementia through acknowledging remaining strengths and enduring personhood (McParland *et al.*, 2017). This can be extended to discourses of mental capacity and recognition of mental capacity on a spectrum, challenging unequivocal definitions and an appreciation of the abilities and values of people with dementia. An example of this is whether the contested diagnosis and label of Mild Cognitive Impairment is clinically and/or culturally useful to understand cognitive changes and conceptualisations of 'normal' or 'abnormal changes in the brain amongst older people (Moreira and Bond, 2008) and how this impacts on clinical management and care (Moreira *et al.*, 2008).

The decision-making ability of people with dementia also commonly remains misunderstood. The repositioning of dementia from a discourse of one of deficit to one of agency and interdependence, supports the role people can have in shaping their social world enabling people with dementia to establish themselves as social citizens. This is critical to countering the overt or covert exclusion of people with dementia and supporting equal participation in social practices such as decision making (Birt *et al.*, 2017). This reinforces the need for social change to meet with the legal changes of the MCA, which enshrine the rights of inclusion in decision making for vulnerable individuals in society. Furthermore, the need for improved models of citizenship which accommodate relational aspects of agency such as interdependence, reciprocity and providing support to people with dementia so they can be active partners in their own care is recognised (Kontos *et al.*, 2017). This emphasises the importance of the supportive role others have in achieving involvement in important decisions.

More broadly, as the cure for dementia remains elusive, and policy continues to emphasise the need for early diagnosis of dementia (Department of Health, 2009; Department of Health, 2015b), there is a need to acknowledge the societal impact of dementia and healthcare. There are growing social pressures involved in providing dementia care, and practitioners in this field must take into account cultural and social representations of

dementia present in everyday life (Higgs and Gilleard, 2017). This reinforces the need for those providing care in all settings to consider different social experiences of people with dementia and apply this understanding to their practice.

Specifically in terms of the implementation of the Act, in 2017, the National Mental Capacity Forum published the Chair's annual report, which sets out the main priorities of hearing the voice of the person supported by proper consultation and involvement; and improving understanding of the Act with professionals across a range of sectors, to decrease inappropriate risk-averse attitudes (HM Government, 2017). This indicates that at policy level, there remains the need for literature which enhances a better understanding of the MCA, underpinned by the primary priority of listening to the vulnerable person whose capacity is under question.

10.3 Reviewing the legal framework in practice

Although this thesis provides a critique of the MCA, this work does not diminish the importance and value of the Act, which is founded on the laudable principles of protecting the rights of some of the most vulnerable people in our society. However, this research provides evidence that the legal framework is complex to understand and enact within the context of dementia and hospital discharge.

Imposing a binary framework onto a condition which is inherently complex and subject to the interpretation and interactions of others is problematic. The Act therefore requires that practitioners must engage in a substantial amount of interpretative work and resource to implement the Act, but despite this, the MCA is not always optimally implemented for people with dementia. This interpretive work may play a positive role in preserving the rights of people with dementia, as demonstrated by the amount of time and energy practitioners routinely devoted to exploring mental capacity. For example, through engaging with the person with dementia, their relatives and colleagues to try and gain a detailed picture of the person with dementia and their lives, rather than simply applying the two-stage test without this contextual knowledge. However, in keeping with the Act, the test of capacity must be applied when concerns are raised about mental capacity, which should be clearly documented. Emphasis should be placed on how the law is interpreted and enacted in the medical environment, and the relevance of understanding different

approaches to judging capacity, rather than changes to the law. This may ensure the person with dementia and their rights as citizens remain at the forefront of judgements and decision making.

However, improving how the MCA is applied in practice must be addressed at a more systematic level as well as considering enactment on an individual basis. To ensure the act is optimally implemented, greater accountability and regulation by an appointed body is highlighted in the House of Lords Select Committee report as fundamental to improving the implementation of the MCA in everyday practice (House of Lords Select Committee on the Mental Capacity Act 2005, 2014). Although this is a general aim, it suggests scope for local ownership of particular issues, and local 'champions' may have a role in health and social care services with regard overseeing compliance with the MCA in relation to decisions regarding residence on discharge from hospital.

10.4 Recommendations for good practice

This research suggests areas for both improved clinical and research practice. It endorses that practitioners involved in determining mental capacity and best interest in the acute hospital setting, must ensure that the views and wishes of people with dementia are sought and respected in relation to important decisions which affect their daily lives and rights as citizens. The areas of good practice identified in this work demonstrate that it is possible - irrespective of capacity to make a decision about place of residence - that people with dementia must be included as fully as possible in the decision-making process.

Although this research highlighted issues with implementation of the MCA, considerable evidence of good practice was also identified. Striking examples include the case of Mrs Friar, for whom the exploration of social arrangements and the successful home visit challenged the negative narrative of the community practitioner; and Mrs Baker, who returned home, as she wished, despite lacking capacity to make this decision herself. These positive experiences have important messages for practitioners and also suggests that problems did not necessarily stem from individual practice but were inherent in the Act, and institutional factors and barriers in the acute hospital setting, which may constrain the practice of individuals and teams.

People with dementia and their families may be better included in the decision-making process through a more systematic approach to the assessment of capacity, and determining best interests. This may be encouraged through the use of improved guidance and resources such as the best interest checklist to explore and record the process of decision making. (Ruck Keene *et al.*, 2016). Inclusive approaches to involvement of families and people with dementia throughout the decision-making process, rather than towards the end may facilitate a shared decision-making approach, and avoid the shocks and surprises which several families reported, especially in instances of discharge into care.

Alongside greater inclusion, this valuable and necessary interpretive work must also be more visible. Decisions of such magnitude should be clearly documented to evidence full and fair assessment of capacity and best interests. Recent work suggests that 79% of documented mental capacity assessments were lacking in information, and even significant decisions were rarely documented (Jones *et al.*, 2017). Ambiguity over assessment occurs if the interpretive work of practitioners remains invisible. Recording such decisions in a systematic way will enable practitioners to justify their judgements and decisions, which is particularly important in complex cases and when decisions are challenged.

As evidenced by the majority of best-interest decisions resulting in discharge to care, risk-aversion dominated residence decisions in the hospital setting. Although practitioners frequently hoped for a more risk-accepting approach to hospital discharge for people with dementia, this was often considered difficult to achieve within the culture of the acute hospital setting and the constraints of community resources available. As this research highlights the prominence of social determinants of mental capacity, practitioners may wish to consider the possibility of if and when possible, delaying the decision about change of place of residence until post-discharge. This may mean that medical practitioners would be under less pressure to undertake decisions which are more social, than medical in nature and enable others who may have longer-term involvement and knowledge of the person with dementia to determine mental capacity and best interests concerning place of residence. Future research in this area may be necessary to gauge if, and to what extent, the situation has changed in the acute sector, possibly taking into consideration experiences in different acute settings and specialism.

Reviewing opportunities for training around understanding of the MCA for health and social care professionals may also be beneficial. The National Mental Capacity Forum have stated that training must be rooted in practice, rather than in legal jargon to improve standards of implementation of the Act (McNicoll, 2016). Recent research also suggests that innovative models of teaching and learning may improve skills and understanding of the Act (Pattinson *et al.*, 2017).

Barriers remain to including people with dementia who lack capacity to consent to participate in research, from both those involved in research and those acting as consultees. Although this may be a complex process which entails encouraging an appreciation that people in the more advanced stages of the condition can still make a valid contribution, this research demonstrates that direct involvement of this participant group is not only possible, but in this case, necessary to understand as broad a range of experiences as possible. This research demonstrates that with support, people who lack capacity to consent to research can still participate and share their essential views and experiences. This inclusive involvement of people with dementia must therefore be applied to future research.

10.5 Concluding comments

The person with dementia must remain at the centre of decisions which affect their well-being and rights as social beings and citizens. People with dementia must have a voice – both as individuals and collectively. This voice must be respected and supported by others. Whilst this includes families, and the health and social care practitioners who are involved in the provision of treatment and care, this extends to society more broadly to ensure that attitudes continue to change for the better and negative assumptions about dementia continued to be challenged. As researchers, practitioners, and social citizens, we must make time to find out and recognise the wishes and preferences of the person with dementia. Furthermore, these must be respected to ensure that people with dementia continue to be better involved in important life-changing decisions, such as place of residence.

To conclude, capacity assessments and subsequent best interest decisions for people with dementia regarding place of residence on discharge from hospital continue to deserve close

attention. This work identifies areas of good practice and areas of implementation which require review to ensure that the enactment of the MCA can be improved, to benefit practitioners and thus patients with dementia and their families. The magnitude of the decision of deciding whether someone has the ability to make their own decision to return home or move into institutional care must be recognised in the context of enabling people with dementia to have the opportunity to preserve and exercise autonomy, personal choice and liberty. This should remain paramount when considering the mental capacity of the person with dementia in connection with place of residence on discharge from hospital.

Appendix A. Statement of contribution

This statement illustrates my contribution to the research as part of the ACBID team and additional work undertaken specific to the study of this thesis.

Literature

- I devised and ran all literature searches, and reviewed the literature with other members of the team (Dr Helen Greener, Prof Julian C Hughes and Ms Charlotte Emmett)
- I completed additional literature searches specific to the thesis including updates and new literature.

Ethics and project information

- I assisted with preparation of the participant information documents and consent forms with other members of the ACBID team
- I attended the ethics meeting with the Principal Investigator (PI), Prof Julian C Hughes

Fieldwork

- The PI negotiated access to the hospitals and wards. I liaised with the ward consultants and staff to negotiate conduct of the research
- I developed all interview schedules
- I recruited all participants
- I conducted all field observations, interviews and record collection, with Prof John Bond shadowing one observation session
- All fieldwork was transcribed by the ACBID project. I checked and anonymised all transcripts

Analysis

- I devised the coding frame
- I coded all data using NVIVO software, and a selection of transcripts were cross-coded with Prof John Bond
- I wrote all 29 case studies
- I produced all of the memos of themes
- Data workshops with Prof John Bond, Prof Julian Hughes, Ms Charlotte Emmett and myself were held in which themes and analysis were discussed
- Further analysis was conducted independently to explore concepts reported in this thesis.

Appendix B. Participant information



Institute of
Health & Society

*Institute for
Ageing and
Health*

INFORMATION ABOUT THE RESEARCH

CARERS - PART 1

Assessment of Capacity and Best Interests in People with Memory Problems on Going Home from Hospital

Introduction

We would like to invite you to take part in a research study. Before you decide to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. You can ask the researcher questions and talk it over with others if you wish.

Part 1, this part, tells you the purpose of the study and what will happen if you take part.

Part 2 gives you more information about the way the study works.

What is the purpose of the study?

This study aims to look at the judgments and decisions that are made when people with memory problems are discharged from hospital. These decisions are important and can have a significant impact on people's lives. The way in which these decisions are made is not clear. We want to improve knowledge and understanding of the decision making process and the factors which influence the final decisions.

To help us do so, we are gathering the views and opinions of different people who are involved when patients with memory problems are discharged from hospital. This includes the person themselves and their carers as well as professional people such as nurses, doctors and social workers. We want to find out what carers think and feel about discharge from hospital and the choices that are made around this time. We also want to re-interview patients and their carers a few months after discharge from hospital so we can get more information about the impact of these decisions.

We hope that this research will lead to improvements in the way that these decisions are made. Using the information we gather we also want to design a system that other professionals could use in hospitals to ensure that they make the right decisions when people with memory problems are discharged.

Why have I been invited?

You have been named as the carer of someone who has memory problems and is currently in hospital. Their discharge from hospital is being planned. A carer is someone who the person is close to and offers them support and help in their day to day life. This can be a spouse, family member or friend. You have either been nominated by the person themselves or identified by the team looking after your relative or friend whilst they are in hospital.

Do I have to take part?

It is up to you to decide. Your decision will not affect the way your relative or friend is cared for either in or out of hospital. If you decide that you would like to take part we shall ask you to sign a consent form to show that you have agreed. You can withdraw at any time and do not have to give a reason. Withdrawing from the study will not affect the standard of care your friend or relative receives.

What will happen if I take part?

You will be interviewed by the researcher. The interview will involve a discussion of your thoughts and feelings. This may cover a wide variety of topics to do with your relative's discharge from hospital, the future, your health and well being, as well as your role as a carer.

The interview will last somewhere between 30 minutes and an hour, but it can be stopped at any time if you wish it to be. The interview will be taped which allows us to have an accurate record. At the end the researcher will ask you if you would like to be interviewed again, around 3 months later.

Will anyone else be involved?

We will interview your friend or relative as well as a professional involved in their care. Alongside this we will observe any meetings, such as ward rounds, during which their discharge is discussed. A researcher will be present during the meeting but would not participate in any way. This means that their presence would not have an effect on what is discussed or decided.

What are the possible disadvantages and risks of taking part?

Caring for a friend or relative can be stressful especially when they are or have been ill. Some of the topics you discuss with the researcher might be upsetting. You do not have to talk about anything that you would rather keep private.

What are the possible benefits of taking part?

Taking part in this study may have benefits for you. You will have a greater opportunity to talk about your experiences of being a carer than would otherwise be the case. You will be able to express your opinions, feelings and ideas and many people find this beneficial, even if it can be difficult. In addition, this study aims to develop a better way of making decisions about discharging people with memory problems from hospital. This could benefit you, a friend or a relative in the future.

INFORMATION ABOUT THE RESEARCH

PATIENTS (C) - PART 1

Assessment of Capacity and Best Interests in People with Memory Problems on Going Home from Hospital

Introduction

We would like to invite you to take part in a research study. Before you decide to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. You can ask the researcher questions and talk it over with others if you wish.

Part 1, this part, tells you the purpose of the study and what will happen if you take part.

Part 2 gives you more information about the way the study works.

What is the purpose of the study?

This study aims to look at the judgments and decisions that are made when people with memory problems are discharged from hospital. These decisions are important and can have a significant impact on people's lives. The way in which these decisions are made is not clear. We want to know more about the decision making process and the factors which influence the final decisions.

To help us do so, we are gathering the views and opinions of different people who are involved when patients with memory problems are discharged from hospital. This includes the person themselves and their carers as well as professional people such as nurses, doctors and social workers. We want to find out what carers think and feel about discharge from hospital and the choices that are made around this time. We also want to re-interview patients and their carers a few months after discharge from hospital so we can get more information about the impact of these decisions.

We hope that this research will lead to improvements in the way that these decisions are made. Using the information we gather we also want to design a system that other professionals could use in hospitals to ensure that they make the right decisions when people with memory problems are discharged.

Why have I been invited?

Your doctors feel that you have problems with your memory. You are currently in hospital and your discharge from hospital is being planned. Our research project is taking place in this hospital and patients with similar problems are being asked if they would like to take part.

Do I have to take part?

It is up to you to decide. Your decision will not affect the way you are looked after either in or out of hospital. We shall describe the study and go through this information sheet, which you can then keep. If you want to take part we will ask you to sign a consent form to show that you have agreed and which aspects of the study you want to be involved in. You can withdraw at any time and do not have to give a reason. Withdrawing from the study will not affect the standard of care you receive.

What will happen to me if I take part?

If you decide to take part the researcher will arrange to interview you. The interview will involve a discussion of your thoughts and feelings about discharge from hospital and the future.

The interview will last somewhere between 30 minutes and an hour, but it can be stopped at any time if you wish it to be. The interview will be taped which allows us to have an accurate record. At the end the researcher will ask you if you would like to be interviewed again, around 3 months later.

Will anyone else be involved?

We also want to get the opinions of other people involved in your care and discharge from hospital.

Carer: A carer is someone who you are close to and offers you support and help in your day to day life. This can be a spouse, family member or friend. The researcher would interview them and record the interviews. They may talk about a variety of subjects related to your health, home life and discharge.

Professionals: The researcher would interview one of the professionals involved in your care. This interview would also be recorded.

Meetings: We would like to observe any meetings, such as ward rounds, where your discharge is discussed. A researcher would watch the meeting and take notes, but would not participate in any way. This means that their presence would not have an effect on what is discussed or decided.

You can participate in the study whether or not you are willing to allow us to speak to your carer /professional or observe meetings. When you complete the consent sheet we will ask you to sign to show which parts of the study you agree to.

What are the possible disadvantages and risks of taking part?

Leaving hospital can be a stressful time. Some of the topics you discuss with the researcher might be upsetting. You do not have to talk about anything that you would rather keep private.

What are the possible benefits of taking part?

Taking part in this study may have benefits for you. You will have a greater opportunity to talk about your experiences of discharge and hospital than would otherwise be the case. You will be able to express your opinions, feelings and ideas and many people find this beneficial, even if it can be difficult. In addition, this study aims to develop a better way of making decisions about discharging people with memory problems from hospital. This could benefit you directly were you to be admitted to hospital in the future.

INFORMATION ABOUT THE RESEARCH

PART 2 - HOW THE STUDY WORKS

Assessment of Capacity and Best Interests in People with Memory Problems on Going Home from Hospital

What if there is a problem?

It is important that we carry out our research in the best way possible. We want to hear any suggestions or advice you might have for us. If you are unhappy with any aspect of the study or the way you have been treated you have the right to make a complaint.

If you have a concern or question about any aspect of this study, you should feel free to speak to the researchers who will do their best to answer your questions:

Marie Poole

Telephone: 01912227215

Email: marie.poole@ncl.ac.uk

Dr Helen Greener

Telephone: 01914455212

Email: helengreener@doctors.org.uk

If you feel uncomfortable contacting them, are unable to do so or wish to make a formal complaint please contact the head of the research project:

Dr Julian Hughes

Telephone: 01912934057

Ash Court

Email: j.c.hughes@ncl.ac.uk

North Tyneside General Hospital

Rake Lane, North Shields,

NE29 8NH

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for compensation against Northumbria Healthcare NHS Trust. You may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

If the researchers were to become aware of any inappropriate practice, the matter would be reported to Dr Hughes, the head of the research project. Dr Hughes would discuss the matter with the most appropriate senior member of staff. In other words, if the inappropriate practice involved a nurse, the ward sister or hospital matron would be informed; if the inappropriate practice involved a junior doctor, the matter would be discussed with the responsible consultant. If the inappropriate practice were to involve a senior member of staff (e.g. a ward sister or a consultant), as well as discussing the matter directly with the professional involved, Dr Hughes would raise the issue with the professional's line manager or chief executive. If the inappropriate practice involved an independent nursing or residential home, Dr Hughes would raise the matter with the manager of the home and with the appropriate independent inspection team.

What will happen to the results of the research study?

The results of this study may be published in national or international, peer reviewed journals. In this kind of research exactly what you say is particularly important but you will not be identified in any report or publication.

Who is organising and funding the research?

The research is being carried out at Newcastle University. All of the people involved in the research are employed by either Newcastle University or the National Health Service. The research is being funded by the Research for Patient Benefit Programme, which is a national Department of Health programme.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. This ensures that your safety, rights, wellbeing and dignity are protected. This study has been reviewed and approved by the Newcastle & North Tyneside 2 Research Ethics Committee.

Will my taking part be kept confidential?

All the interviews which are carried out by the researcher are tape recorded. They are then written down word for word (transcribed). Once transcribed the tapes are destroyed. Your personal information will remain confidential and only available to the research team. The information provided by the tapes is analysed by the research team and forms the basis for the results of the project. Some of the results may include your comments during the interviews. However, all the information gathered during the interviews is anonymised so that you could not be identified from the results. The anonymous written information will be stored on password protected university and National Health Service computers and stored for 10 years.

Will anyone else be told that I am taking part?

A letter will be sent to your GP but it will only let them know you are being interviewed. Your GP will not be told what you say to the researcher except if the researcher is concerned for your wellbeing.

Can the researcher break confidentiality?

There are certain extreme circumstances under which the researcher would break confidentiality. This would only take place if they felt your safety or the safety of other people was at risk. They would only reveal the information necessary to prevent harm. Depending on the situation they might inform the professionals caring for you or your relative in hospital or your GP. We feel that breaking confidentiality is serious and it would only be done if absolutely necessary. The researcher would tell you why and what action they planned to take. Because this decision is important they would also speak to other members of the research team.

Help, Support & Independent Advice

If you feel you would like to discuss any aspects of the study or the issues you have discussed with the researcher, such as dementia or being a carer, there are several voluntary organisations who can offer you support and advice. They can also give independent advice about this project.

Alzheimer's Society
North East Area Office,
Sinclair Court,
Darrell Street,
Brunswick Village,
NEWCASTLE UPON TYNE
NE13 7DS

Telephone: 0191 217 3810
Website: www.alzheimers.org.uk
Email: ron@alzheimers.org.uk

Alzheimer's Society Helpline: 0845 300 0336
Monday to Friday from 8.30am to 6.30pm.

Carers UK
32-36 Loman Street,
Southwark,
LONDON
SE1 0EE

Telephone: 020 7490 8818
Fax: 020 7490 8824
Website: info@carersuk.org
Email: www.carersuk.org

CarersLine: 0808 808 7777
Wednesday & Thursday from 10am-12pm & 2-4pm

**Age Concern Newcastle
upon Tyne**
MEA House,
Ellison Place,
NEWCASTLE UPON TYNE
NE1 8XS

Telephone: 0191 232 6488
Fax: 0191 235 9925
Email: enquiries@acnewcastle.org
Website: www.acnewcastle.org

Age Concern North Tyneside
13 Saville Street West,
NORTH SHIELDS
NE29 6QP

Telephone: 0191 280 8484
Fax: 0191 280 8485
Email: office@ageconcernnorthtyne.org
Website: www.ageconcernnorthtyne.org

Age Concern Helpline: 0800 00 99 66
7 days a week from 8am - 7pm

INFORMATION ABOUT BEING A PERSONAL CONSULTEE

Assessment of Capacity and Best Interests in People with Memory Problems on Going Home from Hospital

Consent and research

Under usual circumstances people need to give their consent before they can participate in research. In order to give consent they must be able to understand the information about the research and be able to retain this information and weigh it before deciding if they want to take part. They must also be able to communicate their decision.

Unfortunately, some people with memory problems cannot give consent. However, their opinions and feelings are still relevant and in some types of research it is important that they can be involved. If this is the case the person can be involved if the researchers have the agreement of a *personal consultee*.

What is a personal consultee?

A consultee is person who cares for or is interested in the wellbeing of someone who cannot consent. They must also be willing to be asked their opinions about the person's involvement in the project. Although can they give their opinion and advice they cannot give consent for another person.

Do I have to be a personal consultee?

If you do not want to be involved or feel unable to give your opinion for any reason you do not have to. The researcher will try to identify another person who can fulfil the role of consultee. If you know of someone else who might be willing to be consulted it would be helpful if you could give their name. Sometimes it is not possible to identify a personal consultee and in these circumstances we will nominate another person who will advise us about whether your friend or relative should be involved in the research.

Why have I been asked to be a personal consultee?

You have been identified as someone who is involved in caring for or is interested in the welfare of a person who is eligible to be involved in our research project. The researcher has met the person and feels they cannot give consent. Nonetheless, the person has not objected to being involved.

What do I have to do if I agree to be a personal consultee?

We will give you the information that a person usually receives if they are being asked to participate in our project. Please take time to read the information carefully. You can ask the researcher questions and talk it over with others if you wish.

We will then ask your advice about whether your friend or relative should be involved in the project. You should think about what the person's wishes and feelings about taking part in the project would be if they could give consent. You should think about their past and present wishes and whether you feel they would be content to be involved now or whether they would find it too difficult or too upsetting.

Do I have to agree for my friend or relative to take part?

It is up to you to decide. If you advise us that the person should not be involved the researcher would not include them in the study. This would not affect the way your relative or friend is cared for either in or out of hospital. If you feel they would have agreed to take part we would ask you to sign a form. This form shows that, had they been able to decide for themselves, you feel they would probably have agreed to take part.

You can withdraw them from the study at any time and do not have to give a reason. In addition, should the person object in any way to being involved they would be withdrawn from the study. Withdrawing from the study would not affect the standard of care your friend or relative receives.

What am I agreeing to?

The project has several parts, as you will see from the information sheet. We will ask you about the different parts of the research separately. You do not have to agree to all of them. We may also ask you to participate in the research as a carer. This is a different role and the researcher will discuss it separately.

Who has reviewed this study?

There are national rules and guidance in place which govern the involvement of people who cannot give consent. These rules ensure that the rights of the person are protected, their wishes and feelings are respected and that research involving people who cannot consent is carried out properly.

Before a research project can involve people who cannot give consent it must show that it adheres to these rules. This project has been reviewed by an independent group of people called a Research Ethics Committee. This ensures that participants' safety, rights, wellbeing and dignity are protected. This study has been reviewed and approved by the Newcastle & North Tyneside 2 Research Ethics Committee. This ethics committee specifically reviews and approves research involving people who cannot consent.

INFORMATION ABOUT THE RESEARCH

PATIENTS (NC)

Assessment of Capacity and Best Interests in People with Memory Problems on Going Home from Hospital

This research is about decisions that are made when people with memory problems leave hospital

Introduction

- We would like ask you to take part in a research study.
- Before you agree to take part it is important that you know about what will happen.
- Please take time to read this information carefully.
- You can ask the researcher questions and talk it over with other people.

What will the study do?

- It will find out more about the way people with memory problems are looked after.
- It will find out more about the important decisions that are made around the time they leave hospital.
- To find out more we want to interview patients and the people who care for them.
- This could lead to improvements in the way that the decisions are made.

What will happen during the study?

- We will talk with you and ask your views and opinions about leaving hospital.
- We would like to talk to someone who cares for you at home.
- We need your agreement to talk to your carer.
- A carer is a friend or relative who helps and cares for you at home, but do not worry if you cannot think of such a person.
- We would also like to talk to someone who is caring for you in hospital, such as a doctor or nurse.
- When there are meetings about your discharge we would like to watch them and take notes.

Why have I been invited?

- Your doctors feel that you have problems with your memory.
- You are currently in hospital but might be leaving soon.
- Other patients with similar problems are being asked too.

Do I have to take part?

- You do not have to take part. It is up to you to decide.
- Your decision will not affect the way you are looked after.
- You can stop at any time and do not have to give a reason.
- If you decide to stop you will be treated in the same way.

What will happen if I want to take part?

- If you want to take part we will ask you to sign a form.
- The form shows that you have given your permission to us to talk to you and to your carer.
- Before the researcher interviews you they must speak to someone else to ensure that your taking part is the best thing for you to do.
- If they are in agreement the researcher will arrange to meet you.
- The researcher will ask you about your thoughts and feelings about leaving hospital.
- This will take around half an hour.
- The interview will be tape recorded so we know exactly what was said.
- At the end the researcher will ask if you would like to be interviewed again in around 3 months time.

What are the possible disadvantages and advantages of taking part?

- You would be able to talk to the researcher about your feelings and thoughts.
- This can sometimes be stressful or upsetting.
- But people can feel better after talking about the way they feel
- You do not have to talk about anything that you want to keep private.

Will my taking part be kept confidential?

- Yes, all personal information would be kept confidential.
- That means it would only be available to certain members of the research team.
- In the end you will not be named in any of the results or written information.
- The written information will be stored safely for 10 years.
- Confidentiality will only be broken if there were to be a big worry about your health or safety or well being.

Is the research safe and is it being properly done?

- The research has been looked at by the National Institute for Health Research, who are paying for it.
- It has also been passed by the appropriate Research Ethics Committee.
- We can give you more details about this and any other further information if you wish.
- If the researchers saw anything being done that they did not think was proper, Dr Hughes (the leader of the research) would talk to those in authority to stop this from happening.

What if there is a problem?

- If you are unhappy with anything that has happened during the study you can make a complaint.
- It might be helpful to speak to a friend or relative as well
- Please feel free to speak to the researchers who will do their best to answer your questions:

Marie Poole	Telephone: 01912227215 Email: marie.poole@ncl.ac.uk
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Dr Helen Greener	Telephone: 01914455212 Email: helengreener@doctors.org.uk
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- If you want to make a formal complaint please contact the Chief Investigator:

Dr Julian Hughes Ash Court North Tyneside General Hospital Rake Lane, North Shields, NE29 8NH	Telephone: 01912934057 Email: j.c.hughes@ncl.ac.uk
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- If you would like any extra support or advice you can contact:

Alzheimer's Society	Telephone: 0191 217 3810
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Alzheimer's Society Helpline: 0845 300 0336
Monday to Friday from 8.30am to 6.30pm.

Age Concern Newcastle upon Tyne	Telephone: 0191 232 6488
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Age Concern Helpline: 0800 00 99 66
7 days a week from 8am - 7pm

INFORMATION ABOUT THE RESEARCH

STAFF ON THE WARD

Assessment of Capacity and Best Interests in People with Dementia on Discharge from Hospital

Introduction

There is currently a research project taking place on this ward. The research is studying what happens when people with dementia are discharged from hospital. As part of the project there is a researcher (Marie Poole) spending time with the clinical team during ward rounds and discharge meetings. Certain patients with dementia and their carers will also be interviewed by Mrs Poole or another researcher, Dr Helen Greener.

What is the purpose of the study?

This study aims to look at the judgments and decisions that are made when people with dementia are discharged from hospital. These decisions are important and can have a significant impact on people's lives. The way in which these decisions are made is not clear. We want to know more about the decision-making process and the factors which influence the final decisions.

To help us do so, we are gathering the views and opinions of different people who are involved when patients with memory problems are discharged from hospital. This includes the person themselves and their carers as well as professionals caring for people with dementia. We are also observing the decision-making process which takes place in clinical meetings.

We hope that this research will lead to improvements in the way that these decisions are made. Using the information we gather we also want to design a system that could assist professionals in making decisions when people with dementia are discharged from hospital.

What are the researchers doing?

Meetings

- The researcher is not present in order to criticise the way the team functions or the decisions that are made. The researcher is present to observe what takes place with minimal interference. She may ask your opinions about whether the patient would be eligible for the study; for example, whether or not a patient has a diagnosis of dementia or if you feel the patient would be unduly distressed by being approached. The only circumstances in which she would make any suggestions would be if she felt there was the risk of a patient being deprived of their liberty without the appropriate legal safeguards.
- If you are discussing a patient who has dementia the researcher might make notes about the decisions the team makes. She will only take information about how the decisions are made and will not take any personal information about the patient.

- If the researcher feels a patient would be eligible to be interviewed as part of the study they may ask you to approach the patient to recruit them to the study. No personal information will be taken during meetings unless the patient agrees not only to be involved but also to have the researcher take these kinds of notes. This is not obligatory and the patient or their consultee makes this decision.
- The researcher will not be involved directly with patients who do not have dementia. She may hear information regarding these patients but will not record anything she hears. She must keep personal information confidential in the same way as clinical staff.

Interviews

- The researcher will interview certain patients with dementia who are being discharged from the ward. Their carers may also be interviewed. The interviews are a discussion of the person's thoughts and feelings about being discharged and will take place on the ward. The plan is to interview the patients and their carers again 3 months later.
- When a patient is identified their capacity will be assessed and consent taken. Patients (or a consultee if the patient lacks capacity) will be asked to give consent for the researcher to interview a member of staff involved in their care. If consent is given the researcher may ask to interview you. These interviews are not obligatory. Full details are available and will be provided if the researcher does request an interview with you.

Do I have to take part?

You do not have to agree to an individual interview and valid informed consent would be necessary, as in any kind of research. However, observation of the team requires the full support of all team members. **If you have any concerns about this observation going on, please feel free to inform the researcher or the ward manager.** Raising concerns or refusing to participate will not affect the terms of your employment or your relationship with the Trust in any way. You have a right to do this. If, on the other hand, you agree to the observation, you will be asked to sign a consent form. You are free to withdraw your consent at any time without giving a reason. Your employment status and relationship with the Trust would not be affected.

What will happen to the information gathered in the meetings and interviews?

The notes taken by the researcher and the interview data will be analysed by the research team. Any personal information will remain confidential and only available to some of the research team. Some of the results may include comments made by staff and patients. However, all the information gathered is anonymised so that no individuals can be identified from the results. The anonymous written information will be stored on password protected university and National Health Service computers and stored for 10 years. Please note that all interviews (*but not meetings*) are tape recorded. They are then written down word for word (transcribed) and then destroyed.

What about confidentiality?

The content of the interviews that the researcher conducts with patients, carers and staff is confidential, as are the observations made by the researchers during meetings. The researcher would only break confidentiality if there were concerned about the safety, health or wellbeing of patient, carer or staff member or a staff member's professional conduct. We feel that breaking confidentiality is serious and we would only do so if absolutely necessary. The researcher would tell you why and what action they plan to take. Because this decision is important they would also speak to other members of the research team.

Who can I discuss the project with?

We want to hear any suggestions or advice you might have. If you are unhappy with any aspect of the study or want to ask any questions please contact the researchers or the Chief Investigator.

Researchers:

Marie Poole

Telephone: 01912227215

Email: marie.poole@ncl.ac.uk

Helen Greener

Telephone: 01914455212

Email: helengreener@doctors.org.uk

Chief Investigator:

Dr Julian Hughes

Telephone: 01912934057

Ash Court

Email: j.c.hughes@ncl.ac.uk

North Tyneside General Hospital

Rake Lane, North Shields,

NE29 8NH

Who is organising and funding the research?

The research is being carried out at Newcastle University. All of the people involved in the research are employed by either Newcastle University or the National Health Service. The research is being funded by the Research for Patient Benefit Programme, a national Department of Health programme.

Who has reviewed the study?

All research in the NHS must be reviewed by a Research Ethics Committee. This ensures that your safety, rights, wellbeing and dignity are protected. This study has been reviewed and approved by the Newcastle & North Tyneside 2 Research Ethics Committee

Appendix C. Consent forms

Centre Number:

Study Number:

Patient identification number:

AGREEMENT OF NOMINATED CONSULTEE

Assessment of Capacity and Best Interests in People with Memory Problems on Going Home from Hospital

Name of patient:	Please initial
<ul style="list-style-type: none"> • I am the general practitioner of the person named above. 	
<ul style="list-style-type: none"> • I confirm that I am not related in any way to the research project nor am I aware of any other conflict of interest. 	
<ul style="list-style-type: none"> • I confirm that I have read and understand the information sheet dated (version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. 	
<ul style="list-style-type: none"> • I understand that my agreeing to their participation is voluntary and that I am free to withdraw them at any time without giving any reason, without the medical care or legal rights of the person named above being affected. I understand that withdrawal would have no impact on my medical care, legal rights, employment status or relationship with the Trust. 	
<ul style="list-style-type: none"> • I understand that the information collected during the study may be looked at by individuals from Newcastle University, regulatory authorities or the NHS Trust where it is relevant to the person named above taking part in this research. 	
<ul style="list-style-type: none"> • <u>I understand that the interview with the person named above will be tape-recorded.</u> 	
<ul style="list-style-type: none"> • In my opinion the person named above would have wished to take part in the study and I agree to their doing so. 	
<ul style="list-style-type: none"> • I agree to the researcher interviewing a hospital professional involved in the care of the person named above. YES / NO Initials 	
<ul style="list-style-type: none"> • <u>I agree to the researcher reviewing the hospital medical notes of the above named person.</u> YES / NO <u>Initials</u> 	
<ul style="list-style-type: none"> • I agree to the researcher observing meetings relevant to their discharge. YES / NO Initials 	

.....
Name of Consultee
Date
Signature

.....
Name of Researcher
Date
Signature

Centre Number:

Study Number:

Patient identification number:

AGREEMENT OF PERSONAL CONSULTEE

Assessment of Capacity and Best Interests in People with Memory Problems on Going Home from Hospital

Name of patient:	Please initial
<ul style="list-style-type: none">I am involved in caring for or am interested in the welfare of the person named above.	
<ul style="list-style-type: none">I confirm that I am not related in any way to the research project nor am I paid for caring for them.	
<ul style="list-style-type: none">I confirm that I have read and understand the information sheet dated (version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
<ul style="list-style-type: none">I understand that my agreeing to their participation is voluntary and that I am free to withdraw them at any time without giving any reason, without my medical care or legal rights being affected nor those of the person named above.	
<ul style="list-style-type: none">I understand that the information collected during the study may be looked at by individuals from Newcastle University, regulatory authorities or the NHS Trust where it is relevant to the person named above taking part in this research.	
<ul style="list-style-type: none"><u>I understand that the interview with the person named above will be tape-recorded.</u>	
<ul style="list-style-type: none">In my opinion the person named above would have wished to take part in the study and I agree to their doing so.	

<ul style="list-style-type: none">I agree to the researcher interviewing a hospital professional involved in the care of the person named above. YES / NO Initials
<ul style="list-style-type: none"><u>I agree to the researcher reviewing the hospital medical notes of the above named person.</u> YES / NO Initials
<ul style="list-style-type: none">I agree to the researcher observing meetings relevant to their discharge. YES / NO Initials

.....
Name of Consultee Date Signature

.....
Name of Researcher Date Signature

Centre Number:

Study Number:

Patient identification number:

CONSENT FORM – PATIENT (C)

Assessment of Capacity and Best Interests in People with Memory Problems on Going Home from Hospital

	Please initial
<ul style="list-style-type: none"> I confirm that I have read and understand the information sheet dated (version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. 	
<ul style="list-style-type: none"> I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. 	
<ul style="list-style-type: none"> I understand that the information collected during the study may be looked at by individuals from Newcastle University, regulatory authorities or the NHS Trust where it is relevant to my taking part in this research. 	
<ul style="list-style-type: none"> <u>I understand that my interview with the researcher will be taped.</u> 	
<ul style="list-style-type: none"> I agree to take part in the above study. 	

<ul style="list-style-type: none"> I nominate the following person as my carer and agree to them being contacted by the researcher to discuss their views about my discharge from hospital. Name Address..... Contact Telephone Number..... <p style="text-align: right;">YES / NO Initials .</p>
<ul style="list-style-type: none"> I agree to the researcher interviewing a professional involved in my care in hospital. <p style="text-align: right;">YES / NO Initials .</p>
<ul style="list-style-type: none"> <u>I agree to the researcher reviewing my medical notes.</u> <p style="text-align: right;">YES / NO Initials</p>
<ul style="list-style-type: none"> I agree to the researcher observing meetings relevant to my discharge. <p style="text-align: right;">YES / NO Initials .</p>

.....
Name of Patient

.....
Date

.....
Signature

.....
Name of Researcher

.....
Date

.....
Signature

Centre Number:

Study Number:

Patient identification number:

PERMISSION - PATIENT (NC)

Assessment of Capacity and Best Interests in People with Memory Problems on Going Home from Hospital

Name of patient:	Please initial
<ul style="list-style-type: none"> I have explained the information from the sheet dated (version) for the above study and given a copy to the patient. The patient has been given the opportunity to think about and ask questions about the project. I have answered all of the patient's questions. 	
<ul style="list-style-type: none"> The patient understands that they do not have to say yes to the research. The patient understands that they can stop whenever they want to. The patient understands that they do not have to give a reason. 	
<ul style="list-style-type: none"> The patient understands and consents to the interview being audio recorded. 	
<ul style="list-style-type: none"> The patient understands and consents to me, (the researcher), reviewing their medical notes. 	
<ul style="list-style-type: none"> The patient understands and consents to me, (the researcher), attending meetings to do with their care. 	
<ul style="list-style-type: none"> The patient agrees to take part in the above study. 	

<ul style="list-style-type: none"> The person below is the patients carer. The patient happy for the researcher to contact them. Name Address..... Contact Telephone Number..... 	YES / NO	Initials	.
---	----------	----------	---

..... Name of Patient Date Signature
..... Name of Researcher Date Signature

Centre Number:

Study Number:

Patient identification number:

**CONSENT FORM – STAFF
PARTICIPANT OBSERVATION**

**Assessment of Capacity and Best Interests in People with Memory
Problems on Going Home from Hospital**

Name of professional: Role of professional:	Please initial
<ul style="list-style-type: none"> I confirm that I have read and understand the information sheet dated (version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. 	
<ul style="list-style-type: none"> I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care, legal rights or employment status being affected. 	
<ul style="list-style-type: none"> I understand that the information collected during the study may be looked at by individuals from Newcastle University, regulatory authorities or the NHS Trust where it is relevant to my taking part in this research. 	
<ul style="list-style-type: none"> I agree to take part in the above study. 	
<ul style="list-style-type: none"> I specifically agree to the presence of the researcher at ward rounds and clinical meetings. 	

<ul style="list-style-type: none"> I would like to receive feedback about the results of the research 	YES / NO	Initials
--	----------	----------

..... Date Signature

Name of Professional

..... Date Signature

Name of Researcher

Appendix D. Interview schedules

Interview guide for patients (Initial interview)

1. Can you tell me a bit about yourself?

Prompts: home-life (who with, where, what kind of house, since when)
Personal history
Preferences
Personal characteristics (usual/different)
Support networks (family/friends)
General health
Formal support (nursing/meals etc)

2. Can you tell me why you are in hospital at the moment?

3. Have you talked to anyone about what will happen when you are ready to leave hospital?

4. What do you think will happen when you are ready to leave hospital?

5. What would you like to happen you are ready to leave the hospital?

6. Who do you think will make the decision about where you go when you leave the hospital?

(prompt here depending on other responses)

7. Do you think your family/friends support/agree with you decision?

8. Have you had a home visit?

Prompts: visited home with the OT?

9. How do you get on with the staff on the ward?

Prompts: ask about different members of staff

10. Is there anything else you would like to tell me about making the decision about where you will live on leaving hospital?

Thank you very much

Interview Guide – Patient Follow-up Interview (Patients who returned home)

1. How have things been for you since you came home from hospital

Prompts: Health

Have you had to go back in to hospital at all?

Coping/managing with day to day tasks?

Support (formal) – new/increased care package?

Support (informal)

Social aspects

2. Do you think coming home was the right decision for you? Why?

Prompts: Did you have any concerns/worries about coming home from hospital?

3. Did you talk to anyone about making this decision

Prompts: Family/friend/Doctor

Did anyone suggest going to live somewhere else where you could get more help or care?

4. Do your family think you made the right choice?

....Prompts:

Did anyone have any concerns/worries about you coming home?

Why?

5. Is there anything else you would like to tell me about your coming home after your stay in hospital?

Thank you very much

Interview Guide – Patient Follow-up Interview (Patients discharged to residential/nursing care)

1. How have things been for you since left hospital and moved to (PLACE NAME)

Prompts: Health

Have you been back to hospital?

Support (formal) – new/increased care package?

Support (informal)

Social

2. Do you like it here/are you happy here? Why?
3. Was it your choice to come here (PLACE NAME)
Prompts: Did anyone (family/Doctors) ask you where you wanted to live when you left hospital?
4. Do you think this was the right decision for you? Why?
5. Do your family think you/your family made the right choice?
6. Is there anything else you would like to tell me about your health or living here?

Thank you very much

Interview guide for relatives (Initial interview)

1. Firstly, can you tell me a little bit about yourself?
2. Can you tell me a bit about (patient)?
Prompts: home-life
 Personal characteristics (usual/different)
 Support networks (family friends)
 General health
 Formal support (nursing/meals etc)
- 3) Can you remind me why (patient) is in hospital at the moment?
4. What was life like before (patient) was admitted to hospital?
5. Have you talked to anyone about what will happen when (patient) is ready to leave hospital?/
6. Has (patient) talked to anyone about what will happen when they are ready to leave hospital?
7. What do you think will happen when (patient) is ready to be discharged?
8. What would you like to happen when (patient) is ready to leave the hospital?
9. Do you think (patient) would want the same?
10. Who do you think will make the decision about where (patient) is discharged to on leaving the hospital?
Prompts: Do you think this is right?
Who should make the decision?
11. What are your main concerns about (patient) and their discharge?
12. Has (patient) had a home visit?
13. Is there anything else you would like to tell me about (patient)'s discharge from hospital?

Thank you very much

Interview Guide – Relative Follow up Interviews

1. To start with, could you remind me what happened when (your relative) left hospital?
2. And is (your relative) still AT HOME/PLACE NAME
3. How have things been for your relative since they were discharged to PLACE NAME/HOME
Prompts: changes in memory
changes in general health
Has had increase in services?
Coping/day to day
Social
4. How have things been for you since your relative was discharged to PLACE NAME/HOME?
Prompts: changes in support
own health
own social situation
5. In your opinion, who made the decision about where your relative was discharged to?
6. Do you think your relative had the mental capacity or capabilities to make a decision about their discharge from hospital?
Prompts: Why/Not?
7. Do you think this is still the case? Or have there been changes that might affect your relatives abilities to make such decisions?
8. Do you think this was the right decision for you? Why?
9. Do you think this was the right decision for you relative? Why?
10. Is there anything else you would like to tell me about the decisions made about your relatives discharge from hospital?

Thank you very much

Interview Guide – Relative Interviews (initial and follow up combined)

1. Firstly could you tell me a bit about yourself?
2. Can you tell me a bit about your relative?
Prompts: home-life
Personal characteristics (usual/different)
Support networks (family friends)
General health
Formal support (nursing/meals etc)
3. Can you tell me why your relative was in hospital?
4. Can you remind me where your relative was discharged to from hospital?
5. And is (your relative) still AT HOME/PLACE NAME?
6. In your opinion, how was the decision made about where your relative was discharged to?
7. Did you feel involved in deciding where your relative was discharged from hospital to?
Prompts: Planning meeting
Spoke to dr's/nurses/social worker
8. Do you feel your relative was involved in deciding where they were discharged to from hospital ?
9. Do you think your relative had the mental capacity or capabilities to make a decision about their discharge from hospital?
Prompts: Why/Not?
10. Do you think this is still the case? Or have there been changes that might affect your relatives abilities to make such decisions?
11. How have things been for your relative since they were discharged to PLACE NAME/HOME?
Prompts: changes in memory
changes in general health
Has had increase in services?
Coping/day to day
Social
12. How have things been for you since your relative was discharged to PLACE NAME/HOME?
Prompts: changes in support
own health
own social situation
13. Do you think this was the right decision for you? Why?

14. Do you think this was the right decision for you relative? Why?

15. Is there anything else you would like to tell me about the decisions made about your relatives discharge from hospital?

Thank you very much

interview guide - key staff members – case specific

1. Can you tell me a bit about the recent discharge of [case]

Prompts

What was the main issue?

who was involved?

Can you tell me a little bit about the patient?

(medical/physical/psychological/historical/family background)

How was the situation resolved?

2. Was this a common type of event or was this an unusual case?

3. What kind of things do you generally think about when you are assessing someone's capacity to make decisions about their discharge?

4. Do you tend to think about capacity in relation to something specific, or is it just a general view of someone's capacity?

5. What do you view as the main problems/issues when making a judgement on capacity?

6. What does 'best interests' mean to you (whose)?

7. Can you think of any other examples when you have had to make a judgement about someone's capacity to make decisions about their discharge?

8. Can you explain to me what happened in that situation?:

Prompts: who was involved?

Can you tell me a little bit about the patient?

(medical/physical/psychological/historical/family background)

What was the main issue?

How was the situation resolved?

9. If you had a key piece of advice to help someone assess capacity for decision making – what would this be?

Thank you for taking part

Interview Guide for staff – Non-case Specific

Interviewee may think generally, or it might help you to draw on some recent examples on the ward

1. Firstly could you tell me a bit about your role on the ward?

2. Could you describe how decisions about whether a patient with dementia has the capacity to decide where they are discharged to are made/reached?
 - Who is involved?
 - Other factors which may influence?
 - how involved is the patient?
 - What are the processes

3. How involved are you in decisions about whether a patient with dementia has the capacity to decide where they are discharged to?
 - a) Could you describe how you would make a decision as to whether a patient with dementia had capacity to decide where they would like to be discharged to?
 - b) who do you think makes the decision
 - c) how often do decisions like this occur

4. What do you view as the main problems/issues when making a judgement on capacity?

5. If a patient is deemed not to have capacity to make a decision, and a best interest decision is made, could you tell me a bit about best interest decisions
 - What does it mean to you?
 - Who is involved?
 - Disagreement/conflict – who between, how is this managed?

6. Can you think of anything that would help to make judgements about capacity of patients with dementia in relation to their discharge from hospital?

7. Finally, is there anything you would like to tell me about assessment of capacity or best interest decisions, or the Mental Capacity Act?

Thank you very much

Nursing/Support staff Interview Guide – Non-case specific

Interviewee may think generally, or it might help you to draw on some recent examples on the ward

1. Firstly could you tell me a bit about your role on the ward?

(Remind re aim of interview)

Basically about whether patients with dementia have the ability to decide if they can return home on discharge from hospital)

2. How are you involved with patients with dementia/memory problems on the ward?

3. Do you think all patients with dementia have the ability to decide if they can return home?

(Ability to make other decisions)

4. How do you think decisions are made about whether a patient with dementia has the capacity to decide where they are discharged from hospital to?

Who is involved?

Other factors which may influence?

how involved is the patient?

What are the processes

5. How involved do you feel you are in the process of how these decisions are made?

a) Does anyone ask your opinion?

b) Do you discuss patients capacity with colleagues?

c) Do you write in the patients notes?

d) Are you involved in any cognitive assessments eg MMSE?

- General thoughts on MMSE

6. In your opinion, who do you think makes the decision as to whether a patient has capacity to decide on their discharge from hospital?

7. What do you think are the main problems/issues when making a judgement on capacity?

8. If a patient is deemed not to have capacity to make a decision, and a best interest decision is made, could you tell me a bit about best interest decisions

What does it mean to you?

Who is involved?

Disagreement/conflict – who between, how is this managed?

9. Can you think of anything that would help to make judgements about capacity of patients with dementia in relation to their discharge from hospital

10. Finally, is there anything you would like to tell me about assessment of capacity or best interest decisions, or the Mental Capacity Act?

Thank you very much

Appendix E. Glossary

ACBID	Assessment of capacity and best interests in dementia: On discharge from hospital
CMHT	Community Mental Health Team
CPN	Community Psychiatric Nurse
CPRD	Article 12 of the UN Convention on Human Rights, the Convention on the Rights of Persons with Disabilities
CT scan	Computerised Tomography scan
DoLS	Deprivation of Liberty Safeguards (2009)
EMI	Elderly Mental Infirm care
GP	General Practitioner
IMCA	Independent Mental Capacity Advocate
LPA	Lasting Power of Attorney
MEAMS	Middlesex Elderly Assessment of Mental State
MMSE	Mini-Mental State Examination
MCA	Mental Capacity Act (2005)
MDT	Multi-disciplinary team
NHS	National Health Service
NICE	The National Institute for Health and Care Excellence
OT	Occupational therapist

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