

Understanding hospital transfers from care homes in England: An ethnographic study of care home staff decision-making

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Thesis submitted for the degree of
Doctor of Philosophy
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UNIVERSITY OF
LEICESTER

January 2021

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ABSTRACT

Background: When deciding whether or not to transfer a resident to hospital, a careful consideration of the potential benefits and risks is required. International research suggests that transfer decisions are complex and influenced by both clinical and non-clinical factors, yet this has not been widely studied within the context of care homes in England.

Aim: To develop an in-depth understanding of hospital transfers from care homes in England and produce a conceptual model to describe the decision-making processes of care home staff.

Methods: Data collection occurred in two phases: the first consisted of 28 semi-structured interviews with 30 members of staff across six care homes; the second consisted of 113 hours of ethnographic observations, documentary analysis and informal conversations (with staff, residents, family carers and visiting healthcare professionals) at three of the care homes that had taken part in phase one.

Findings: In the context of care homes in England, hospital transfers can be conceptualised as a series of escalations in which staff make multifactorial decisions about potential benefits and risks. This can include risks to: residents, staff (as decision-makers) and their social relationships, care homes (as organisations), and wider health and social care systems. In order to assess the likely benefits and risks of each transfer, care home staff placed importance on 'knowing' residents but also drew upon advance care plans, structured clinical observations, and interactions with others (residents, family carers, colleagues within the care home and visiting healthcare professionals). The involvement of others in decision-making could provide a way for staff to minimise risk (particularly for themselves as an individual), but disagreements about the most appropriate course of action were challenging.

Conclusion: Staff make complex, risk-based decisions about potential transfers, often as a series of escalations. Understanding this can help to inform further research, policy and practice.

DEDICATION

Dedicated to Ann Wildsmith
(1940-2020)

My Nan, role model and friend.

ACKNOWLEDGEMENTS

I am thankful to many people who have supported me throughout my PhD journey. First and foremost, my fiancée Kay Hyde (soon to be Harrad-Hyde) has been wonderful throughout this process and has helped me to develop my ideas by putting up with my constant talk about care homes for the last three to four years. I am so thankful for your love and support and for the life we are building together.

It would take many pages to acknowledge everyone in my extended family individually, but I am thankful for the laughter they bring and for reminding me what really matters in life. In particular, I am thankful for the unwavering support of my Mum (Karen Wildsmith) and my Nan (Ann Wildsmith). Thank you for teaching me to aim high but stay grounded and for convincing me that all my dreams are possible with the right amount of work.

I have been very fortunate to be supervised by Dr Chris Williams and Professor Natalie Armstrong at the University of Leicester. They have provided their expertise, knowledge, continuous encouragement and thoughtful feedback, as well as much appreciated support at times life felt more challenging. I have also benefitted from discussions with several other people in the Department of Health Sciences and I am thankful for the interest people have shown in my work and the time people have taken to discuss my project with me and to share their thoughts and expertise.

During my PhD I have been employed by the NIHR Clinical Research Network West Midlands as part of the ENRICH (Enabling Research in Care Homes) team. I am thankful for the support of my manager, Sandra Prew, and of the wider team (past and present), for the support they have shown me, for allowing me to work flexibly alongside my PhD and for the opportunity to develop a better breadth and depth of knowledge about how to carry out research in care home settings.

Last, but certainly not least, I would like to thank the care home managers who generously gave their time to talk with me in the early stages of the project when I was still formulating my ideas. I am also very grateful to the care home staff, residents, family carers and visiting healthcare professionals who took part in this research project. As is usual with research I can only thank them anonymously, but without them the project and the ideas put forward in this thesis would not have been possible.

ABBREVIATIONS

CQC	Care Quality Commission
DoH	Department of Health
DNR	Do Not Resuscitate
ENRICH	Enabling Research in Care Homes
GP	General Practitioner
LPOA	Lasting Power of Attorney
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
ReSPECT	Recommended Summary Plans for Emergency Care and Treatment

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INTRODUCTION

There are over 15,000 care homes in England, offering over 400,000 beds (CQC, 2019, Skills for Care, 2020). People living in care homes (i.e. care home residents) often have complex health and social care needs (Gordon et al., 2014) and are more likely to attend and be admitted to hospital than the general population (Wolters et al., 2019). Studies conducted outside of England have suggested that some hospital transfers may be initiated ‘inappropriately’. This widely used but contested term includes hospital transfers that are not primarily driven by an expectation of improved health and/or quality of life for a resident and hospital transfers that are related to medical conditions which could be considered to be preventable and/or manageable outside of a hospital setting (Arendts et al., 2013, Khoujah and Hirshon, 2017, Parkinson et al., 2021).

The suggestion that some transfers are initiated ‘inappropriately’ is concerning. Although some hospital transfers can be beneficial for care home residents – for example residents may have access to additional tests and treatments in hospital that are not available in the care home – a transfer to hospital can also be burdensome. As well as experiencing higher in-patient mortality than community dwelling older people, a hospital transfer may be associated with physical decline (due to iatrogenic illnesses or prolonged inactivity), cognitive decline and new or worsening delirium (Calnan et al., 2013). Furthermore, being transferred to hospital can be distressing and confusing, particularly for residents who are living with cognitive impairment (Ahearn et al., 2010).

A growing body of research has begun to suggest that decision-making about potential resident hospital transfers is influenced by numerous contextual factors. This can include ‘patient factors’ (i.e. the characteristics of individual care home residents) and ‘organisational’ factors (i.e. the characteristics of particular care homes and the wider health and social care sectors that they exist within) (Dwyer et al., 2015). Due to the variability of care home organisations, resident populations and wider health and social care systems, it is important to understand hospital transfers as they occur at a local level (Dwyer et al., 2015).

Within this thesis I explore the decision-making processes of care home staff when determining whether or not to transfer a resident to hospital. Care home staff play a

crucial role in managing residents' health and wellbeing, both on a day-to-day basis and in the event of an acute event or deterioration. Therefore, although several people may be involved in deciding whether or not to transfer a resident to hospital (for example residents, their family carers and visiting healthcare professionals such as GPs or paramedics), in this thesis I focus on the decision-making of care home staff.

Despite the important role they play, until recently few research studies had sought to understand the decision-making processes of care home staff when faced with a resident who potentially requires a transfer to hospital. Although there have been a number of systematic reviews published in recent years (Arendts et al., 2013, Laging et al., 2015, O'Neill et al., 2015), very few of the primary studies included within these reviews have been conducted in England. Instead, the majority of existing literature is from studies conducted in the United States or Australia. Given the importance of understanding hospital transfers as they occur at a local level, the applicability of findings from studies carried out internationally to the decision-making of staff working in care homes in England is not clear (Dwyer et al., 2015). Therefore, in this thesis I have sought to investigate staff decision-making within the context of care homes in England by exploring the processes (chain of events) that precede a transfer and the factors that influence staff decision-making about potential hospital transfers.

In order to produce a detailed understanding of hospital transfers from care homes in England, throughout this thesis I draw on literature from a range of disciplines including sociological theories of risk and uncertainty - in particular, the concept of 'risk work' developed by Gale et al. (2016) – as well as models of clinical decision-making and help-seeking behaviour. Interestingly, many of these concepts have been developed and used more extensively outside of the care home context, usually focussed on health rather than social care settings.

A central argument of my thesis is that within the context of care homes in England, staff decision-making about potential resident hospital transfers can be conceptualised as a series of escalations, in which staff make complex and multifactorial decisions in which they weigh up the likely benefits and risks of transferring a resident to hospital. This includes risks to the resident, to staff (as

decision-makers), their social relationships (for example with colleagues, residents, their family carers, or external healthcare professionals), to the care home (as an organisation) and to wider health and social care systems.

My findings highlight the importance of attending to the wider social context in which transfer decisions are made. Therefore, my thesis suggests that to fully understand why hospital transfers occur, one must focus on the factors that influence staff decision-making beyond the immediate clinical signs, symptoms or acute events that staff find themselves faced with. Furthermore, my thesis outlines a range of important factors which influence staff decision-making at a number of levels, including: the micro - related to individual residents and decision-makers; meso - related to interpersonal relations between staff and other stakeholders; and macro - related to influences at an organisational (care home) and institutional (wider health and social care system) level.

This thesis is divided into nine chapters. In Chapter 1, I provide an overview of the care home sector in England. Existing research has suggested that it is important to understand hospital transfers as they occur in their local context (Dwyer et al., 2015). Therefore, this chapter serves to orient the reader to the broader social context in which staff make decisions about whether or not to transfer residents to hospital. In Chapter 2, I explore existing research into hospital transfers from care homes, including research that has sought to: determine the prevalence of hospital transfers from care homes; identify particular symptoms and events that are likely to lead to a resident transfer; and research that has evaluated different interventions intended to reduce hospital transfers from care homes. Within this chapter, I explore the concept of 'inappropriate' hospital transfers and discuss the ways in which this concept can be problematic. In Chapter 3, I introduce theories and concepts from wider literature that will be used as tools to develop a better understanding of the decision-making processes of care home staff when deciding whether to transfer a resident to hospital in the context of care homes in England.

My research project, described within this thesis, was guided by the philosophical paradigm of critical realism which ascribes to a realist ontological position - that there is an external 'reality' that exists independently of human thought and explanation, with an interpretivist epistemological position - that all knowledge is socially

constructed and therefore can only be known imperfectly. In Chapter 4, I provide a justification for approaching my study in this way, alongside a discussion of several other methodological choices that I made throughout the project, for example for my choice of interactional, ethnographic research methods and the decision to use a Straussian approach to data analysis. Then, in Chapter 5, I describe the process of selecting and recruiting potential research sites (care homes) and participants alongside a discussion of the ethical issues that I considered. In both Chapters 4 and 5 I reflect on the ways that my prior experiences, preconceptions and personal connections with care homes may have influenced the findings of the project and the steps I have taken to reduce the influence on the ideas presented within this thesis.

In Chapters 6, 7 and 8 I present my findings. In Chapter 6, I explore staff views of hospital transfers and their perceptions of risk and uncertainty during the decision-making process. Then, in Chapter 7, I describe the ways in which care home staff come to know these risks, by exploring the different sources of 'risk knowledge' that staff draw upon. In addition, in this chapter I also explore the ways that staff navigate tensions within and between knowledge sources. In recognition that the decision-making of care home staff can be influenced by and occurs within the context of multiple social relationships, in Chapter 8, I explore the perceived power and responsibilities of other people and their influence on staff decision-making.

In Chapter 9, I draw together the data presented across the three preceding empirical chapters to present a conceptual model of the decision-making of care home staff during potential hospital transfers. Within this chapter, I provide a summary of the project findings, before bringing together and discussing key threads that run throughout the thesis. Then, by contextualising the findings of this study within broader bodies of literature, I discuss how the findings of this project compare and contrast with existing knowledge, highlighting the new insights they contribute. In this chapter, I also consider the strengths and limitations of the study, before discussing the potential implications of the findings for research, policy and practice.

CHAPTER ONE: The care home sector in England

1.1. Care homes in England

1.1.1. Defining the term 'care home'

In the United Kingdom, adult social care is a devolved policy matter: England, Scotland, Wales and Northern Ireland are governed by different regulatory bodies and policy frameworks (BGS 2011, CMA 2017). In England, the adult social care sector encompasses a wide range of care services. This includes care homes, domiciliary care, day centres, sheltered-housing, hospices and retirement villages (CMA 2017). This project focuses solely on care homes. In England, care homes are categorised based on the type of care that they provide. The Care Quality Commission (CQC), the main regulatory body of health and social care services in England, differentiates between 'care homes with nursing services' and 'care homes without nursing services', often referred to as 'nursing' or 'residential' homes respectively. In addition, some facilities may be 'dual-registered' homes, supporting residents who require nursing services and resident who do not.

Across health and social care, academic disciplines and different countries, a range of terms are used to describe and refer to care homes (BGS 2011). This can include 'care home', 'residential home', 'nursing home', 'homes for the elderly', 'long-term care facility' and 'residential aged care facility'. Throughout this thesis I use the terms 'care home with nursing' or 'care home without nursing' on occasions where doing so aids the reader, for example when describing existing research that has focussed on a specific type of facility. The term 'care home' is used more broadly to encompass both types of facility.

1.1.2. The separation of health and social care services in England

As mentioned in the preceding section, in England, care homes fall under the umbrella of social care. Historically, health and social care services in England were developed based on an assumption that it was possible to distinguish between people who were 'sick' or 'frail' (Lewis, 2001). Whereas people who were categorised as 'sick' were deemed to require accommodation due to health needs, people who were categorised as 'frail' were deemed to require accommodation due to social care needs (Glendinning and Means, 2004, Lewis, 2001). On one hand, the

National Health Service (NHS) was established to provide “a comprehensive health service” for all (National Health Service Act, 1946, c81) and was allocated responsibility for providing long-term care for older people with chronic health needs. On the other hand, local authorities were allocated responsibility for providing accommodation for people “who by reason of age, infirmity or any other circumstances [were] in need of care and attention” (National Assistance Act, 1948, c29).

It is now recognised that the distinction between those who are ‘sick’ or ‘frail’, and thus requiring ‘health’ or ‘social care’, is somewhat arbitrary and often health and social care needs occur simultaneously (BGS, 2011). Therefore, this distinction can be problematic for people who do not fit neatly into the artificial health or social care divide, for example people living with dementia (Keady et al., 2009). Historically, people living with dementia were accommodated in large psychiatric hospitals. However, widespread closure of these facilities during the late twentieth century left many, predominantly older, people with dementia requiring alternative accommodation (Lewis, 2001). A small proportion of older people with dementia were cared for in long-stay geriatric beds provided by the NHS, yet many were deemed to have predominantly ‘social care’ needs and therefore required assistance from local authorities (Lewis, 2001). The demand for local authority support soon exceeded supply, sparking debates about which services should be responsible for meeting the needs of older people who required accommodation and support (Glendinning and Means, 2004).

Debates about the responsibilities of the NHS and local authorities continue to this day. Despite the shortcomings of determining individual needs based on an artificial divide between ‘health’ and ‘social’ care, the wording of the National Health Service Act (1946) and National Assistance Act (1948) continues to influence the provision of services. For people requiring support in a care home setting, this distinction remains pivotal because it determines the type of services that individuals are entitled to and whether or not these services should be provided at a cost to the individual (BGS, 2011, Glendinning and Means, 2004). Today, many people with dementia, a condition that was traditionally considered a medical problem, now receive care from organisations that fall under the ‘social care’ umbrella.

1.1.3. Ownership and funding

There are approximately 15,000 care homes in England, of which around 4,500 provide nursing services (i.e. nursing homes) and 10,500 do not (i.e. residential homes) (CQC, 2019). Therefore, with the exception of care that is delivered by informal carers, care homes are the main providers of long-term care in England (Froggatt et al., 2009). Over the past 30 years, there has been a shift in ownership of care homes in England. Today, a large majority of care homes are owned and managed by independent companies operating as private for-profit or private not-for-profit businesses (CQC, 2017). The size of care home providers varies greatly. Although the majority of care home providers are small (approximately 4,000 of the 5,500 providers own only one home), the sector also has a number of large providers with over 100 care homes (CMA, 2017).

The process of obtaining social care funding has been described as “opaque, impenetrable and increasingly inequitable” and often individuals find it difficult to navigate the system and to know what financial support they are entitled to (Eynon and Conroy, 2017, p201). The care of individuals living in care homes can be funded by the NHS, a local authority, a charitable or religious organisation, the individual receiving care or a mixture of these sources. People with predominantly health or ‘nursing’ needs may have their care funded (or partially funded) by the NHS under the Continuing Healthcare scheme. People who require support with predominantly ‘social care’ needs are not eligible for NHS support but may be eligible for financial support from their local authority. Eligibility is means-tested and an individual’s assets must be worth less than £23,250 (NHS, 2020). If the person requiring support has assets that are greater than the threshold then they are deemed to be a ‘self-funder’ and to be responsible for paying for their own care (Age UK, 2020).

Only a small proportion of care home beds in England are funded by the NHS, and although private companies dominate the care home sector, a large majority of residents are funded or partly-funded by local authorities (CQC, 2019). Table 1, below, was produced using data collected by the CQC (2019) and describes the distribution of different types of funding for care home beds in England.

Table 1: A table to describe the funding of care home beds in England

	Approximate % of care home beds funded	Approximate equivalent number of beds
Fully self-funded	21%	86,100
Self-funded + local authority	12.5%	51,250
Fully local authority funded	50%	205,000
Local authority funded + NHS or charity	9%	36,900
Fully NHS funded	7.5%	30,750
Total	100%	410,000

At present, the rate that self-funders pay for their care can be substantially higher than the rate that local authorities pay, even when individual living circumstances and care needs are comparable (CMA, 2017). Care homes accommodating a higher proportion of self-funding residents have higher profit margins than homes predominantly accommodating individuals funded by the local authority. However, a recent investigation found that many care home providers felt that local authority fees did not fully cover the cost of care (CMA, 2017).

1.1.4. Regulation

In England, the CQC is the main regulatory body of all health and social care services. All services are required to register with the CQC and to provide details on the type of service they offer and the number of people they support (CQC, 2017a). The CQC inspects and produces a rating of all services and can take legal action in circumstances where they feel they have identified substandard care (CQC, 2017a). Ratings are made across five key domains which seek to determine whether a service is 'safe', 'effective', 'caring', 'responsive' and 'well led'. Each domain is rated separately before an aggregate rating of the service is produced. Services can be rated as 'outstanding', 'good', 'requires improvement' or 'inadequate'. Inspection ratings are displayed on the premises and website of each service and are made publicly available on the CQC website (CQC, 2017a). In the year 2018/19, 72% of all care homes with nursing services and 82% of care homes without nursing services were rated as 'good' in England (CQC, 2019).

Concerns have been raised about the CQC's approach to regulating care homes, with the process of inspection described as inflexible, inconsistent and ineffective (Knight, 2017). Suggestions have been made that the role of the CQC as a

regulatory body should be to provide support for 'failing' care homes rather than to simply rate each service (Knight, 2017). An evaluation of the CQC's inspection process provided support for this suggestion. The evaluation found that interactions between providers, the CQC and other stakeholders before, during and after inspection were key to achieving improvement amongst services. As a result, the authors recommended that the CQC should turn its attention towards more frequent, informal contact with providers, rather than focussing on infrequent inspections (Smithson et al., 2018).

1.2. Care home residents

There are approximately 410,000 beds in care homes across England (CQC, 2019), which is more than three times as many beds as there are in hospitals (NIHR Dissemination Centre, 2017). Although it is important to acknowledge that care home residents are a diverse group of individuals (BGS, 2011), research into the demographic profile of care home residents has suggested that they are usually the 'oldest old' in society, with over half of all residents aged 85 years and above (Smith et al., 2015). Care home residents have an average life expectancy of 12 to 30 months (NIHR, 2017) and are more likely to be female, in part due to longer life expectancies amongst women (Smith et al., 2015). In addition, care home residents are likely to have a number of long-term co-morbid health conditions and to require assistance with activities of daily living (BGS, 2011, NIHR, 2017).

Gordon et al. (2014) explored the health status of care home residents and found residents to have high levels of physical dependency, cognitive impairment and multimorbidity¹. Research has also suggested that care home residents frequently experience hearing loss, difficulties with vision, falls, fractures and depression. Common health conditions amongst care home residents include cardiovascular disease, respiratory disease, cognitive impairment, stroke and arthritis (Alzheimer's Society, 2013, Bowman et al., 2004, Rai et al., 2006). As a result, residents often have complex health and social care needs that require careful management (Goodman et al., 2017b). Furthermore, there is evidence to suggest that over the last

2

¹ NICE (2016) defines multimorbidity as "the presence of 2 or more long-term health conditions, which can include; defined physical and mental health conditions such as diabetes or schizophrenia, ongoing conditions such as learning disability, symptom complexes such as frailty or chronic pain, sensory impairment such as sight or hearing loss and alcohol and substance misuse." (NICE, 2016, p5)

two decades there has been an increase in the level of disability and complexity in the health problems of care home residents in England (Barker et al., 2020).

1.3. The care home workforce

Care homes provide approximately 665,000 jobs in England (Skills for Care, 2017). The majority of the workforce, approximately 84%, are women and those working in the sector are more likely to be older than the average working population (Skills for Care, 2019b, Skills for Care, 2019a). The care sector workforce is diverse in terms of nationality. Approximately 17% of the workforce, 220,000 people, are of a non-British background. Furthermore, approximately 7% of the workforce, 46,550 people, were born in a European Union country (Skills for Care, 2017). At the time of writing, as the United Kingdom leaves the European Union, there is uncertainty about how this decision might affect EU migrants working in the adult social care sector, care organisations and people receiving care.

Within care homes, more than 89% of staff are employed on a permanent contract. However, approximately 9% of care home staff are employed on a 'zero-hours' contracts which do not offer a set number of working hours for employees. Zero hours contracts offer employees flexibility in their workload and enable employers to address staffing shortages without relying on expensive agency staff, but have been criticised due to the lack of financial security that they provide for employees, which may deter some people from entering the caring professions (Skills for Care, 2020). The difficulties that many care homes face in recruiting and retaining staff will be considered later in section 1.4.4.

1.4. Challenges for health and social care service in England

1.4.1. England as an ageing population

Health and social care services across England are currently facing a number of challenges. Like many countries, England has an ageing population. By 2035, the number of people aged 65 and over in England is expected to rise by 48.5% - from 9.7 million to 14.5 million (Age UK, 2017). An even greater rate of growth is expected amongst people aged 85 years and over. It has been predicted that there will be a 113.9% increase - from 1.3 million to 2.8 million people (Age UK, 2017). However, increased life expectancy does not guarantee additional years of good health

(Barnett et al., 2012, Kingston et al., 2017, WHO, 2015). Approximately 70% of people in their late 60s in England have at least one formally diagnosed long-term health condition, which rises sharply to over 90% of people in their late 80s (Smith et al., 2015).

The term 'frailty' describes a multidimensional geriatric syndrome, that is associated with ageing, which consists of a physiological state that is characterised by impaired homeostasis and decreased physiological reserve across several of the body's systems. Frailty results in an increased vulnerability to experiencing adverse outcomes from relatively minor stressor events and is associated with an increased risk of functional decline, mortality and hospitalisation (Clegg et al., 2013). Although data concerning the prevalence of frailty amongst care home residents in England is lacking, it would be reasonable to assume that the prevalence of frailty in this population is high, given that care home residents are likely to be older than the general population and to have complex health and social care needs (Gordon et al., 2014, Smith et al., 2015).

Concerns have been raised about whether current health and social care systems will be able to meet the needs of the future population (Age UK, 2017, Humphries et al., 2016, Oliver et al., 2014, WHO, 2015). These concerns may be logical: as the age of the population increases, so too will the number of people living with long-term chronic conditions. Given that ageing and multimorbidity are associated with increased healthcare utilisation (Marengoni et al., 2011), it is likely that there will be an increased demand for health and social care provision to meet the needs of this group (Age UK, 2017, Guzman-Castillo et al., 2017). However, for many people ability is only loosely associated with chronological age. A cohort study of over 850 people aged 85 years and over in Newcastle found that despite a high prevalence of multimorbidity, approximately one fifth of all participants required no assistance with activities of daily living and were able to live at home independently (Collerton et al., 2010). Therefore, whilst age is linked with ill-health and disability, not all older people will require a high level of support from health and social care services.

It has been suggested that focussing on the ways in which older people overwhelm or deplete services may reflect negative cultural attitudes and stereotypes about ageing (Age UK, 2017, Spijker and MacInnes, 2013, WHO, 2015). Furthermore,

Spijker and MacInnes (2013) have questioned the suggestion that an ageing population represents an inevitable 'time-bomb' for services. The authors criticised the use of the 'old age dependency ratio'², a measure used to make predictions about how an ageing population might impact on service utilisation. The measure does not account for variability amongst older people and assumes all people above the state pension age require care and support. Therefore, the measure may not accurately reflect the nature and the scale of the challenge that an ageing population may present to health and social care services.

1.4.2. An increased prevalence of dementia

The term 'dementia' describes a broad set of symptoms that can include difficulties with memory, problem-solving, thinking and communication (Keady et al., 2009). Over 100 types of dementia have been identified but, at present, a cure for any type of dementia is yet to be found. Dementia is not a normal part of healthy ageing, but the prevalence of dementia increases with age. For example, dementia affects approximately 0.9% of people aged 60-64 years, 6% of people aged 74-79 years and 29.9% of people aged 85-89 years (Alzheimer's Society, 2014). The prevalence of dementia is particularly high in care homes and over 80% of care home residents have some form of memory impairment (Alzheimer's Society, 2013).

Keady et al. (2009) suggested that supporting people with dementia is both an 'art', concerned with building therapeutic relationships, and a 'science', concerned with evidence-based practice and treatments. Therefore, caring for people with dementia presents specific challenges for health and social care staff who may find themselves responsible for managing a broad range of individual needs. This can include assisting with activities of daily living, managing multiple health conditions and proxy decision-making for people who may not be able to make their wishes known and may not be aware that they need help (Bowman, 1998).

² The 'Old Age Dependency Ratio' is calculated by dividing the number of people above the state pension age by the number of working age people. This crude measure of dependency does not account for a person's medical, social or economic circumstance and instead assigns people to one of two categories (dependant / not dependant) based on chronological age. The measure does not account for the growing number of people that remain physically and financially independent after they reach the state pension age. Nor does this measure account for the number of people that fall within the 'working population' age bracket that are not currently employed.

1.4.3. Financial pressures

Although the population in England is ageing, public spending on older people's care has fluctuated over the last decade (Age UK, 2017). Between 2010/11 and 2015/16 significant cuts were made to social care services for older people at a time when many were calling for investment in order to meet the needs of future generations (Age UK, 2017, World Health Organisation, 2015). At the same time, the total budget for healthcare services increased. This increase mainly occurred across secondary care services, despite longstanding efforts to shift care into the community (Age UK, 2017). As a result, social care services for older people have been described as "the NHS's poor relation" (Age UK, 2017, p56) and a "Cinderella service" (Glendinning and Means, 2004, p453).

Taken together, reduced spending on adult social care, combined with increased costs of providing healthcare has resulted in an increase in the number of people whose needs are not being met, which in turn has placed pressure on informal carers (Age UK, 2012, BGS, 2011). In 2015, informal care work across the United Kingdom (i.e. unpaid care predominantly provided by family members and friends) was valued at £132 billion³ (Buckner and Yeandle, 2015). There are currently over two million informal carers aged 65 years and over in England, many who have their own health and social care needs. As a result, concerns have been raised about the sustainability of relying on informal support as the prevalence of dependency continues to increase as the population ages (Kingston et al., 2017).

1.4.4. Staff recruitment and retention

Across health and social care, services are struggling to recruit and retain staff at all levels (Age UK, 2017, Skills for Care, 2017). Within social care, low rates of pay, the physically demanding nature of work, poor working conditions and a lack of opportunity for career progression all contribute to ongoing issues in recruitment and retention of staff (CQC, 2019, Skills for Care, 2017). Staffing levels can influence the quality of a service: the CQC (2019) has suggested that high staff turnover levels can lead to services being rated poorly. This is particularly true for the turnover of

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Bucker and Yeandle (2015) estimated the value of informal care by multiplying the number of hours carers spent providing care by the hourly cost of replacement care (which in 2015 was taken as £17.20). Further information is available in Appendix B of the 'Valuing Carers' report.

managerial staff, as strong leadership has been identified as a key factor in high-performing services (CQC, 2019).

Care homes in England have high levels of staff vacancies: 6.3% for care homes with nursing services and 5.5% for care homes without, equating to approximately 18,500 and 17,000 vacancies at any one time respectively (Skills for Care, 2019b, Skills for Care, 2019a). Furthermore, there are also high staff turnover rates: 31.5% for care homes with nursing services, and 29.6% for care homes without, equating to 87,000 and 86,000 people leaving their role over a 12 month period respectively (Skills for Care, 2019b, Skills for Care, 2019a). Staff are more likely to leave their role if they are younger, receiving a low rate of pay, on a zero-hours contract and less experienced in the care sector (Skills for Care, 2017).

In addition, across England there are also staffing issues within health professional groups that support care homes. Although there has been an overall rise in the number of doctors and nurses in the NHS, in part due to recommendations about safe staffing levels, increases have been uneven across services. Despite an increase in the number of secondary care nurses, there has been a decrease in the number of community nurses, on whom many older people living in care homes rely (Age UK, 2017). In addition, although the number of doctors in hospitals has increased, there has been a decrease in the number of community based GPs who also play a key role in healthcare provision in care homes (Age UK, 2017, Goodman et al., 2017a).

1.4.5. Negative portrayal of care homes in the media

In addition to the aforementioned challenges shared by both health and social care services in England, care homes also face an additional challenge in that they are often viewed by the public as a negative place to live and work (CQC, 2012). Indeed, it has been suggested that care homes in England are suffering from a 'broken image' (Hockley et al., 2017). Age UK (2012) has called for more respect for the large majority of care workers that provide high quality care in difficult working environments. However, negative public attitudes towards care homes are longstanding, influenced by late twentieth century reports of the negative effects of living in institutional care and the dehumanizing treatment of people living in both psychiatric hospitals and care homes (Barton, 1966, Goffman, 1961, Townsend,

1962). Although the provision of care has changed dramatically since the era in which the authors were writing, at present public attitudes are largely characterised by concern and a lack of confidence in the quality of care that care homes provide (CQC, 2012).

Although the exposure of inadequate care can lead to improvements in health and social care services (Bowman, 1998), highly publicised accounts of suboptimal care can also undermine the public's confidence in the social care sector (CQC, 2019). Concerns about the quality of care provided in care homes have, in part, been fuelled by a number of highly publicised instances of abuse and neglect in adult social care facilities. In addition, there have been instances in which lay media articles have selectively reported figures about the quality of care in care homes. For example, between 2014 and 2017 the CQC rated approximately 67% of all care homes providing nursing service across England as either 'good' or 'outstanding' (CQC, 2017). However, the same data was described in an article in the Guardian entitled "one in three nursing homes is failing" (Brindle, 2017). Although factually accurate, this example highlights the ways in which news articles can selectively (re)produce information to undermine the general public's perceptions of care homes.

1.5. Healthcare provision in care homes

There have been long-standing concerns surrounding healthcare support for people living in care homes in England. The current organisation of healthcare provision in care homes has been described as "haphazard" (RCP et al., 2000, p1), "ad-hoc and reactive" (Goodman et al., 2017a, p12), "fragmented, un-coordinated and variable" (NHS England, 2016, p12). Unlike care homes in other countries such as the Netherlands, care homes in England do not directly employ physicians. Instead, when a resident's health deteriorates, care home staff call for support from external organisations. Research has suggested that although care home staff wish to care for residents during acute deteriorations in their health, the lack of healthcare support available to them can lead staff to transfer residents to hospital (Alcorn et al., 2020).

Until very recently, there was a lack of clarity surrounding healthcare support in care homes and no explicit statement that outlined the NHS's obligations to care home residents (BGS, 2011). Furthermore, research had highlighted extensive inequality

and variation in the ability to access and receive healthcare support for residents (Glendinning et al., 2002). This included support from GPs and other healthcare professionals who may be part of a wider multidisciplinary team - for example physiotherapists, speech and language therapists and occupational therapists (Goodman and Woolley, 2004, Gordon et al., 2014, O’dea et al., 2000, Ong et al., 2011).

Inequalities in healthcare provision in care homes may be related to the development of health and social care services as two separate entities. Reflecting on the closure of both psychiatric hospitals and long-stay NHS geriatric beds, Bowman (1998) argued that the shift towards care in smaller community settings brought about “a transformation” in care, away from “multidisciplinary team care for the individual in typically hostile institutions” to “a domesticated care environment with an isolation or even divorce from health services care and support” (Bowman, 1998, p109).

Little more than a decade ago Goodman et al (2009) identified a lack of research focussing on how care home and healthcare staff could work together. However, since then, research studies have identified ways to provide better healthcare support in care homes. For example, Robbins et al. (2013) provided insight into the barriers and facilitators to achieving appropriate healthcare provision in these settings, identifying: i) a mismatch between the healthcare needs of care home residents and the amount of time a GP can offer; ii) a lack of clarity about the role of care home staff; and iii) tensions around which health and social care professionals are responsible for healthcare provision in care homes. In addition, a number of research studies have highlighted the important roles that GPs play in providing healthcare for care home residents. At present, responsibility for healthcare provision in care homes in England lies with primary care services, predominantly GPs. It has been suggested that formally contracting (and thus financially rewarding) GPs to work with care homes would enable better healthcare support in care homes by legitimising the extensive use of GP time and acknowledging the importance of care home medicine (Glendinning et al., 2002, Goodman et al., 2017a, Oliver et al., 2014).

More recently, improving healthcare provision in care homes has been prioritised. For example, the Five Year Forward View (NHS England, 2014) outlined a vision for

new models of care that focussed on healthcare inequalities. This included an 'Enhanced Health in Care Homes' model in which six vanguards were set up to improve the quality of life and health of care home residents (NHS England, 2016). As a result, a framework to guide partnership working between care homes and healthcare services was developed and a number of key components for collaborative working were identified. The second version of the Enhanced Healthcare in Care Homes framework, published in March 2020 asserts that "People living in care homes should expect the same level of support as if they were living in their own home" (NHS England and NHS Improvement, 2020, p4). This framework may provide guidance for future interventions and service developments that seek to reduce the healthcare provision inequalities that care home residents experience.

1.6. The development of care home research in England

In England, although there are more than three times as many people living in care homes as there are beds in hospitals, care homes have historically been neglected in academic research (Burns and Nair, 2014). As a result, the evidence base for effective treatments in hospitals is stronger than the evidence base surrounding the maintenance of health and well-being in care home settings (NIHR Dissemination Centre, 2017). A number of explanations for the lack of research have been put forward. Vesperi suggests that "researchers who have never conducted fieldwork in a nursing home might assume such a setting to be among the most pedestrian and familiar, hence among the least credible" (Vesperi, 1995, p8). In addition, Froggatt et al. (2009) puts forward a number of possible pragmatic explanations, suggesting that researchers may find it difficult to understand the care sector, which is fragmented and constantly in a state of flux. They also suggested that researchers may face difficulty in accessing care homes, the majority of which operate as private businesses and, once inside the care home, care staff may be reluctant to participate in research due to fear it could add to their workload and portray themselves or their profession in a negative light.

Although there are examples of research conducted in care homes in England during the 20th century, for example in the seminal work of Peter Townsend (1962), the turn of the 21st century saw a growth in studies that sought to understand the needs of people living, visiting and working in care homes. This surge of interest has been

described by Burns and Nair (2014) as a “blossoming” of care home research, with the authors pointing to an increase in the amount of research into issues affecting care home residents (e.g. falls, incontinence, medication, the use of psychotropic medication, frailty, end-of-life care etc.) and a growing number of randomised controlled trials in care home settings to substantiate their claim (Burns and Nair, 2014, Gordon et al., 2012).

In addition, a number of guidance documents surrounding care home research have been produced over the last decade which describe the impact of several care home research studies (Froggatt et al., 2009) and draw on the knowledge of experienced researchers (Luff et al., 2011). There has also been a growing interest in patient and public involvement⁴ in care home research. This is evident in published guidance (Twiddy et al., 2013) and in a number of exercises that have sought to identify the research priorities of people working in care homes (Shepherd et al., 2017) and more broadly across adult social care (Department of Health and Social Care, 2018). Collectively, the aforementioned documents provide guidance for researchers entering the field of care home research. Many of these documents will be referred to in later parts of this thesis.

In addition to a growing interest in care home research, over the last decade, a number of national organisations across England that have traditionally been concerned with healthcare have broadened their focus to include non-NHS settings, including care homes, domiciliary care, schools and hospices. For example, in 2013 NICE⁵, an organisation set up to provide evidence-based guidance for healthcare professionals, began to produce guidelines for the social care sector. At present, the NICE website enables visitors to select ‘care home’ to view a comprehensive list of

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⁴ The term ‘Patient and Public Involvement and Engagement’ refers the ways in which patients and the public can be involved in a research project, from identifying research priorities, providing advice on the way in which data is collected and assisting in the analysis of research data. When carrying out research into care homes, patient and public involvement and engagement can include staff, residents, their families and friends and healthcare professionals working in and alongside the home.

⁵ National Institute of Clinical Excellence (referred to by the acronym NICE) was founded in 1999 to produce evidence-based guidance for healthcare professionals. In 2013, NICE changed from a special health authority to a non-departmental public body, responsibility for producing evidence-based guidance for social care organisations,. Despite changing its name to the ‘National Institute for Health and Care Excellence’ Despite its regeneration and new the acronym NICE is still used today.

guidance materials relevant for health and social care professionals working with care home residents (NICE, 2020).

Similarly, the National Institute for Health Research (NIHR), which was established to provide infrastructure for healthcare research, has expressed a commitment to supporting research in non-NHS settings and published reviews of social care studies supported by the NIHR and its associated research centres (Goodman, 2017b). The NIHR also supports care home research through the 'Enabling Research in Care Homes (ENRICH) initiative, which was established in response to recommendations that there should be greater opportunities available for people living in care homes and people living with dementia to participate in research (Davies et al., 2014). This national initiative is delivered locally, through the NIHR's regional Clinical Research Networks.

Despite the progress in care home research in England, at present research is hindered by the lack of national, population level datasets regarding care home residents (Burns and Nair, 2014). Indeed, Burton and Guthrie (2018) have suggested that the lack of a central register makes it difficult to identify care home residents in existing datasets. Whilst attempting to establish risk factors that increase the likelihood that a hospitalised older person might be discharged into a care home, Harrison et al. (2017) concluded that prediction was not possible based on current data. At present, research is currently seeking ways of integrating health and social care data to better understand the needs of the care home population (NIHR, 2020, NIHR, 2019).

1.7. Summary

This chapter has provided an overview of the care home sector in England. Care homes in England form part of the adult social care sector and whilst care home residents have complex health and social care needs, care home services remain somewhat separate from healthcare services provided by the NHS. At present, care home organisations in England and the staff they employ face a number of challenges. Care home staff are tasked with caring for an ageing population with significant health and social care needs amidst cuts to services and difficulties in recruiting and retaining staff. The care home sector in England is also suffering from

a 'broken image', with many members of the public perceiving care homes to be a negative place to live or work.

The separation of health and social care services in England is problematic for healthcare provision in care homes. Historically there have been tensions about which services should be responsible for providing support to care home residents and there remains a lack of clarity and consistency in the healthcare support residents should expect to receive. Over the last decade there has been a growing interest in both policy and research in care homes and the healthcare needs of care home residents. Whilst research into this area is still in its relative infancy, on-going work has the potential to identify ways to improve healthcare provision in these settings.

CHAPTER TWO: Hospital transfers from care homes

Care home residents often have complex health and social care needs (Goodman et al., 2017a). As such, they are vulnerable to experiencing deteriorations in their health which may result in them being transferred to an acute hospital setting (Goodman et al., 2017a, Trahan et al., 2016). In the previous chapter, I provided an overview of the care home sector in England in order to orientate the reader to the broader social context in which hospital transfers occur. Given that concerns have been raised about whether current health and social care systems can support an ageing population, transfers from care homes to acute healthcare settings are of interest to researchers worldwide (Jablonski et al., 2007).

In this chapter, I examine existing research into hospital transfers from care homes and describe what is already known about this phenomenon. However, before introducing existing research surrounding hospital transfers from care homes, it is important to consider the limitations of the available evidence. As previously noted in Chapter 1, although work is underway to investigate ways of integrating health and social care data (NIHR, 2019), at present it is difficult to identify care home residents in existing routinely collected data due to the lack of population level datasets (Burns and Nair, 2014, Burton and Guthrie, 2018, Harrison et al., 2017). Because of this it is difficult to accurately determine the prevalence of transfers from care homes to hospitals in England.

The majority of existing research into hospital transfers from care homes has been carried out in countries outside of England. Given that each country has its own health and social care systems, it is not clear to what extent existing literature is applicable to hospital transfers that occur within the context of care homes in England. This issue is compounded by the aforementioned lack of population level datasets in England, which make comparisons between countries difficult. For example, in Sweden higher rates of hospital transfers occur in homes that are managed by private-for-profit providers (Kirsebom et al., 2014), yet whether this trend is replicated in England, in which the majority of care homes are owned and managed by private providers, is unclear. Existing research has also largely focussed on care homes that provide nursing services. In England, approximately two thirds of all care homes do not provide nursing services (CQC, 2019) and it is

not clear to what extent existing literature is applicable to hospital transfers that are initiated from these care homes.

2.1. Hospital transfers from care homes

2.1.1. How many and for what purpose?

A systematic review of 13 studies, all of which were conducted outside of England, suggested care home residents accounted for 0.4% - 2.4% of all emergency department attendances and found that there were between 0.1 and 1.5 transfers per resident bed each year (Arendts and Howard, 2010). Research conducted in England by Gordon et al. (2014) which mapped the healthcare utilisation of 227 care home residents over 180 days found that less than half of the sample used secondary care services, but those who did so used them intensively. Godden and Pollock (2001) have suggested that care home residents in England are more likely to experience an emergency admission than older people living in the community. However, research has also suggested that care home residents only account for around 1-3% of all emergency attendances (Quinn et al., 2011, Witt et al., 2013), providing challenge to the assumption that care home residents account for a significant proportion of emergency department use. Despite this, residents who are transferred to hospital often have complex needs (Witt et al., 2013).

Smith et al. (2015) sought to quantify the healthcare utilisation of care home residents through the use of routinely collected Hospital Episode Statistics (HES)⁶ data. Although it is not possible to definitively identify care home residents using HES data, it is possible to identify people living in a postcode that contains a care home. As such, they compared hospital admission rates of people aged 75 and over living within a postcode that did or did not contain a care home. Over a one year period, there were almost three million hospital admissions for people aged 75 and over in England. Approximately 247,000 (8.2%) of these admissions were initiated from a postcode which contained a care home (Smith et al., 2015). Furthermore,

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⁶ The term 'Hospital Episode Statistic (HES)' refers to data that is routinely collected during hospital admissions, outpatient appointments and A&E attendances across NHS hospitals in England. The data contains demographic, clinical, administrative and geographical data that is anonymised and made available for secondary use, such as for research purposes.

people living within a postcode that contained a care home were more likely to experience an unplanned, emergency hospital admission and less likely to experience an elective admission than people of the same age living in a non-care home postcode (Smith et al., 2015).

More recently, Wolters et al. (2019) used linked datasets to explore emergency attendances and admissions to hospital amongst care home residents across England. The authors suggested that for the year 2016/17 there were approximately 269,000 emergency hospital attendances from care homes, of which 192,000 resulted in a hospital admission. This figure accounts for 6.5% of all attendances and 7.9% of emergency admissions for people aged 65 and over, despite care home residents accounting for just 2.8% of this population. Care home residents were more likely to attend hospital than people aged 65 or older living in their own homes - 0.98 times per person per year and 0.43 times per person per year respectively. Care home residents were also more likely to be admitted to hospital as an emergency than the general population aged 65 or older - 0.70 times per year vs 0.25 per year respectively (Wolters et al., 2019).

Therefore, taken together, the work of Godden and Pollock (2001), Gordon et al. (2014) Smith et al. (2015) and Wolters et al. (2019) all suggest that in England, care home residents are more likely to be transferred and admitted to hospital in an emergency situation than people living in the community. Despite this overall trend, research has suggested that care home residents with a diagnoses of dementia are less likely to be transferred to a hospital setting within the last 90 days of their life than a person living with a diagnosis of dementia in their own home (Leniz et al., 2019). International research conducted in Belgium, Netherlands, Spain and Italy identified a similar trend – across all residents (i.e. not just residents with a diagnosis of dementia), people living within a care home were less likely to experience a hospital transfer in the final 90 days of their life than people living in their own homes (Van den Block et al., 2015).

Existing research has attempted to understand the reasons for which care home residents may be transferred to hospital. A survey of care homes providing nursing services in the United States suggested that residents were likely to be transferred to hospital when they experienced a sudden and unexpected change in their health

status, shortness of breath, a change in consciousness, decreased oxygenation, chest tightness and muscle or bone pain (Ashcraft and Owen, 2014). In England, Smith et al. (2015) found that transfers could be associated with both acute and progressive long-term conditions, identifying common diagnoses associated with a hospital admission as pneumonitis due to aspiration of solids or liquids, Alzheimer's disease and epilepsy. A higher prevalence of hospital transfer and admissions has been observed amongst residents who have multiple long-term conditions and mild cognitive impairment (Smith et al., 2015, Stephens et al., 2014), supporting calls for the input of multidisciplinary healthcare input and dementia expertise in care homes (British Geriatrics Society, 2011, Glendinning et al., 2002, Goodman et al., 2017a, NHS England, 2016, Oliver et al., 2014, Royal College of Physicians et al., 2000)

2.1.2. Variation in hospital transfer rates

Although the aforementioned studies provide estimations of healthcare utilisation across all care home residents in England, there is considerable variation in acute emergency care use between residents of different care homes, even when the demographic and health profile of residents are similar. A growing body of research has started to suggest that resident hospital transfer rates are influenced by numerous contextual factors.

Research conducted in Norway suggested that fewer acute hospitalisations occur amongst residents living in care homes that were larger in size and with a lower proportion of short-term beds (Graverholt et al., 2013). In England, fewer emergency hospital admissions are observed across care homes that provide nursing services in comparison to care homes that do not (Godden and Pollock, 2001, Wolters et al., 2019). In addition, an analysis of variation in ambulance call outs in one small geographical area of England found that lower call out rates were observed amongst care homes that: i) provided nursing services on site; ii) did not specialise in dementia care; and iii) failed the quality standard for suitability of management - suggesting that lower transfer rates may not necessarily be a sign of better quality care (Hancock et al., 2017). In England, at a population level, variation in avoidable emergency admissions are largely explained by deprivation (O'Cathain et al., 2014). Therefore, there may also be wider, population level influences that influence hospital transfer rates from care homes.

In a large systematic review of 78 studies (primarily quantitative studies that used health administration data collected in countries outside of England), Dwyer et al. (2015) identified a broad range of factors that influenced transfer rates, which they categorised into two categories. Whilst 'patient factors' described characteristics of individual care home residents (for example, the presence of cognitive impairment, having reduced functional ability, particular comorbidities or the absence of an advance care plan), 'organisational factors' highlighted characteristics of particular care homes (for example, being a 'for-profit' care home, having lower staff to resident ratios or poor support from other healthcare professionals). Based on their findings the authors suggested that because care home resident populations, care home organisations and healthcare services can differ between countries, it is important to understand hospital transfers as they occur at a local level.

International comparisons of care homes are lacking. However, it is recognised that there are important differences between countries in both the clinical characteristics of care home residents and the structure of long term care provision which are likely to affect transfer decisions. An international epidemiological study, conducted by Pivodic et al. (2018) to determine the quality of end-of-life care in care homes across six European countries (Belgium, Finland, Italy, the Netherlands, Poland and England), found variation in the characteristics of residents included in their sample and the care homes where they resided. Residents in England were more likely to be older and to have a lower functional status than residents across the other five countries. In addition, residents in England were more likely to receive most of their care from staff who were not registered nurses and more likely to live in privately-owned care homes that operated on a for-profit basis. The authors noted that England was the only country in their sample in which there existed care homes that did not offer nursing services on site and, unlike care homes in Italy and the Netherlands, care homes in England do not employ physicians. Instead, when a care home resident's health deteriorates, external healthcare services are contacted (Pivodic et al., 2018). These differences highlight the importance of understanding transfers in the specific context of care homes in England.

2.2. Potential harms associated with a hospital transfer

A transfer to hospital can be potentially detrimental to the health and well-being of care home residents. Perhaps unsurprisingly given their complex health and care needs, once in hospital, care home residents have a higher risk of cause-specific (Menec et al., 2002) and overall mortality (Ahearn et al., 2010, Ong et al., 2011). Although research into outcomes other than mortality specifically for care home residents is scarce, there is a wider body of literature that suggests hospital transfers and admissions can be harmful for older people, particularly older people living with frailty and/or cognitive impairment.

For older people, a hospital admission can be associated with physical decline (due to iatrogenic illnesses or prolonged inactivity), cognitive decline and the onset of delirium (Ashcraft and Owen, 2014, Creditor, 1993, Hirsch et al., 1990, Inouye et al., 1993, Ouslander and Maslow, 2012). Calnan et al. (2013) go as far as to suggest that hospital environments are not suitable for many older people, arguing that the organisation of acute care, which is usually speciality-focussed, does not meet the needs of older adults who may require a more holistic, multidisciplinary approach to care. The authors suggests that “acute hospitals do not seem to be working for their major client group” and calls for a recognition that “the place and system itself must change to accommodate the majority of patients” (Calnan et al., 2013, p482).

Research has also suggested that for individual's living with frailty, hospital transfers can be burdensome. Despite a national focus on reducing the amount of time frail older people spend in hospital, a number of studies have suggested that frail older people who are rapidly discharged from hospital settings are vulnerable to experiencing poor short-term outcomes including increased mortality, increased dependency, reduced mental well-being and high rates of hospital readmission (Edmans et al., 2013, Wou et al., 2013). In addition, research that has sought to understand the longer-term outcomes associated with a hospital admission found frailty to be associated with two-year mortality, even if the admission had been short (i.e. less than 72 hours). Based on these findings it has been suggested existing services may not adequately meet the needs of this population following a discharge from hospital (Keeble et al., 2019).

For people living with cognitive impairment, a transfer to a busy emergency department can be physically and psychologically stressful (Kirsebom et al., 2014). In comparison to older people without a diagnosis of dementia, older people who are admitted to hospital with a diagnosis of dementia are at a higher risk of death, delirium, falls, dehydration, reduction in nutritional status and decline in physical and cognitive function (Fogg et al., 2018). In addition, patient and carer experiences of hospital admission are often poor (Fogg et al., 2018). Given that care home residents are likely to be the 'oldest old' in society (Bowman et al., 2004, Gordon et al., 2014) and approximately 80% of all care home residents have a diagnosis of dementia (Alzheimer's Society, 2014), this wider body of research is likely to be applicable to the majority of care home residents.

Hospital transfers can also present a challenge to continuity of care and place strain on family carers, who may become responsible for transporting their relative back to the care home if they are not admitted and who may feel the need to visit the hospital frequently if an admission occurs (Jablonski et al., 2007, Tsai et al., 2016). As a result, national guidance promotes the management of health conditions in the care home wherever possible and emphasises the need to plan for discharge from the day of admission to ensure residents do not spend unnecessary time in hospital (NICE, 2017).

2.3. Interventions to reduce transfers from care homes

There have been numerous attempts to reduce emergency healthcare use in recent years. Whilst some attempts have occurred at a national population level, others have targeted specific groups of people such as older people and/or care home residents. In England, attempts to reduce emergency care use across the population have been multifaceted, aimed at improving general practice and urgent care pathways, and integrating health and social care (Steventon et al., 2018). However Steventon et al. (2018, p18) note that "despite more than a decade of trying, there are comparatively few well-evidenced examples of what works". The authors raise questions about the plausibility of reducing emergency care use at a time when health services are increasingly supporting an ageing population with complex health and care needs. Furthermore, concerns have been raised that interventions to

reduce healthcare utilisation in one area may create higher demand elsewhere in the system (Kumar and Grimmer-Somers, 2007).

A systematic review of international literature outlined three types of intervention aimed at reducing hospital admissions from care homes: 'interventions to structure or standardise clinical practice', for example promoting standardised decision-aids and assessment tools; 'geriatric specialist services' that provide specialised healthcare for residents; and 'interventions that aimed to increase influenza vaccinations' (Graverholt et al., 2014). The authors suggested that there was only weak evidence available to suggest that these approaches are effective and therefore stronger evidence is required to make recommendations for policy.

Another common strategy for reducing hospital transfers from care homes is to ensure, where appropriate, care home residents have advance care plans in place. Advance care planning is a process through which individuals and healthcare professionals discuss and document wishes and preferences regarding future care. In England, advance care planning can take many forms and can include a general statement of preferences, refusal of treatments and interventions, or the completion of specific forms such as Do Not Attempt Cardio-Pulmonary Resuscitation (DNA-CPR) or Recommended Summary Plans for Emergency Care and Treatment (ReSPECT). Advance care planning has been identified as a potential way to reduce hospital transfers from care homes (Givens et al., 2012, Kirsebom et al., 2014) and has been highlighted in both research and national policy as a way of improving end-of-life care (Ahearn et al., 2010, DoH, 2008, NHS, 2019, NICE, 2019b, Wendrich-van Dael et al., 2020). This is based on an assumption that the process of advance care planning provides an opportunity to weigh up the potential harms and benefits of a transfer, which in turn would reduce transfers that are less likely to result in better clinical outcomes or improved quality of life. However, the degree to which advance care planning achieves this aim is unclear (Detering et al., 2010, Konttila et al., 2019).

Planning for the future care needs of care home residents can be difficult, in part due to unpredictable illness trajectories, yet still possible in general terms (Alcorn et al., 2020, Barclay et al., 2014). Although a small proportion of individuals do not wish to engage in advance care planning, the majority of frail older people welcome the

opportunity to do so (Sharp et al., 2013). If able to do so, many care home residents are willing to discuss end-of-life situations (Mathie et al., 2011). However, in reality, only a small minority of individuals have the opportunity to participate in advance care planning (Sharp et al., 2013). There is a growing body of evidence that has sought to explore advance care planning, the majority of which focuses on the experience of individuals engaging in advance care planning discussions (Sharp et al., 2018). Much less is known about the way in which advance care planning documents are used and interpreted during decision-making about whether or not a hospital transfer may be appropriate at the time of a deterioration in a resident's health.

Given the crucial role that care home staff play in the everyday management of residents' health and in responding to deteriorations, it is crucial that research seeks to understand how advance care planning is viewed and utilised during 'in-the-moment' decision-making by this group. Research conducted in care homes providing nursing services in the United States has suggested that registered nurses consider the presence or absence of DNA-CPR forms when determining the most appropriate course of action for residents who are acutely ill (Lopez, 2009). In addition, research that aimed to measure adherence to "No To Hospital" advance directives amongst care home residents in Nova Scotia found that over half of all transfers occurred in residents with an advance directive in place, due to unclear written plans, inadequate symptom control in the care home or due to a perceived need for investigative procedures that were only available in hospital (Nemiroff et al., 2019). Therefore, advance care planning is only the 'first step' in a decision-making process and the mere presence of an advance care plan document does not eliminate the need for an in-the-moment discussion (Cohen et al., 2017, Palan-Lopez et al., 2017).

Interventions to reduce transfers from care homes often identify a reduction in emergency care use as a primary outcome measure, framing emergency care use as a problem to be solved. However, reducing hospital transfers from care homes could have an unintended negative consequences, preventing residents from accessing treatment that would be beneficial to them. Although a shared conceptualisation of a problem is necessary in order to resolve a 'problematic behaviour' (Malone, 1995), to date academic research has largely neglected to

explore the ways in which care home staff perceive interventions to reduce hospital transfers (O'Neil et al., 2017). Moreover, whilst being able to demonstrate effectiveness can increase the likelihood that an intervention will be implemented (Huntley et al., 2017), there is a need to explore how interventions and measures used to evaluate them are perceived by the health and care professionals that are expected to put them in to practice.

During a qualitative study of hospital transfers from care home, McCloskey (2011) suggested that she observed “a culture in which practitioners were expected to dismiss the knowledge and expertise of others who worked in different settings”, which led to poor relationships between staff working in care homes and emergency departments (McCloskey, 2011, p722). Similarly, whilst evaluating an intervention to improve care transitions for care home residents, Sutton et al. (2016) found tensions between the ways in which hospital and care home staff defined the ‘problem’ they were trying to address. This in turn led to conflicting views about the interventions most appropriate to address the problem and how to measure ‘success’, limiting the intervention’s effectiveness. As a result, the authors suggest that a shared conceptualisation of the problems to be addressed, the interventions to address them and the measures used to evaluate success are essential prerequisites to ‘improving’ hospital transfers from care homes.

2.4. Inappropriate transfers from care homes: Prevalence and definitions

Across academic literature, reports, policy and national guidance, there has been a growing interest in identifying hospital transfers that could be deemed to be ‘inappropriate’. When discussing inappropriate hospital use, several terms are used interchangeably including ‘avoidable’, ‘preventable’, ‘unnecessary’ and ‘inappropriate’ (Jablonski et al., 2007, Trahan et al., 2016). Khoujah and Hirshon (2017) helpfully differentiate between inappropriate transfers that are either ‘avoidable’ or ‘unnecessary’. Whereas the term ‘avoidable’ is used to suggest the presenting condition could have been prevented (for example, if a resident becomes dehydrated due to a lack of fluids), the term ‘unnecessary’ is used to suggest that a transfer to a hospital was not required as the presenting complaint could have been managed within the care home or by another community service.

More recently, Parkinson et al. (2021), put forward three categories of 'inappropriate' emergency hospital attendances in England, each based on the type of care that an individual presenting within that subset would require. Whereas the term 'clinically divertible' attendances is used to refer to instances where the individual could have been cared for elsewhere in the healthcare system, the term 'clinically preventable' attendances is used to refer to instances in which the individuals would have benefitted from better or earlier intervention from primary care services, and the term 'clinically unnecessary' attendance refers to instances where the individual did not require any clinical care and instead may have benefitted from other forms of care (for example self-care or a referral to social care services, rather than support from a healthcare service).

Parkinson et al. (2021) suggest that categorising hospital attendances in this way could be helpful in identifying the aspects of the healthcare system which could be targeted by policy interventions. The authors suggest that whilst 'clinically divertible' attendances are likely to be responsive to increasing capacity elsewhere in the system (for example, primary care or urgent care services), and 'clinically preventable' attendances may be responsive to improving access to and the quality of primary care and specialist community services, 'clinically unnecessary' attendances are less likely to be amenable to change via policies focussed solely on healthcare systems and may instead require public health education and improvements in other sectors, for example in social care (Parkinson et al., 2021).

Although the distinctions put forward by Khoujah and Hirshon (2017) and Parkinson et al. (2021) are helpful for conceptualising inappropriate use of hospital care, at a population level, there remains a lack of consensus about what constitutes an 'inappropriate' transfer, both in academic research (Lemoyne et al., 2019) and amongst healthcare professionals who work with care home residents. Due to the lack of agreement about what exactly constitutes an inappropriate hospital care use, a commonly used proxy-measure is care that is related to Ambulatory Care Sensitive (ACS) conditions. ACS conditions include: chronic conditions for which effective management in the community would prevent a need for hospital care (e.g. diabetes); acute conditions that can be prevented via early intervention (e.g. dehydration); and conditions that are vaccine-preventable (e.g. influenza) (NHS Digital, 2019). In the year 2012/13, at a population level, there were almost 5.3

million emergency admissions to NHS hospitals in England. Over one million of these, approximately 20%, were recorded as being due to an ACS condition, leading Blunt (2013) to conclude that these admissions could have been avoidable.

Estimates of the prevalence of 'inappropriate' hospital care use vary. An international systematic review conducted by Arendts and Howard (2010) suggested that over 40% of hospital transfers from care homes do not result in a hospital admission, which raises questions about whether these transfers were initiated inappropriately. However, existing research (conducted in care homes providing nursing services on site in Canada and the United States) have produced estimates ranging from 7% (Bergman and Clarfield, 1991) to 23% (Jones et al., 1997) and 40% (Saliba et al., 2000). Jablonski et al. (2007) provide two explanations for the variation. Firstly, some studies include mortality as an indicator of inappropriateness (Bergman and Clarfield, 1991, Jones et al., 1997), whereas others do not (Saliba et al., 2000). Second, the variation may be due to the features of the specific healthcare systems. For example, the authors suggest that particularly low estimates in Bergman and Clarfield's (1991) findings may be related to the Canadian healthcare system, which encourages primary care physician visits to care homes and discourages transfers to acute healthcare facilities (Jablonski et al., 2007).

Variation in estimates of (in)appropriate healthcare use amongst care home residents may also be influenced by *who* is making a judgement on appropriateness. Harrison et al. (2016) asked healthcare professionals in Scotland to make a judgement on the appropriateness of a hypothetical care home resident hospital admission. The author's findings suggested that GPs and care home liaison nurses (i.e. professionals with direct experience of working with care home residents) were significantly more likely to suggest that a transfer to hospital was inappropriate than healthcare professionals working in secondary care.

2.5. Criticisms of the 'inappropriate' transfers literature

2.5.1. The social construction of care home residents as problematic

It has been suggested that emergency care services provide a 'window' through which it is possible to observe wider societal issues (Malone, 1995). Given that the current preoccupation surrounding 'inappropriate' hospital use is occurring alongside concerns about the ability of health and social care services to support an ageing

population at a time of increased financial pressures, there is a need to critically assess current discourses (McCloskey and van den Hoonaard, 2007). However, concern about inappropriate emergency care use is not a new phenomenon. Over 25 years ago, Malone (1995) examined the discourses surrounding 'heavy users' of emergency departments in the US. Malone (1995) acknowledged that people who were categorised as 'heavy users' – determined at the time as someone who had four or more visits to the emergency department over a 12 month period - were more likely to be individuals facing significant health inequalities. This included “the socially marginalised; the mentally ill, and drug- and alcohol-dependant, the poor, minorities and those with unstable family situations or without social support” (Malone, 1995, p470).

Malone (1995) suggested that 'heavy users' of healthcare services were constructed in two distinct ways. On one hand, the biomedical approach to health, which emphasised self-care, independence and personal responsibility, constructed 'heavy users' as 'abusers' of the healthcare system. On the other hand, the public health approach, which emphasised interdependence between the individual and their wider social context, constructed the same individuals “not as a problem... instead as a symptom of deterioration in the system itself” (Malone, 1995, p472).

It could be suggested that the language use to discuss '(in)appropriate' healthcare use, situated within a (bio)medical model of care, encourages the framing of care home residents as 'problematic' for healthcare systems, detracting attention from the broader social context that surrounds such hospital use. The terminology surrounding 'inappropriate' hospital use can be emotive and value-laden, invoking a sense that there is a need to ensure that individuals are 'appropriately', and therefore responsibly, making use of a limited shared healthcare resource. Furthermore, Glasby et al. (2016) suggests that the terminology surrounding 'inappropriate' hospital use unhelpfully presents an overly-simplistic, polarised view of hospital transfers and admissions (between those that are either appropriate or inappropriate).

Attempts to reduce hospital transfers from care homes – which could be conceptualised as ‘rationing’⁷ - often centre on two justifications. Firstly, reducing hospital transfers from care homes is discussed in terms of reducing the potential harms associated with a transfer for care home residents (discussed in more detail in section 2.2). Secondly, reducing the number of residents that are transferred to hospital is often discussed in terms of reducing costs for healthcare services. It is possible to address both of these issues together – ensuring residents are transferred to hospital only when doing so would result in improved health outcomes or quality of life would be advantageous for residents and may also reduce costs for healthcare services. However, it is important to recognise that reducing hospital transfers from care homes could have unintended negative consequences, preventing resident from accessing treatment that would be beneficial to them (Ouslander and Maslow, 2012).

As well as the two issues described above, there may also be other justifications for reducing hospital transfers from care homes that are rarely discussed explicitly which relate to broader negative assumptions about care home residents. Although rarely stated explicitly, there is arguably an assumption that care home residents, are older, sicker and closer to the end-of-life than many others in the general population and therefore resources could be better directed towards others who are more likely to obtain greater benefit. Arber and Ginn (1998) suggest that the measure against which many rationing decisions are based, ‘Quality Adjusted Life Years’ (QALY)⁸, inherently privileges younger people. The authors also point to upper age limits on screening programmes and the absence of robust evidence into the effectiveness of drug therapies in older people as evidence of the way in which ageist assumptions are embedded within healthcare systems.

⁷ ‘Rationing’ is a concept used to describe the ways in which resources are allocated (or not) to certain groups of people or under certain circumstances (Arber and Ginn, 1998). The decision to ration particular forms of healthcare may be rooted in economic or ethical justifications and it is often assumed that rationing will lead to a ‘better’ allocation of resources (i.e. resources will be directed towards those who will experience the most benefit from such an allocation).

⁸ Quality Adjusted Year of Life (QAYL) is a widely used measure of healthcare outcomes. QAYL takes into consideration both the quantity (i.e. years of life) and quality of life to determine the potential benefit of a treatment. One QAYL is equal to one year of life in perfect health.

2.5.2. The neglect of the influence of non-clinical factors on transfer rates

Framing a group of people or a particular behaviour as problematic can attract the interest of researchers, yet this interest is often focussed on the characteristics of the 'offenders' and interventions to reduce undesirable behaviours rather than the wider social context that influences behaviour (Malone, 1995). Often, determining the (in)appropriateness of a hospital transfer is based solely on the primary clinical symptoms, with little consideration afforded to the wider social context in which a transfer decision was made.

Until recently there has been an absence of research that has explored the wider social context in which transfer decisions are made. However, more recently a number of studies have explored variation in transfer rates (see section 2.1.2 for more details) and suggested that transfer rates can be influenced by a range of clinical and non-clinical factors. This body of research highlights the importance of understanding transfers as they occur at a local level (Dwyer et al., 2015). It could be hypothesised that once the wider context surrounding a transfer is understood, the rate of inappropriate transfers becomes much lower than some published research suggests. Therefore, before policies or interventions to reduce 'inappropriate' hospital transfers can be identified and introduced, a holistic understanding of transfers, that looks beyond a singular focus on clinical factors is necessary (Arendts et al., 2013).

2.5.3. Limitations of using ACS conditions as an indicator of 'inappropriate' healthcare use

As previously noted, healthcare that is related to ACS-conditions is a commonly used proxy-measure of 'inappropriate' healthcare use. It would be plausible to suggest that care home residents are more likely than the general population to experience admissions related to ACS conditions due to the higher prevalence of multiple long-term health conditions in this population and because ACS-related admissions occur disproportionately in older people (e.g. chronic obstructive pulmonary disease, pneumonia, cellulitis) and young children (e.g. ear nose and throat infection, epilepsy and convulsions) (Blunt, 2013). However, whilst ACS conditions occur disproportionately in these two age groups, seldom is it suggested

that reducing care related to ACS-conditions amongst children would prevent the depletion of scarce healthcare resources.

Using ACS conditions as a proxy-measure of inappropriate healthcare usage is based on an assumption that for some conditions adequate management in the community can prevent a hospital admission. However, this assumption may not always hold true, particularly when caring for people with complex health and care needs and individuals with cognitive impairment. For example, even with outstanding care and support, a care home resident with advanced dementia may not experience thirst and may refuse to drink, causing them to become dehydrated. Whilst there are strategies that staff may be able to implement to encourage a resident to drink, there may be some circumstances in which dehydration is not as preventable as one might assume.

Hodgson et al. (2019) suggest that in addition to simply quantifying healthcare use related to ACS conditions, there is a need to carefully consider the multifactorial nature of hospital admissions and the wider context surrounding healthcare utilisation. This includes a consideration of the wider healthcare system and of broader influences on health. For example, they highlight that level of deprivation is consistently associated with health (Hodgson et al., 2019). Therefore, the authors suggest that ACS conditions can be used as a proxy monitoring tool to assess the effectiveness of healthcare systems, providing that it is used with caution.

2.6. Decision-making about potential hospital transfers

2.6.1. Exploring staff experiences of hospital transfers

At present, the majority of research that has sought to reduce hospital transfers from care homes has been situated within hospital-centric assumptions about the nature of the 'problem' and its potential 'solutions'. In order to better understand the multifaceted nature of decision-making surrounding hospital transfers from care homes, McCloskey and van den Hoonaard (2007) suggest that research should focus on the experiences of care home staff to "identify those whose voices have not been heard" (McCloskey and van den Hoonaard, 2007, p192). In line with this suggestion, and in recognition that care home staff play a crucial role in resident hospital transfers (Jablonski et al., 2007), there has been a growing body of research that has sought to understand the decision-making and experiences of care home

staff involved in resident hospital transfers (Arendts et al., 2013, Jablonski et al., 2007, Lopez, 2009, McCloskey, 2011, O'Neill et al., 2015).

Jablonski et al. (2007) asked staff in three care homes with nursing services in the United States to describe their decision-making process during resident hospital transfers. The authors found that whilst there were occasions where everyone involved in decision-making was in agreement about the appropriateness of a hospital transfer, at other times there was the potential for disagreement (Jablonski et al., 2007). Where there was initial disagreement, decision-making was characterised as a process of 'cogency', in which individuals attempted to persuade one another, either by enlisting the support of others or by using targeted communication – for example highlighting the features of a resident's presentation that best fitted with their idea of what was an appropriate action to take (Jablonski et al., 2007). The description of transfer decisions as a process of 'cogency' was supported by Lopez (2009) who suggested that nurses used indirect communication and coded language to persuade physicians to set out a treatment plan that aligned with the wishes of residents and family members. Based on these findings, Lopez (2009) developed a model of staff decision-making entitled the 'satisfying all sides' model, highlighting the work that care home nurses did to take into account the wishes of residents, family carers and healthcare professionals. This model will be discussed further later in this chapter, in section 2.6.3.

More recently, O'Neill et al. (2015) sought to describe care home nurses' perceptions of hospital transfers by conducting a synthesis of seven qualitative studies. The authors highlighted the complexity of transfer decisions, suggesting that nurses required a range of knowledge, skills and resources to be able to assess and manage a deteriorating resident. They also suggested that nurses were aware of the power that family carers hold, which could influence the decision-making and actions of nurses, as they sought to ensure families were informed and in agreement with the actions they proposed. The authors also suggested that ambiguity about the resident's condition, strained relationships between nurses and other stakeholders (e.g. healthcare professionals and family carers), and negative perceptions of residents' experiences of transfers could make decision-making particularly difficult as they introduced the possibility for conflict amongst the people involved. As a result of their findings, the authors concluded that "the overarching message is that nurses

need and want some structure or 'plan' to help them to manage transfers" (O'Neill et al., 2015, p427). The authors are not alone in calling for more structure in decision-making. There are frequent calls for standardised assessments and responses to deteriorating residents, for example through advance care planning or standardised decision-aids (Ahearn et al., 2010, Givens et al., 2012, Kirsebom et al., 2014, O'Neil et al., 2017).

A focus on the experiences of care home staff may provide new insights into hospital transfers from care homes. However, at present very little work has been conducted in care homes in England. All of the primary research papers presented in this section, as well as all of the primary studies included in the O'Neill et al. (2015) review, describe studies conducted outside of England, predominantly in the United States or Australia. Given that it is important to understand transfer decisions within the context in which they occur (Dwyer et al., 2015), at present it is not clear to what extent and how existing literature is applicable to hospital transfers initiated within the context of care homes in England.

2.6.2. Factors influencing the decision to transfer

As well as research that has sought to explore the experiences of care home staff when involved in transfer decisions, other research studies have sought to identify and categorise factors that influence staff decision-making. In their systematic review, Arendts et al. (2013) suggested that the factors affecting staff decision-making about potential hospital transfers could be categorised into two domains. The 'resident dominant' domain included decision-making which was influenced by the expectation of improved clinical outcome or quality of life for the resident, whereas the 'resident subordinate' domain included decision-making in which transfers were initiated without this expectation. These transfers were usually associated with a broad range of socio-structural influences such as concerns about litigation, a lack of resources, a lack of care planning, difficulties in communication and the preferences of residents, families, physicians and staff (Arendts et al., 2013).

Laging et al. (2015) conducted a meta-synthesis of the factors that influenced care home staff decision-making regarding potential resident hospital transfers. The authors suggested that staff decision-making was influenced by a broad range of factors. In particular, they pointed to unclear expectations surrounding the role of

care home staff in transfer decisions, the fear that staff felt to work outside of their usual scope of practice, as well as inadequate multidisciplinary support and difficulties communicating with other decision-makers (Laging et al., 2015).

Furthermore, a review of 19 studies, conducted by Trahan et al. (2016), identified five categories of factors that influence potential transfer decisions. This included: *'nursing factors'* related to the skills and knowledge of staff; *'facility/resource factors'* related to diagnostic equipment and tools available within the care home; *'physician/nurse factors'* related to the availability of healthcare support in the care home; *'resident/family factors'* related to the preferences of these individuals; and *'health system factors'* related to bureaucratic influences on transfer decisions and a perceived lack of respect for the work of care home staff (Trahan et al., 2016).

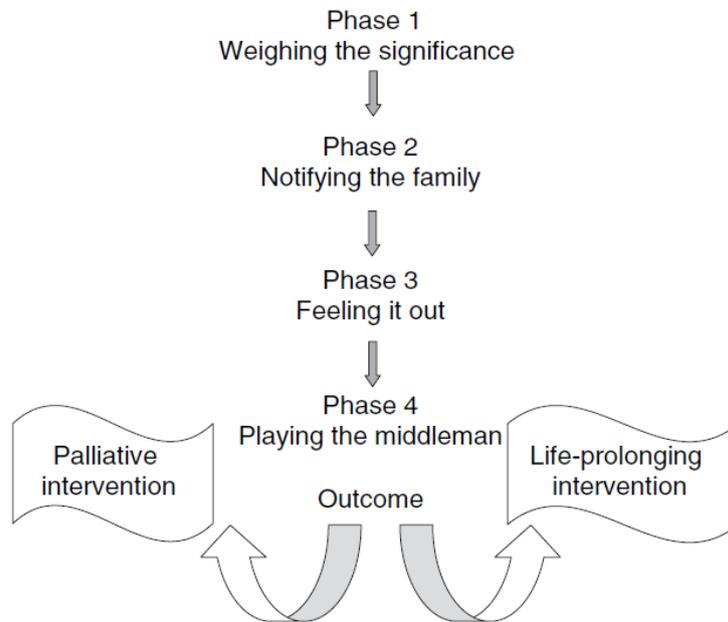
Taken together, the work of Arendts et al. (2013), Trahan et al. (2016) and Laging et al. (2015) all suggest that care home staff decision-making is complex and influenced by multiple factors and the wider social context in which the decision is made. However, none of the papers included in the three reviews originated from studies of care homes in England. As a result it is not clear to what extent findings are applicable in this context.

2.6.3. Models of care home staff decision-making during resident transfers

Modelling staff decision-making during potential resident transfers could provide an opportunity to make decision-making processes and the factors that influence those processes more explicit. In turn, this may provide a useful framework to better understand and further investigate hospital transfers from care homes. Based on their study of care home nurses' decision-making whilst caring for acutely ill residents, Lopez (2009) developed the 'satisfying all sides model' (previously discussed in section 2.6.1 and reproduced in Figure 1 below). This model describes the way care home nurses 'weighed the significance' of the information available to them (including symptoms, known wishes and preferences) before 'notifying the family' in order to prepare the family for further deterioration and to protect themselves from litigation. Once the family was notified, nurses undertook a process of 'feeling out' their options to determine whether they should initiate life-prolonging or palliative treatment. Once a decision had been made, nurses were required to

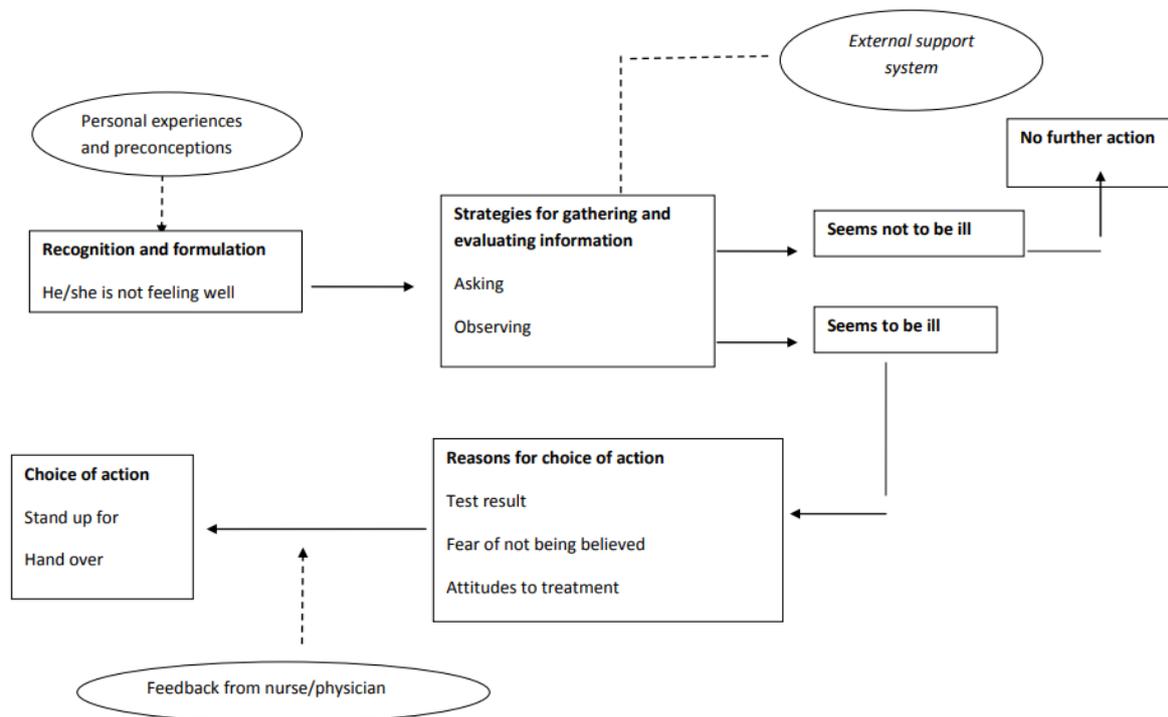
'play the middleman', using coded language to achieve consensus and to guide doctors' actions and family expectations.

Figure 1: The 'satisfying all sides' model developed by Lopez (2009)



In Sweden, Sund-Levander and Tingström (2013) explored and modelled the experiences of nursing assistants involved in decision-making about residents with suspected infections. Their model, reproduced in Figure 2, suggested that nursing assistants' assessments were rooted in their knowledge of each resident and their own personal beliefs about ageing. In addition, the authors suggested that the way in which nurses and physicians responded to nursing assistants' concerns had an influence on the actions that nursing assistants took.

Figure 2: A model of nursing assistants' clinical decision-making developed by Sund-Levander and Tingstrom (2013)

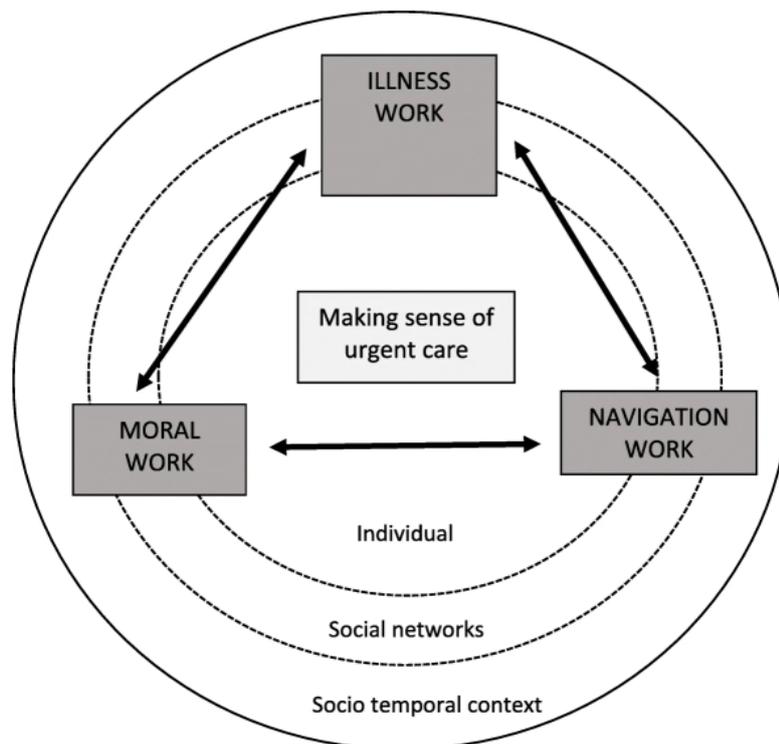


The models outlined above could provide insights into the decision making of care home staff. For example, Lopez (2009) model provides a useful conceptualisation of the decision-making process that care home nurses undertake regarding the treatment options for acutely-ill residents and the model outlined by Sund-Levander and Tingström (2013) provides insights into some of the non-clinical factors that have been found to influence staff decision-making. However, the extent to which each model would be applicable to the decision-making of care home staff working in England is unclear.

Based on their research conducted in England, Turnbull et al. (2019) developed a conceptual model of how people make sense of and seek urgent care (defined by the authors as healthcare that is required promptly, typically within 24 hours, but that is not for life threatening conditions). The model differentiates between three types of 'work' that individuals undertake when help-seeking. These are: 'illness work' to assess and interpret symptoms and risks; 'moral work' to present oneself as legitimately seeking help; and 'navigation work' to identify an appropriate service. In their model, Turnbull et al. (2019) highlight the influence of social networks and the

wider socio-temporal context on help-seeking. In addition, the authors suggest that people do not deliberately use services inappropriately, instead their actions are a result of the work that they undertake, which in turn is influenced by the wider social context.

Figure 3: A conceptual model of urgent care sense-making and help- developed by Turnbull et al., 2019)



Turnbull’s (2019) model concerns the way in which people seek urgent care for themselves rather than on behalf of others and therefore may have limited applicability to the decision-making of care home staff. Despite this, the model foregrounds the work that individuals do in order to interpret symptoms and seek help, and highlights the complexity of these processes. In addition, Turnbull’s (2019) model provides a suggestion for reducing seemingly ‘inappropriate’ healthcare use, proposing that research should move away from identifying ‘inappropriate help-seeking’ and towards changing the work that patients have to undertake to make sense of healthcare services.

2.7. Summary

Whilst a lack of population level data makes it difficult to accurately determine how many residents are transferred to hospital each year, research has suggested that

care home residents are more likely to seek emergency care than the general population. Although transfers are often necessary, for some residents a transfer may be associated with adverse consequences and poor outcomes. As such, there have been efforts to reduce the number of hospital transfers from care homes, particularly those that might be considered 'inappropriate'. However, at present there is a gap in the evidence base surrounding 'what works' to reduce emergency care use.

Given the associated burdens, reducing transfers from care homes may appear, on the face of it, to be a sensible policy objective. In addition, differentiating between transfers that are appropriate and inappropriate may provide a framework for developing interventions to reduce transfers that may not be beneficial for residents. However, questions have been raised about the suitability of the over-simplistic and value laden terminology when discussing the healthcare utilisation of care home residents. At present there is a lack of consensus about what constitutes an 'inappropriate' transfer, across research studies and amongst healthcare professionals that support care home residents. In addition, critical assessments of predominant discourses surrounding 'inappropriate' transfers from care homes have suggested that residents are socially constructed as problematic for healthcare services. As such, a preoccupation with reducing healthcare use may also partly reflect wider ageist assumptions and concerns about the ability of health and care services to meet the needs of an ageing population. Moreover, concerns have been raised about the use of ACS conditions as a proxy-measure of inappropriate healthcare use.

Often, determining the (in)appropriateness of a hospital transfer is based solely on the primary clinical symptoms, with little consideration afforded to the wider social context in which a transfer decision was made. However, there has been a growth in studies that have sought to qualitatively explore and conceptualise the decision-making of care home staff, in order to understand the decision-making processes that care home staff undertake and to identify factors that may influence decision-making. This body of literature has suggested that decision-making is complex and multifactorial, involving multiple stakeholders and influenced by the wider social context. Although this body of research highlights the importance of understanding hospital transfers as they occur within their local contexts, the majority of existing

research has been conducted outside of England, predominantly in care homes that provide nursing services. As such, further work is required to assess the applicability of existing research to care homes in England, particularly to homes that do not provide nursing services.

CHAPTER THREE: Risk, risk work, and decision-making

In Chapter 1 I provided an overview of the care home sector in England and in Chapter 2 I outlined existing research into hospital transfers from care homes. Here, in Chapter 3, I introduce theories and concepts that can be used as tools to develop a better understanding of the decision-making processes of care home staff when deciding whether to transfer a resident to a hospital. Some of the concepts discussed in this chapter were considered during early stages of the project. For example, at the beginning of the project I was interested in the ways in which different stakeholders, such as residents, their family carers, care home staff and external healthcare professionals, might influence staff decision-making. My use of other concepts, in particular the framing of decisions about hospital transfers as a form of 'risk work', was developed through an iterative process of data collection and analysis and a search to identify theories and concepts that could help to explain themes identified within the dataset. Therefore this chapter considers sociological theories of risk, models of clinical judgment and decision-making and the role of intuition and power dynamics in decision-making.

3.1. Sociological theories of risk

During the turn of the twenty-first century, sociological literature related to risk covered a number of broad themes (Zinn, 2004). Whilst some scholars suggested that risk was a central feature of modern life (Beck, 1992, Giddens, 1990, Giddens, 1991), others sought to demonstrate the ways in which risk was socially constructed (Douglas and Wildavsky, 1982, Lash, 2000, Tulloch and Lupton, 2000) and to outline the ways in which organisations and institutions come to govern the actions of individuals (Foucault, 1991). In addition, scholars examined the ways in which risks are communicated in different societies (Luhmann, 1993) and sought to explore the world of voluntary risk taking, focussing on high-risk leisure activities such as skydiving and rock-climbing (Lyng, 2005).

The aforementioned approaches to understanding risk provide different lenses through which risk can be explored and understood. In this chapter I discuss a number of approaches to understanding risk that are of relevance to this thesis. I outline early sociological theories of risk from Ulrich Beck and Anthony Giddens that suggested that an increased preoccupation with risk is a central feature of late-

modernity, alongside the work of Mary Douglas who emphasised the ways in which risks are socially constructed. In addition, I outline research that has sought to understand how everyday risk practices are enacted in the real world, before moving on to the work of Nicola Gale and Patrick Brown, who introduced the concept of 'risk work' to foreground the practices that health and social care workers engage in to assess and manage risk.

3.1.1. Late-modernity and the 'risk society'

During the nineteenth and twentieth centuries, there was a growing preoccupation with risk in many Western societies (Beck, 1992, Giddens, 1990). Weber (1948) suggested that a key feature of modernity was the increased importance attached to objective forms of knowledge. Weber referred to this process as 'rationalisation', which he described as the belief that "one can, in principle, master all things by calculation" (Weber, 1948, p139). Rationalisation relies on an assumption that objective knowledge can be collected and used to calculate the likelihood of a particular risk occurring. Therefore, whilst individuals in pre-modern times explained negative events as 'fateful acts of god', via concepts such as magic and religion, during modernity these systems were largely replaced by medical and scientific explanation, which encouraged a focus on events that occurred as a result of human (in)action (Alaszewski, 2015, Beck, 1992, Zinn, 2008).

In modern Western societies the growing importance placed on objective, rational knowledge influenced approaches developed to manage risk. For example, there was an emergence of insurance practices and actuarial approaches that focussed on the objective scientific calculation of risks (Zinn, 2008). In the United Kingdom, Turnbull (2017) notes that the design and commissioning of NHS services is often based on cost-benefit models, which are influenced by somewhat predictable patterns of mortality and morbidity. Evaluations of interventions to improve healthcare often consider the costs and benefits, both in monetary terms and in health outcomes. Furthermore, social care services are also often influenced by actuarial risk approaches that seek to determine the likelihood of a negative event occurring and to categorise individuals and practices that are deemed to be 'risky' or 'at risk' (Turnbull, 2017).

Towards the end of the twentieth century, often described as 'late-modernity', sociological theories of risk, put forward by Giddens (1990, 1991, 1994) and Beck (1992, 1994), heavily influenced the ways different forms of 'risk' were conceptualised and understood. Often discussed together as the 'risk society' thesis, Beck and Giddens suggested that the industrialisation of many Western societies presented a number of 'new' risks that could be potentially catastrophic on a global scale, for example via genetic modification or global pollution (Beck, 1992). As a result, traditional insurance models became insufficient to deal with the complexity and scale of many of the risks associated with late-modernity (Beck, 1992). As society became aware of the limitations of actuarial approaches to risk, a process that Beck (1994) termed 'reflexive modernisation', sociological theories of risk moved towards understanding the ways in which risks are socially constructed within particular social and temporal contexts.

Alongside the increasing realisation that it may not be impossible to control all risks, late-modernity was also characterised by increased individualisation, in which traditional social categories that ordered the lives of individuals were de-stabilised and questioned (Beck, 1994). In an era of individualisation, individuals are, at least in principle, afforded more choice over their lives. Although individualisation and increased choice may be liberating for some, the degree to which people have the ability to choose, or the options that they are able to choose from, are influenced by power relations, the resources available to them and their ability to access and make sense of information relating to their available choices (Giddens, 1994). Applying the concepts of choice and individualisation to risk, it has been suggested that risk is increasingly discussed in terms of individual choices rather than as a result of broader social, cultural, political and structural forces (Beck and Beck-Gernsheim, 2002).

3.1.2. Risk as socially constructed

It has been suggested that the risk society thesis "has become a victim of its ambition and scale – its grand claims being open to criticism about detail, much in the same way that global maps are simplified representations, failing to capture the intricate detail of terrain, or indeed the cultural life of those living there" (Turnbull, 2017, p35). As such, Tulloch and Lupton (2000) suggested that the risk society

thesis does not account for the variation in individual responses to risk. For Mary Douglas, an anthropologist interested in dangers and risk, and for sociocultural theorists who drew upon Douglas' work (for example Lash (2000) and Tulloch and Lupton (2000)), culture was central to understanding how risks are understood and communicated across different contexts.

Douglas suggested that risks are socially constructed within particular historical and cultural contexts (Douglas and Wildavsky, 1982). Douglas raised questions about how certain risks came to be known and prioritised in different cultures, whilst others were ignored (Douglas and Wildavsky, 1982). Sociocultural risk theorists suggested that during modernity there was not an increase in objective risk, but there was an increase in perceived risks (Lash, 2000). Therefore, whilst risks can be objectively 'real' and present objective danger to an individual, the framing of a particular risk is always embedded in a broader social context (Douglas, 1966, Zinn, 2009). Based on this tenet, to understand risk, one must be attuned to the broader social context in which the risk is known and understood (Douglas and Wildavsky, 1982). Based on sociocultural theories of risk there is no superiority between objective and subjective or expert and lay knowledge of risk. Instead, different forms of risk knowledge are borne out of the different social contexts in which they occur (Zinn, 2004).

Douglas was particularly interested in risks associated with pollution and the way in which these risks were culturally framed around notions of purity and danger (Douglas, 1966). She described 'dirt' as something that was essentially "matter out of place". Using the example of soil, she suggested that when something is in place, for example when soil is found in a garden, it presents no risk, yet when something is out of place, for example when soil is found in a house, it is treated as dangerous. The notion of being 'out of place' can be extended to people. Discussing the ways that individuals can be bound to, and thus belong or not belong to places, Douglas stated; "if a person has no place in the social system and is therefore a marginal being, all precaution against danger must come from others" (Douglas and Wildavsky, 1982, p98). What is more, Douglas suggested that notions of risk can be used to socially construct boundaries that are used to stigmatise particular groups of people (Douglas, 1992). During times of social, political or economic uncertainty, certain groups of people can be constructed as presenting a risk to wider society. Often those who are presented as 'risky' are individuals who may also be considered

'vulnerable' in a society - for example migrants, young people, women and individuals from lower socioeconomic backgrounds, and individuals with physical and mental illness (Douglas and Wildavsky, 1982).

The concept of being 'out of place' could be applicable to my project. On one hand, care home residents may be viewed as 'out of place' in a care home if they experience a deterioration in their health or become acutely unwell, requiring additional care and treatments that are not available in a care home setting. On the other hand, due to the tensions between the aims of care homes (which primarily provide support in managing long-term health conditions) and the aims of emergency care services (which prioritise curative acute care), care home residents may also be perceived as 'out of place' when they are transferred to hospitals, particularly if the transfer is related to a chronic health condition. As a result of being 'out of place', care home residents are presented as both 'risky' to the wider healthcare system and as 'at risk' of experiencing a burdensome and potentially inappropriate hospital transfer.

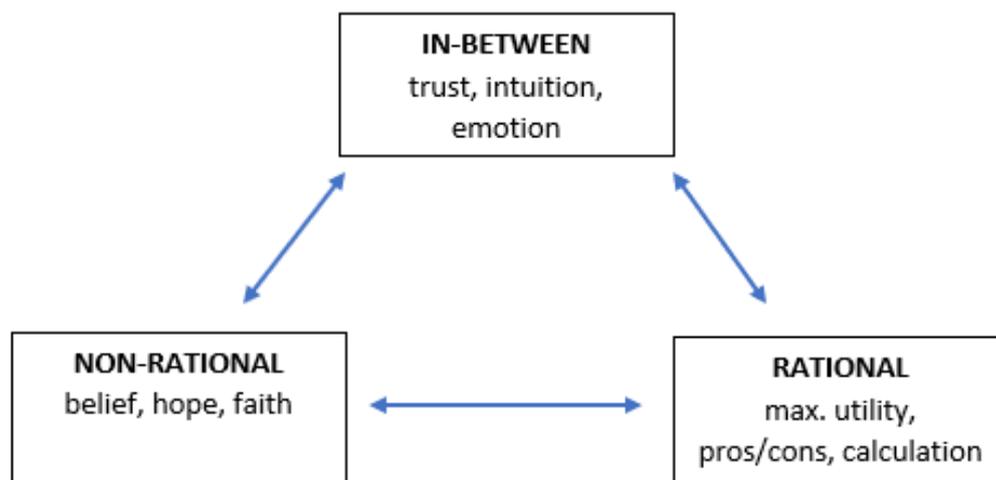
3.1.3. Sociological approaches to everyday risk-related practices

Although the work of Beck and Giddens shaped contemporary understandings of risk, and the work of Douglas highlighted the central importance of culture, neither sought to demonstrate how everyday risk-related practices are enacted in the real world (Horlick-Jones, 2005). Horlick-Jones (2005) placed importance on direct observation as a method for studying everyday risk-related practices as they occurred in context. For example, whilst researching policing at the Notting Hill carnival, he described the way that police officers chose to ignore some risks in order to achieve an overall goal of 'keeping the peace' – thus demonstrating how some risks may be (de)prioritised and viewed as more acceptable or tolerable than others in a particular social context. Despite the importance attached to objective 'formal' forms of risk knowledge in modern and late-modern societies, Horlick-Jones (2005) suggested that individuals develop their own 'informal logics' of risk that are influenced by both individual perceptions of risk and the broader social context in which individuals operate.

Research has suggested that when assessing risk, individuals draw on a broad range of knowledge sources which can be 'bricolaged' together (Horlick-Jones et al.,

2007). This can include objective, calculative information about risk as well as subjective information based on individual experiences and concepts such as religion and magic (Alaszewski, 2015, Brown, 2015, Horlick-Jones et al., 2007). Zinn (2008, 2016) outlined a framework for understanding different approaches to managing risk and uncertainty which included 'rational', 'non-rational' and 'in-between' strategies (see Figure 4). Zinn (2008, 2016), alongside Andy Alaszewski (2003, 2015), asserts that although rationality, based on 'objective' knowledge, is one approach for managing risk and uncertainty, this approach is not necessarily superior to other 'non-rational' approaches based on subjective knowledge. In addition, the authors argued that, in reality, people use a combination of approaches when managing risk and uncertainty.

Figure 4: Different approaches to managing risks and uncertainty developed by Zinn (2016)



Whilst early risk studies were dominated by a focus on rational, objective knowledge, Zinn and Alaszewski have sought to highlight the importance of non-rational and in-between everyday risk-practices that individuals undertake. The authors suggest that all three approaches to managing risk and uncertainty – rational, non-rational and in-between - are 'reasonable' and that to determine the most appropriate approach one must attend to the nature of the situation at hand. In-between strategies may be particularly useful when there is limited or insufficient objective knowledge available or in situations where individuals have to make potentially fateful decisions without enough time to carefully weigh up and scrutinise available information sources (Baillergeau and Duyvendak, 2016, Zinn, 2016). Furthermore, there are situations in

which non-rational risk logics, such as those based on magic and religion, may at times be superior to rational calculative risk logics. For example, Alaszewski notes that although rational approaches “provide the objective basis for identifying the causes of disasters and misfortunes...they cannot explain why a particular individual suffered a particular misfortune at a particular moment in time. Nor can they change uncertainty into absolute certainty in the same way as magic” (Alaszewski, 2015, p253).

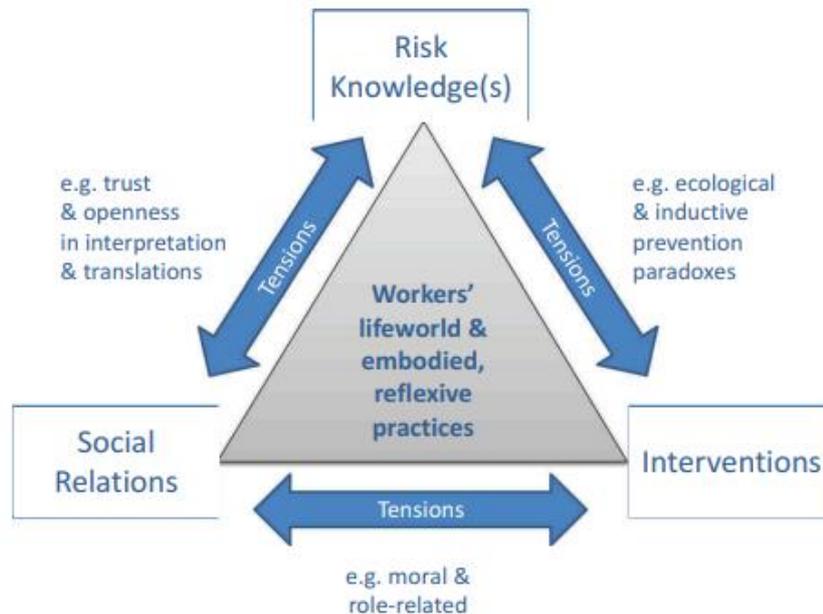
Empirical research has uncovered important real-world implications of Alaszewski and Zinn’s central argument, that focussing solely on objective, rational risk knowledge can have limitations when seeking to manage risk. Both Duff’s (2003) research into drug-taking amongst young people and Hobson-West’s (2003) research into lay understanding of childhood vaccinations have suggested that public health campaigns focussed solely on objective rational approaches to risk have been limited in their effectiveness because they have not incorporated the informal, non-rational and in-between risk logics that individuals hold.

3.1.4. ‘Risk work’ in client-facing contexts

Although early research into risk was focussed on insurance and high-hazard engineering, many people-based professions such as nursing and social work have become dominated by discussions of risk (Horlick-Jones, 2005). In recognition that academic research had widely neglected the impact of risk on the experiences of healthcare workers, Gale et al. (2016) outlined the concept of ‘risk work’, to foreground the practices that individuals use to assess and manage risk. Building on existing literature into the sociology of risk and uncertainty and the sociology of work and employment, Gale et al. (2016) suggested that ‘risk work’ could be used to understand these practices. The authors suggested that risk work is comprised of three interconnected components: risk knowledge, risk interventions and social relations. Whilst ‘risk knowledge’ concerns the ways in which individuals come to assess and conceptualise risk, ‘risk interventions’ describe the practices that individuals use to mitigate against and manage risk. In addition, the component ‘social relations’ highlights the ways in which risk practices are influenced by and embedded within interpersonal relationships to examine how individuals care for

others within contexts that are laden with risk and uncertainty (Brown and Gale, 2018a, Gale et al., 2016).

Figure 5: A conceptual model of 'Risk work' reproduced from Brown and Gale (2018a)



Brown and Gale (2018a, 2018b) have called for a better understanding of the lived experiences of workers undertaking risk work in client-facing roles. They have suggested that such roles are of particular interest because it is in these situations that risk work involves “taking risk knowledge (as understood at the population level) and interpreting and applying it at the individual level” (Brown and Gale, 2018a, p2). This creates a paradox for individuals involved in client-facing risk work. Whilst it is possible to determine the prevalence of risk across a population, it is more difficult to ascertain the likelihood of a particular risk for an individual.

When deciding whether or not to initiate a resident hospital transfer, staff consider the potential benefits and risks to that individual (Laging et al., 2015, Trahan et al., 2016). Although the likely biomedical outcomes of some procedures are understood at a population level, the benefit of certain procedures for individual care home residents (who may have multiple health conditions, uncertain health trajectories and their own subjective values and preferences regarding their care) may be less clear. In addition, despite the emphasis on evidence-based practice in the NHS in England, it may be particularly difficult to determine the efficacy of specific interventions for people who lack capacity, as research studies often exclude this group of people. In the context of care home research, Shepherd et al. (2019) suggest that this trend,

which they describe as 'protection by exclusion', can lead to a lack of empirical evidence that is applicable to people who lack capacity.

Interactions between the three key components of risk work can generate a range of tensions which may in turn impact on the everyday risk practices that individuals undertake. Brown and Gale (2018b) suggest that some tensions may be visible, whilst others may be intentionally 'veiled'. This suggestion supports the work of Horlick-Jones (2005) who argued that within organisations, formal bureaucracy "may provide an outward appearance of control and efficiency while masking a diverse tapestry of emergent practices" (Horlick-Jones, 2005, p304). Therefore, the concept of risk work may provide a means of making visible the 'awkward tensions' that arise when care home staff are faced with a situation that could potentially require a resident hospital transfer.

At the centre of Brown and Gale's (2018) conceptual diagram (see Figure 5, above) borne out of each of the three components, is the worker's 'lifeworld', which represents the common-sense and often taken for granted social world as experienced by the individual. Drawing on the work of Schutz (1967) and Habermas (1987), Brown (2016) suggested that the concept of a 'lifeworld' can draw attention to the broader social processes which shape and constrain individual knowledge and experiences of risk. Brown (2015) suggested that despite the emphasis on social context, sociological theories of risk tend to focus on the ways in which risk is understood and experienced at an individual level. Citing the work of Seppola-Edvardsen et al. (2016) who described the ways in which cancer patients develop their understanding of risk through interactions with others, and the work of Rodrigues (2016) who found risks related to everyday medicine were collectively managed by a process of negotiation with others, Brown (2016) called for a move towards balancing individual considerations of risk with the social relations that shape them.

Like Douglas (1992), Brown and Gale (2018b) assert that intervening based on an assessment of risk is always a 'moral act' which can have potential consequences for the assessed, the assessor and the relationship between the two. Within the context of hospital transfers from care homes this could include members of staff, the resident and the relationship between them. This point is reiterated by

Alaszewski (2018) who suggests that when performing risk work “individuals not only have to take actions to manage risk but also have to subsequently account for what they have done” (Alaszewski, 2018, p13). Existing research has suggested that risk work is characterised by uncertainty and moral ambiguity and that perceptions about the ‘right’ thing to do may be influenced by both individual moral beliefs and wider socio-structural influences, such as a ‘blame culture’ (Farre et al., 2017). Therefore the concept may be particularly relevant to hospital transfers from care homes as decision-makers have to weigh up the benefits and burdens, both for the resident and for themselves as a decision-maker, whilst also considering the views of family carers and healthcare professionals, when deciding how to respond to a resident who may potentially require a hospital transfer (Alcorn et al., 2020, Dwyer et al., 2014, Lopez, 2009).

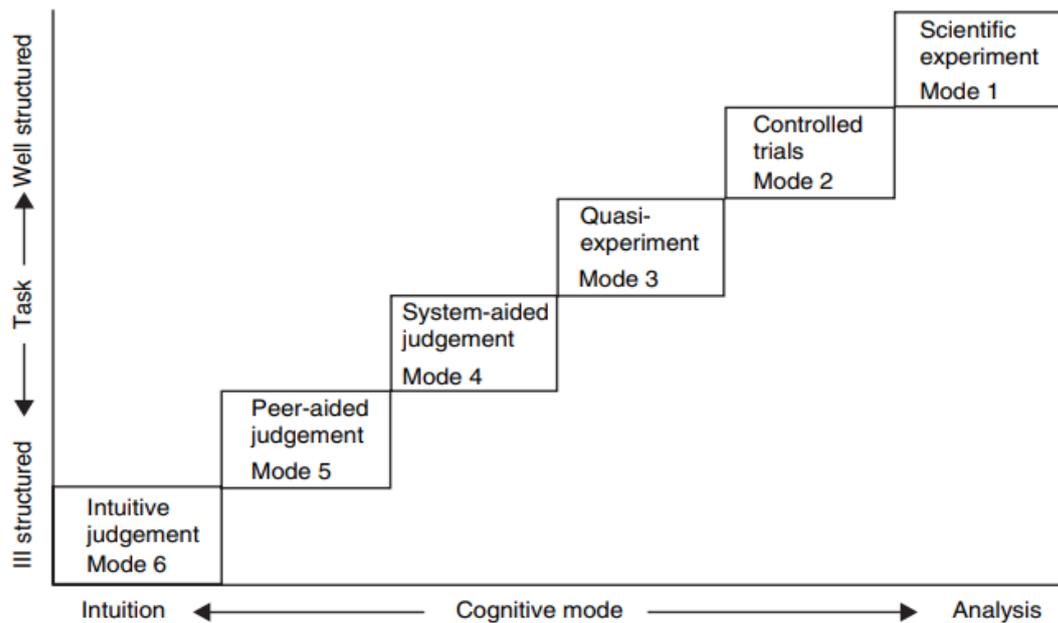
3.2. Models of clinical decision-making

Health and social care workers are often required to make decisions about the people that they are working to support. Alongside a body of literature that has sought to understand the ways in which individuals assess and manage risks, a separate body of research, originating from the disciplines of psychology, economics and nursing, has sought to explore decision-making in clinical contexts. An influential body of literature into clinical decision-making was developed by Mooi Standing (2008, 2010, 2014). Although Standing’s work was developed to conceptualise the clinical decision-making of nurses in hospital environments, the models that she presented may also be applicable to nurses and care staff working within care homes. Standing (2014) suggests that nursing involves planned, unplanned and emergency decisions in which individuals are required to assess a situation and mentally explore the consequences (or risks) before committing to a decision. Therefore, as with many other health and care professions, decision-making is a key skill that nurses must acquire (Standing, 2010).

Prior to the publication of Standing’s work, the widely cited ‘Cognitive Continuum Theory’, first developed by Hammond (1981) and later applied to medicine by Hamm (1988) suggested that decision-making could include three modes of cognition – analysis, intuition and quasi-rationality. Whilst, at one end of the continuum, ‘analysis’ referred to a slow and conscious processing of available information and,

at the other end of the continuum 'intuition' referred to rapid unconscious processing, the term 'quasi-rationality' referred to cognition that includes a mixture of the two (see Figure 6).

Figure 6: Six modes of enquiry based on the Cognitive Continuum Theory (Hamm, 1988), reproduced from Cader, Campbell and Watson (2005)

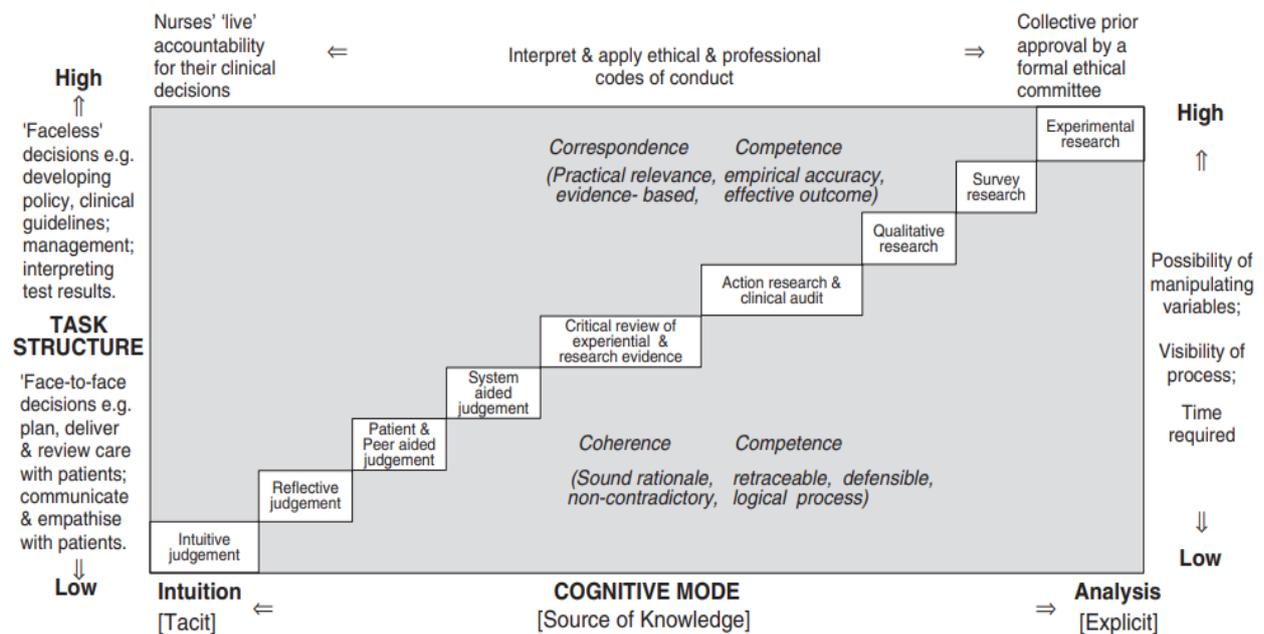


Based on the Cognitive Continuum Model, the most appropriate mode of enquiry is dependent on the nature of the task (Cader et al., 2005, Hamm, 1988, Standing, 2008). When tasks have a high degree of structure, individuals are more likely to utilise an analytical style of processing based on explicit knowledge. A task may be considered 'well-structured' when there is sufficient objective information available, the individual is familiar with the task and there is enough time to objectively scrutinize available evidence. Conversely, a task may be considered to be 'ill-structured' when there is less objective information available, the individual is unfamiliar with the task and where there is a greater degree of uncertainty. When faced with less structured tasks individuals may rely on intuitive reasoning.

Cader et al. (2005) suggest that the language associated with the Cognitive Continuum Model may provide a means for nurses to explicitly discuss and validate their decision-making based on intuitive judgements. However, this model may also be of use to other health and social care professionals that are required to explain their decision-making processes, including care home staff. In 2008, Standing

revised the Cognitive Continuum Model and presented nine modes of analysis for clinical judgment and decision-making in nursing (see Figure 7). In the revised model, the ordinal numbers associated with each mode were removed to avoid an association with a ranking that may inadvertently suggest that one mode is 'better' than another. Similarly, the terms 'well-' and 'ill-defined' were replaced with 'high' and 'low' task structure.

Figure 7: The revised cognitive continuum model of nurses' clinical judgement and decision-making developed by Standing (2008)



Models of clinical decision-making may provide a useful lens through which the decision-making of care home staff can be viewed when faced with a situation that may potentially require a resident hospital transfer. Although developed separately from sociological theories of risk and uncertainty, there is clear overlap between the two bodies of literature. Like sociological risk theorists such as Zinn (2008, 2016) and Alaszewski (2003, 2015, 2018), who suggested that rational, non-rational and in-between approaches to managing risk may all be 'reasonable' dependant on the nature of the situation an individual is faced with, the Cognitive Continuum Model avoids presenting different modes of analysis as 'rivals'. Instead, the most appropriate mode of enquiry is dependent on the degree to which a task is 'structured' (Hamm, 1988). As a result, within the clinical decision-making literature, subjective intuitive reasoning is positioned as a legitimate approach to decision-

making (Cader et al., 2005, McCutcheon and Pincombe, 2001, Pearson, 2013, Standing, 2014). In particular, echoing the work of Zinn (2008, 2016) and Alaszewski (2003), authors from the clinical decision-making literature suggest that intuitive reasoning may be particularly useful when there is not sufficient time to carefully analyse and scrutinise objective information, or when there is not sufficient objective information available (Standing, 2014).

3.3. Intuition as pattern recognition

Intuition has been described as a “gut feeling”, a “hunch” and a “sixth sense” (Pearson, 2013, p212). Although the terms ‘intuition’ and ‘experiential’ knowledge are often used interchangeably, Standing (2014) differentiated between the two, suggesting that whilst ‘experiential’ knowledge refers to embodied and tacit knowledge, ‘intuition’ refers to having a pre-conscious feeling without being fully able to explain or articulate that feeling. A crucial feature of intuition is that the individual is not aware of their thought processes. This is reiterated in Standing’s description of intuition as a “subconscious process using pattern recognition to make connections between various information cues embedded in a particular context” (Standing, 2014, p113). The majority of the literature that examines the role of intuition in clinical decision-making focusses on the decision-making of nurses. However, there is emerging evidence that highlights the role of intuition in other health and social care professional groups, for example staff in care homes and domiciliary home care (Perkins and Supiano, 2019, Sund-Levander and Tingström, 2013).

Psychological research has sought to determine the extent to which intuitive reasoning is useful in decision-making. This body of research encompasses literature focussed on occasions where intuitive judgements based on experience and skill are highly accurate, often referred to as the ‘Naturalistic Decision-Making’ approach (Klein et al., 1993) It also includes occasions where a reliance on heuristics and biases lead to incorrect intuitions, often referred to as the ‘Heuristics and Biases’ approach (Gilovich et al., 2002, Tversky and Kahneman, 1974). More recently, authors from both strands of research, have come together to discuss the similarities and differences between the two approaches (Kahneman and Klein, 2009).

Kahneman and Klein (2009) agree that intuition stems from rapid, automatic and involuntary processing of information. The authors suggest that what is experienced as 'intuition' is the unconscious recognition of cues that guide decision-making. Whilst authors from the Naturalistic Decision-Making approach have sought to identify the cues that experts use to make their judgments, authors from the Heuristics and Biases approach have sought to identify occasions where over-reliance on such cues (i.e. heuristics) have led to erroneous judgments. Despite the different foci of each approach, Kahneman and Klein (2009) suggest that in order for intuitive judgements to occur, two conditions must be present. Firstly, the environment must provide valid cues. This is more likely in highly predictive situations or, to use the language of Standing (2008), situations that have a high task structure. Secondly, individuals must have the opportunity to learn about relevant cues, for example through formal training or through experience.

Kahneman and Klein (2009) suggested that when either of the two conditions are absent, individuals do not have the opportunity to develop intuitive thinking based on skill and expertise and instead rely on heuristics and biases to guide judgements and decision-making. Whilst heuristics and biases can be useful, particularly when objective information to guide decision-making is lacking or when there is not enough time to scrutinise all sources of information, they can also be prone to error. As a result, Kahneman and Klein (2009) suggest that one way of evaluating an individual's decision-making is to assess the validity of the cues available to the individual and the opportunities afforded to them to learn about such cues.

Kahneman and Klein (2009) also make reference to the term 'fractionated expertise' to describe the way that physicians and nurses display intuitive expertise in some activities but not in others. This may occur when an individual is undertaking a routine task in an unfamiliar environments or when trying to apply knowledge from one context to another.

The two conditions for intuitive decision-making can be applied to decision-making in care homes, when care home staff are faced with a situation that may potentially require a hospital transfer. Whilst making decision about potential hospital transfers, staff evaluate both disease specific and resident specific cues. Some situations may provide high-validity cues, for example a swollen or immobile arm (disease-specific cue) after a fall would raise a concern about a fracture, or a known tendency for a

resident to display particular behaviours when their health is deteriorating (resident-specific cue). However, care home residents may also display atypical symptoms and have less predictable illness trajectories (Alcorn et al., 2020, Barclay et al., 2014) making it more difficult to interpret cues. Furthermore, whilst there may be some situations that occur frequently, providing staff an opportunity to learn associated cues, at times staff will have to make decisions in unfamiliar situations in which they have not had the opportunity to learn about the associated cues.

3.4. Individual power whilst decision-making about risk

Existing research into hospital transfers from care homes has suggested that decision-making can include a range of stakeholders including residents, their family members or next-of-kin, care home staff and external healthcare professionals such as GPs or paramedics (Arendts et al., 2015, Arendts et al., 2013). At times, different interpretations of the severity of the presenting situation, of a resident's wishes and of what would be in the resident's 'best' interests can be a source of conflict between stakeholders (Pulst et al., 2019). Existing sociological research, both research that has explored decision-making in a clinical context and research that has explored strategies individuals use to manage risk, have highlighted the importance of power relations. In their seminal text, Douglas and Wildavsky (1982) suggested that "a cultural theory of risk would be trivial if it shirked considering the distribution of power in relation to the pattern of risks incurred" (Douglas and Wildavsky, 1982, p8). In addition, sociological research has also suggested that the ways in which individuals are able to contribute towards decision-making may be influenced by broader social influences.

Bainbridge and Purkis (2011) suggested that the historically powerful position of medicine in Western society privileged the knowledge and opinions of medical professionals over the opinions of other stakeholders such as nurses and patients. However, although medical doctors have historically dominated decision-making, nurses often had greater informal influence than was explicitly acknowledged (Reeves, 2011). Stein (1967) described a 'doctor-nurse game' in which doctors were guided by nurses' suggestions, provided they were made covertly and were not perceived as a direct challenge to the doctor's authority. Therefore, involvement in

decision-making was constrained by the broader social norms surrounding the two professions.

Following the formalisation of nursing training during the 1980s and 1990s, Stein et al. (1990) found nurses were making autonomous decisions more frequently and, when they perceived it to be necessary, were overtly challenging doctors. These findings suggest that individual involvement in decision-making can be influenced by wider social processes, which in turn may evolve and have a degree of fluidity in different spaces and times. Given that many decisions in health and social care involve balancing risks, the findings provide support for Brown's (2016) call to explore the ways in which individual understandings of risks are located within broader social processes. Although Stein's work described interactions in GP practices, similar experiences have been reported in existing research into hospital transfers from care homes. For example, research has suggested that nurses use 'targeted' or 'coded' language to persuade physicians to make decisions that align with the wishes of a resident's family (Lopez, 2009).

Although there is a wealth of existing literature regarding the power of the medical profession and the relationship between doctors and nurses, less attention has been given to the relationship between nurses and other members of health and social care teams. Early research from Daykin and Clarke (2000) explored the division of labour between nurses and healthcare assistants on two NHS hospital wards in England, identifying strong hierarchical divisions of labour that reflected wider beliefs about the knowledge of each staff group. In particular, nurses believed care delivery should be exclusive to the role of nursing, due to their enhanced education and theoretical knowledge. However, the authors draw on the concept of 'professional identity' and suggest that this belief may have been rooted in attempts to create clear boundaries around their work in order to preserve their power and status within the ward environment (Daykin and Clarke, 2000).

The findings of Daykin and Clarke (2000) may be applicable to hospital transfers that occur from care homes that provide nursing services (i.e. that employ registered nurses to work alongside carers – the latter role being equivalent to a healthcare assistant in a hospital). The findings also raise questions about potential power relationships between different members of staff within care homes. Approximately

two thirds of all care homes in England do not employ registered nurses (i.e. 'residential' homes). Therefore future research could also explore relationships between other groups of care home staff, for example between senior and junior care staff.

Another key stakeholder in decision-making about potential hospital transfers, often neglected by academic research, is the care home resident. Despite rhetoric around shared decision-making and person-centred care, the ways in which residents contribute to decisions about potential hospital transfers are poorly understood. Research has also suggested that transfer decisions are "far from ideal and [do] not contain the basic elements of informed consent" (Lopez, 2009, 1007). Instead, Lopez (2009) suggests that decision-making about potential hospital transfers is characterised by "negotiated consent" between stakeholders and that often the wishes of the family were given more precedence than the wishes of the resident. In addition, in their exploration of resident, staff and family views on hospital transfers, Arendts et al. (2015) found differences between the three stakeholder groups' experience of the transfer process. Residents were least likely to contribute to the decision-making process yet most likely to support a transfer to hospital. Although there were occasions where residents expressed a desire to be more involved in decision-making, the authors found that, overall, residents' experiences were characterised by a sense of resignation and acceptance that others would be making decisions on their behalf.

The tendency to privilege the views of the family over the views of the resident is perhaps not surprising, given that existing literature has repeatedly suggested that family members have a strong influence on the decision-making process (Arendts and Howard, 2010, Lopez, 2009, O'Neill et al., 2015, Trahan et al., 2016, Tsai et al., 2016). The privileged status of family members during decision-making appears to be rooted in two main sources. Firstly, there is an assumption that family members have a detailed knowledge of the resident and their wishes. Secondly, care home staff and external healthcare professionals fear litigation if they come to a decision that family members do not agree with (O'Neill et al., 2015, Trahan et al., 2016). These concerns, coupled with a high prevalence of dementia amongst care home residents and the associated need to involve family carers in best interests decision-

making (DoH, 2005), could be contributing towards the exclusion of residents from the decision-making process.

Zinn (2004) linked power relations to individual risk practices and suggested that a lack of power can lead individuals to partake in 'risky' behaviours even when they hold adequate risk knowledge and understand the risks associated with their actions. This suggestion may be applicable when exploring hospital transfers from care homes. For example, existing research has suggested that, at times, staff may choose to transfer a resident to hospital when it is unlikely that the transfer will result in a better quality of life for the resident, due to pressure from family carers (Arendts et al., 2013), which may suggest a power imbalance between staff and family carers.

3.5. Summary

This chapter has introduced theoretical concepts and literature that can be used to explore decision-making about hospital transfers from care homes. Building on sociological theories of risk highlights the need to understand the social context in which risks are understood and to examine the everyday strategies that individuals use to manage risks. Understanding transfer decisions as a form of risk work may also provide new insights into hospital transfers from care homes, by providing a framework to explore the ways that care home staff conceptualise risk, attempt to manage risk and navigate the social relations that surround their decision-making. In addition, drawing on existing models of clinical decision-making may provide a new lens through which to view transfer decisions, emphasising the need to consider the task in hand. Finally, sociological literature relating to individual power dynamics during decision-making highlights the need to consider broader social processes that influence and limit involvement in decision-making. Therefore, examining hospital transfers in relation to these bodies of literature may provide a means to further explore the contribution of different stakeholders, including the resident, their family carers and/or next of kin, care home staff and other healthcare professionals.

CHAPTER FOUR: Methodological approach to the study

4.1. Development of a research question

The aim of this project was to develop an in-depth understanding of the decision-making processes of care home staff when deciding whether to transfer a resident to hospital within the context of care homes in England. In doing so, I aimed to develop a model of escalation to describe the decisions and processes that occur in the care home prior to the transfer of a care home resident.

In order to achieve the project's aims, the following research question guided the project: 'How do care home staff decide whether to initiate a resident hospital transfer within the context of care homes in England?'

In order to answer this broad research question, a number of specific questions to be addressed were developed at the beginning of the project:

- What are the processes (chains of events) that precede a potential or actual resident hospital transfer?
- What factors influence decision-making about potential hospital transfers?
- How, and to what extent, is decision-making influenced by the wider social context in which staff operate?

Although the questions posed at the outset of the project were originally descriptive and applied in nature, during the research process additional questions were raised based on the data. For example, emergent themes led to further research questions around risk.

- How do care home staff understand and seek to manage risk during transfer decisions?
- How are staff perceptions of risk influenced by the wider social context in which they operate?

4.2. Philosophical approach

Because philosophical assumptions guide every stage of the research process, it is important to state the project's ontological, epistemological and methodological assumptions (Guba and Lincoln, 2005, Thyre, 2012). This research project was guided by critical realism, a philosophical paradigm that was developed during the

second half of the twentieth century (Guba and Lincoln, 2005). During this time two existing philosophical paradigms dominated the social sciences. On the one hand, scholars within the naturalist tradition argued that the aim of the social sciences should be to emulate the physical sciences; to be committed to objective data and observable events in order to produce generalised laws of cause-and-effect. On the other hand, some scholars, particularly those in the hermeneutics tradition, began to disregard the need for objectivity and suggested that social scientists should seek to understand and describe the way in which the world is socially constructed and to 'give voice' to those who are seldom heard (Danermark et al., 2002). More recently, scholars have also suggested that the aim of research should be to move beyond mere description and towards building theories that can explain events and phenomena (Robson and McCartan, 2016).

Research philosophies are often portrayed as distinct, mutually exclusive paradigms, with scholars on each side described as "warring tribes" (Robson and McCartan, 2016, p18). However, instead of emphasising the ways in which the two approaches differ, it is important to consider the ways in which they may be compatible and complementary (Barbour, 2014). Critical realism combines a realist ontological belief - that there is an external 'reality' that exists independently of human thought and explanation, with an interpretivist epistemological belief - that all knowledge is socially constructed and therefore can only be known imperfectly (Danermark et al., 2002).

Based on critical realist beliefs, the aim of both the natural and social sciences is to produce concepts and explanations that are as close to reality as possible.

Theorising on the nature of 'reality', Bhaskar (1978) proposes that there are three realms of reality: 'the actual' consisting of events that occur independently of human consciousness, 'the real' consisting of the relations and structures that have the power to produce changes in the actual realm (i.e. underlying causes of events), and the 'empirical' consisting of what is perceived, albeit imperfectly, by the human consciousness. Therefore, Bhaskar (1978) suggests that there is an objective reality (situated in the actual domain) but human knowledge of reality will only ever be partial and flawed (situated in empirical domain). In a world where humans can only ever know the world imperfectly, social scientists should seek to uncover the

underlying structures and processes (in the real domain) that have the power to bring about changes that occur in an external reality.

Critical realism is particularly well suited to address research questions that seek to understand complex phenomena. Therefore this philosophical approach was appropriate for my project which seeks to explore the decision-making processes of care home staff when deciding whether to initiate a resident hospital transfer (Robson and McCartan, 2016). Scholars that ascribe to the critical realism paradigm suggest that all knowledge is socially constructed and thus created by the researcher and participants (Rosenberg, 2012). As a result, the current project utilised research methods that encouraged interaction between myself and participants, namely interviews with care home staff and ethnographic fieldwork in care homes. Each of these methods is discussed in more detail in Section 5.1 and 5.2 respectively.

4.3. Selection of appropriate methods

In order to achieve the project's aims, data collection was deliberately carried out in two phases. During the first phase of data collection, I conducted semi-structured interviews with care home staff across six care homes, whereas in the second phase I carried out more detailed ethnographic work at three of the six sites. The decision to structure data collection in this way was borne out of concerns that although ethnographic research places importance on looking and listening, a common problem for researchers in the field is knowing where to focus their attention (Silverman, 2011). Care homes are complex environments, made up of a range of staff and residents. Each care home has an established staffing structure, operational policies and procedures and ways of working. Goodman et al. (2011) suggest that when preparing to undertake research in a care home, researchers need to understand the care home's broad approach to care, including the home's formal and informal staff hierarchy and the ways in which staff view their role.

Conducting interviews before embarking on an ethnographic study enabled me to become sensitised to the world of the care home and to develop a basic understanding of the transfer process. Data collected during interviews was used to inform the second phase of data collection, in which I aimed to build on and combine the data from both phases to develop a richer, holistic understanding of the decision-

making processes that care home staff undertake during transfer decisions within the context of care homes in England.

4.3.1. The use of interviews and vignettes

Given the qualitative, exploratory nature of the project and the theoretical assumptions underpinning its conduct, interactive research methods were required (Guba and Lincoln, 2005, Rosenberg, 2012). At the beginning of the project, I had considered both focus groups and/or individual interviews as potentially suitable research methods that would enable me to become sensitised to the world of each care home and to the decision-making processes that care home staff undertook regarding potential and actual hospital transfers. However, during a period of stakeholder engagement, care home managers suggested that talking to several members of staff at once, for example in a focus group, would be impractical in a care home setting due to the need to ensure safe staffing levels. As a result, I decided that individual semi-structured interviews would be an appropriate method of data collection for the first phase of the study in which I would seek to develop a basic understanding of the decision-making processes that care home staff undertake when encountering a potential transfer situation.

The use of semi-structured interviews enabled me to ground the interview questions within existing literature, whilst also allowing new topics of conversation to emerge (Braun and Clarke, 2013, Hansen, 2006). Semi-structured interviews can be time consuming and require a rapport to be built with participants (Barbour, 2014). However, this method of data collection allowed me to gather information directly from participants and to hear, in their own words, the decision-making processes and actions that they undertook when faced with a situation in which a resident potentially required a hospital transfer.

During the interview process, participants were asked to read and respond to a number of vignettes: short, descriptive scenarios designed to elicit the participants' thoughts and opinions on transfer-related situations that could occur in a care home. Vignettes can be used to assess decision-making in both an experimental and exploratory manner. Vignettes have been used experimentally in care home research to examine staff views on same-sex encounters (Hinrichs and Vacha-Haase, 2010) and in a qualitative, exploratory manner to explore how nurses detect

and respond to medication discrepancies (Vogelsmeier et al., 2013). In the current study, the purpose of using vignettes was to provide additional stimuli to elicit conversation from staff about their decision-making regarding potential resident hospital transfers.

Within my study, the use of vignettes was both practical, enabling me to address the research questions, and ethical, ensuring that participants were given some control over the nature of the information they shared. Vignettes have been identified as a particularly useful tool in social care and nursing research that addresses potentially sensitive or distressing topics. Examples include research into individual experiences of domestic, child and elder abuse and neglect (Bradbury-Jones et al., 2014, Killick and Taylor, 2011, Taylor et al., 2011) and research into older people's views about their home as a place of care at the end-of-life (Gott et al., 2004).

As discussed in section 1.4.6, Hockley et al. (2017) argue that care homes are currently suffering from a 'broken image', with the public perceiving care homes as a negative choice. This is, in part, due to highly publicised media 'scandals' documenting instances of suboptimal care. As a result, care home staff may feel concern about taking part in research, for fear their responses may portray themselves, their place of work or their profession in a negative light (Luff et al., 2011). Vignettes can lessen fear by asking participants to 'imagine' a scenario and provide a hypothetical answer (Hughes and Huby, 2002). Vignettes are also useful as they enable the researcher to introduce and focus on specific topics as the vignette unfolds (Hughes and Huby, 2002).

4.3.2. Short-term ethnography

Ethnography, an approach that originated amongst anthropologists studying non-Western cultures, has been defined as both an "art and science of describing a human group" (Angrosino, 2007, p14). Despite ethnography's roots in studying 'exotic' cultures, this approach to data collection is now frequently used to examine more common and mundane settings that exist closer to home (Latour and Woolgar, 1986, Robson and McCartan, 2016). Ethnography has been used to study social care settings such as care homes, for example the seminal work of Townsend (1962) and more recent research of Keyser-Jones (2002). It has also been used extensively to study healthcare settings, for example to explore the care that people

receive whilst visiting emergency care departments (Crowe et al., 2019, Hughes, 1989, Jeffery, 1979). Furthermore, some authors have also used ethnography to examine interventions that exist at the interface between care homes and hospitals and the relationships between staff across both settings. As discussed in section 2.3, following an ethnographic process evaluation of a quality improvement project designed to improve care transitions for older people, Sutton et al. (2016) suggested a lack of consensus - between hospital and care home staff - about the nature of the 'problem' the project was trying to address was a key barrier to implementation and improvement.

Given the exploratory nature of the current study, ethnography was identified as an appropriate approach. Ethnographic studies utilise a number of specific research methods, including observations and the analysis of documents and artefacts to provide a 'thick description' of a culture by getting "inside the fabric of everyday life" (Silverman, 2011, p113). In addition, ethnographic research is often concerned with understanding the processes involved in behaviour and the social context(s) in which individuals operate (Silverman, 2011). Therefore, an ethnographic approach to data collection was consistent with the current project's primary aim: to develop an in-depth understanding of the decision-making processes of care home staff when deciding whether to transfer a resident to hospital. Ethnographic studies can also help to illuminate and unpick the underlying factors that influence behaviour, often leading to the de-mystification of behaviours that, on face-value, appear illogical (Barbour, 2014). This was particularly relevant to the current project in which existing research has suggested that care home staff initiate a transfer to the hospital without the expectation of better clinical outcomes or quality of life for the resident (Arendts et al., 2013, McCloskey, 2011).

The term 'ethnography' has been subject to debate, specifically with regards to what does and does not constitute an ethnographic study. However, it is generally accepted that ethnography involves a specific approach to studying a group of people and the social context in which they operate (Cupit et al., 2018). A specific issue of debate concerns the amount of time that a researcher should spend in any given field. Traditionally, researchers have spent long periods conducting ethnographic work. For example, Timmermans and Tavory (2007, p508) suggest: "In order to grasp interactional nuances, a full temporal cycle of the phenomena under

study, notice repetitions, acquire inside expertise, and observe variations, an ethnographer will almost always need to spend a lengthy period of time in the field; years rather than months or weeks” (p508).

Ethnography can be a time-intensive method and undertaking such a lengthy research project is not always possible or desirable within current academic climates (Vindrola-Padros and Vindrola-Padros, 2018). In recent years, particularly within healthcare research, there has been a growing interest in ‘rapid’ ethnographic work of a shorter duration. These types of projects are often borne out of pressing health concerns and a need to produce findings in a timely manner in order to inform practice (Vindrola-Padros and Vindrola-Padros, 2018). Although ethnographies of a shorter duration have been criticised as ‘quick and dirty’ (Hughes et al., 1995), a recent systematic review suggested that such studies have the potential to generate findings that inform changes in healthcare organisation and delivery (Vindrola-Padros and Vindrola-Padros, 2018).

Pink and Morgan (2013) have outlined an approach to what they have termed ‘short-term theoretically informed ethnography’ and suggested that short-term ethnographies compensate for reduced time in the field with an increased research intensity. The authors position this approach as different from other forms of rapid ethnography by emphasising the need for more deliberate engagement with the research field and by highlighting the importance of continually bringing theoretical questions into the ethnographic process. Short-term ethnography encourages a researcher to deliberately situate their self near to specific actions, to ask questions whilst observing and to explicitly state the intended goals of the research project. Furthermore, the authors suggest that although the period of data collection may be short, the ethnographic process extends beyond the immediate fieldwork setting and encompasses different times and spaces. Pink and Morgan suggest that this can include the time a researcher spends analysing, discussing, presenting and writing up findings. Pink and Morgan suggest that “far from being a ‘quick and dirty’ route to doing qualitative research, short-term ethnography is characterised by forms of intensity that lead to deep and valid knowledge” (Pink and Morgan, 2013, p351).

Short-term ethnography, as outlined by Pink and Morgan (2013) is an approach that was consistent with the aims and methods of the current project. In the current

project, ethnographic data collection occurred in three care homes over a period of ten months. However, the time spent at each home was shorter and visits were conducted sporadically over a period of approximately six to eight weeks at each site. Ethnographic work at each site was deliberate and the ethnographic-theory dialogue (i.e. the time I spent iteratively collecting data, searching for and re-examining data in light of relevant theories and concepts that could be potentially applicable) extended beyond the time spent in each individual care home. For example, data analysis occurred outside of the care home, both immediately after each visit and throughout the remainder of the project. Therefore, attempts to compare and contrast data with existing research, and to situate the findings of the current project in wider bodies of literatures, continued outside each of the care home sites.

Like all research methods, ethnography has its advantages and limitations. There is a danger that researchers conducting an ethnography may find it difficult to maintain the necessary distance and objectivity if they become too involved in the community that is to be studied. Timmermans and Tavory (2007, p508) warn that the “need to stay betwixt and between for long periods... can have a disorientating pull on researchers”. This phenomenon is often termed ‘going native’. Within the current study, adopting a short-term ethnographic approach to data collection provided the necessary distance between myself and the people living and working within the care home, which in turn allowed for reflection in-between fieldwork.

In addition, conducting interviews prior to undertaking further ethnographic fieldwork allowed me to gain insight into contextual factors that shaped the phenomenon of study, reducing the need for longer periods of subsequent ethnographic fieldwork. However, unlike data collected via interviews, data collected during ethnographic fieldwork allowed me to spend an extended period of time within the setting, to observe and consider behaviour as it occurred, to acquire further information about the social context in which transfers occurred (beyond information that could be gathered in interviews), and to identify disconfirming data that led to new insights.

Foner suggests that through direct observation of participants, a researcher can “view people with their hair down... to see whether people actually live up to the norms and values they say they follow” (Foner, 1994, p246). Therefore, conducting

ethnographic fieldwork also provided me with an opportunity to triangulate data and to compare what was reported in the interviews with what was observed in practice – this distinction is sometimes referred to as ‘work as done’ rather than ‘work as imagined’ (Braithwaite et al., 2013, Cupit et al., 2018, Hollnagel, 2012).

4.4. Selection of appropriate approach to data analysis

Once appropriate methods of data collection were chosen, the selection of an appropriate method of data analysis was also required. The Grounded Theory Method of data analysis, originally developed as an approach to analysing ethnographic data, is now commonly used to analyse a range of qualitative data sources (Timmermans & Tavory, 2007). The Grounded Theory Method provides researchers with a systematic and robust approach to analysing qualitative data. The method encourages researchers to move back and forth between data collection and analysis to identify codes that are developed into a theoretical understanding of the phenomenon of study (Bryant and Charmaz, 2007a). In doing so, the Grounded Theory Method aims to produce useable, mid-range theories that are grounded in the data, able to capture the lived experiences of participants and located in conceptual and theoretical literature (Timmermans and Tavory, 2007).

The Grounded Theory Method approach to analysis was developed and outlined by Glaser and Strauss in two seminal texts. The first, ‘Awareness of Dying’ (Glaser and Strauss, 1965), was an ethnographic study of death and dying. The second, ‘The Discovery of Grounded Theory’ (Glaser and Strauss, 1967), further explicated the principles of the method an approach to gathering and analysing qualitative research data (Bryant and Charmaz, 2007b). During the time that the Grounded Theory Method was developed, social science research was dominated by quantitative social survey research (for example the work of Robert Merton and Talcott Parsons) or qualitative research that Glaser and Strauss considered to be unsystematic, insufficiently grounded in data and therefore empirically unfounded (Timmermans and Tavory, 2007). As a result, Glaser and Strauss aimed to produce an approach to analysing qualitative data that could be considered to be equally robust as findings produced using quantitative data analysis methods that were dominant at the time.

The Grounded Theory Method approach differs from other forms of qualitative thematic analysis due to the emphasis on moving beyond description and towards

generating a theory or explanation of the phenomenon of study (Barbour, 2014, Braun and Clarke, 2006, Silverman, 2011). In the current study, I sought to explore the issue of care home resident transfers to hospital by focussing on the factors that influence the decision-making of care home staff. In line with the Grounded Theory Method, I sought to both *describe* the phenomenon of interest (by asking “when is a transfer deemed necessary?”, ‘what happens when a resident is transferred to hospital?’ and ‘who is involved?’) and to provide an *explanation* as to why it occurred (by asking ‘what factors influence staff decision-making?’, ‘how do these factors influence decision-making?’ and ‘how is decision-making influenced by the wider social context in which staff operate?’).

The seminal work of Glaser and Strauss (1967) suggested that researchers should collect data before engaging with existing theoretical literature. Singh & Estefan (2018) suggest that Glaser and Strauss’s focus on induction was a deliberate attempt to challenge the tradition within the social sciences at the time in which the majority of research sought to confirm or refute existing theories. As a result, Glaser and Strauss (1967) encouraged researchers to approach their data with an open mind. However, Bryant and Charmaz point out that “an open mind does not imply an empty head” (Bryant and Charmaz, 2007b, p20) and the later works of Glaser and Strauss acknowledged the need for familiarity with existing literature in order to engage in theoretical and conceptual debate (Bryant and Charmaz, 2007b).

Within the current project, an initial literature review was conducted prior to data collection. However, the purpose of the literature review was to become familiar with existing debates surrounding hospital transfers from care homes and to develop a set of ‘sensitising concepts’. Rather than being used to develop a framework to guide analysis, sensitising concepts were used as useful provisional starting points for thinking about hospital transfers from care homes that could be shaped or discarded throughout the process of data analysis (van den Hoonaard, 2008). The process of inductively coding data, rather than imposing a pre-existing framework was particularly appropriate given that the current study also sought to understand whether existing research, conducted within health and social care systems of other countries, was applicable to care homes in England.

Despite Glaser and Strauss (1967) arguing that the Grounded Theory Method has always been theoretically flexible, it has been suggested that the approach originated from a positivist theoretical position. Timmermans and Tavory (2007) note that although Glaser and Strauss positioned themselves against the orthodoxy of positivist quantitative methods, at the same time they advocated for an approach that utilised the same positivist assumptions to analyse qualitative data. Such positivist assumptions are evident in the way in which Glaser and Strauss (1967) use the term 'data'. In their early works, the authors use the term 'data' as representative of a 'true' external reality, with little attention afforded to the way in which the researcher influences what data is collected and how data is analysed, interpreted and presented (Bryant and Charmaz, 2007a).

Since the publication of Glaser and Strauss' (1965, 1967) seminal work, questions have been raised about the existence of universal social 'truths' that can be uncovered and accurately represented by research (Bryant and Charmaz, 2007a, Seale, 1999). Reflecting such debates, Glaser and Strauss have developed the Grounded Theory Method in different ontological and epistemological directions. There are now several approaches to Grounded Theory Method, which can be broadly categorised as: Glaserian or objectivist; Straussian; and constructivist as outlined by Kathy Charmaz (2006, 2014) (Bryant and Charmaz, 2007b, Singh and Estefan, 2018). Key components of the Grounded Theory Method that exist across all three approaches include: the focus on observing interaction as it occurs in a naturalistic setting; the assertion that data should be collected and analysed concurrently, and the use of constant comparison to identify patterns and variations across the dataset (Bryant and Charmaz, 2007b, Timmermans and Tavory, 2007). However, differences exist across the three approaches which, in part, are the result of each author's underlying theoretical assumptions.

One of the subtle but key differences between the three approaches is the intended aim of conducting research. Whereas the Glaserian approach aims to discover universal social scientific theories and the constructivist approach places emphasis on creating plausible truths, the Straussian approach aims to build a theory that is as close to reality as possible (Singh and Estefan, 2018). Therefore, a Straussian approach was compatible with the theoretical underpinnings of critical realism on which the project rests. Furthermore, whereas the Glaserian approach suggests that

codes emerge from data and are therefore not influenced by the researcher, Straussian and constructivist approaches emphasise the influence of the researcher's own experiences and preconceptions on this process. As a result, both Straussian and constructivist approaches highlight the need for researcher reflexivity throughout the research process (Singh and Estefan, 2018). In keeping with this principle, during my doctoral research I kept a reflexive diary and made a number of reflexive memos, some of which are reproduced, summarised, or paraphrased throughout this thesis.

The current project also aligns well with the constructivist approach to Grounded Theory in a number of ways. This includes the suggestion that social science research should aim to understand phenomena as it occurs, in context, and to construct theoretical conceptualisations of people's lived experience (Singh and Estefan, 2018). However, a point of departure between constructivist and Straussian approaches surrounds the process of abduction and the degree to which the researcher's own views and experiences should influence the research process and, ultimately, the research findings. The constructivist approach calls for researchers to actively draw on their own experiences and to engage in creative thought to make sense of data to develop richer and more plausible truths. However, the Straussian approach holds a more conservative view on abduction, describing abduction as outlined in the constructivist approach as 'speculation'. Instead, researchers adopting a Straussian approach accept that the research process will inevitably be influenced by the researcher but advocates for the need to minimise this influence wherever possible. As a result, I aimed to represent the views of care home staff and to build a theory of hospital transfers from care homes that was as close to reality as possible. In doing so, I sought to ensure the findings were grounded in the data rather than based on my own prior experiences. In order to do this, I aimed to be reflexive and transparent throughout the research process to minimise subjectivity.

4.5. Reflexivity: Bringing my own experiences to the research field

Robson and McCartan (2016, p16) firmly assert that "you can't leave your humanity behind when doing research". In line with the epistemological stance of critical realism, which suggests that research data is co-created by both the researcher and participants (Rosenberg, 2012), and in line with the Straussian approach to

grounded theory which emphasises the need for researcher reflexivity (Bryant and Charmaz, 2007a, Singh and Estefan, 2018), I have sought to reflect on my experiences and pre-conceptions throughout the research process. In doing so I have sought to turn “a self-critical eye onto one’s own authority as an interpreter and author” (Alvesson and Skoldberg, 2000, p.viii).

Prior to starting the project, I had both personal and professional experiences of providing care for older people with physical disabilities, learning disabilities, mental health problems, and different forms of dementia. Although I had never been employed in a care home setting, I had experience of working as a Healthcare Assistant on an NHS inpatient mental health unit for people with different forms of dementia, and as a Support Worker for adults with learning disabilities in a small, supported living service in the community. Both roles involved providing physical support (for example with activities of daily living such as eating, dressing and bathing) as well as emotional support (for example by building relationships with individuals receiving care) to others and therefore could be considered similar to the role of care home staff. In addition, at the time I was formulating my ideas about what the aims of this project would be and how best to achieve those, I was involved in providing informal support and care for my Nan (to whom this thesis is dedicated) who was living at home with a diagnosis with dementia. During my PhD I was also employed as a Care Home Research Facilitator, as part of the ENRICH team at the NIHR Clinical Research Network West Midlands (see section 1.6 for more details), supporting care home related research projects. Whilst this provided an opportunity to learn more about the practicalities of conducting care home research, my role was centred around liaising with care home managers and researchers in order to increase recruitment to care home studies and did not involve any direct care work with staff or residents.

My prior experiences will have shaped my views about what a care home is and ought to be and about what ‘good’ care looks like. On starting the project, I held a number of beliefs about care work. These included the belief that care work is emotionally and physically challenging and that the skills involved in providing good care are often unrecognised, unacknowledged and undervalued. These beliefs, alongside calls for a better understanding of the experience(s) of care home staff involved in hospital transfers (McCloskey and van den Hoonaard, 2007), are likely to

have influenced my decision to focus solely on the experiences of care home staff and to be sympathetic to the challenges they face. Although other stakeholders may be involved in decision-making during hospital transfers (for example residents, their family members and/or next of kin and external healthcare professionals), my aim was to provide a detailed account of the experiences of care home staff, or to use the words of Wolcott (1990, p62) to “do less, more thoroughly”.

4.6. Summary

In summary, through undertaking this project I aimed to understand the decision-making processes of care home staff when deciding whether to initiate a resident hospital transfer. In order to achieve this aim, the project was guided by critical realist theoretical assumptions, that an external reality exists, independently of human consciousness, yet human knowledge of this ‘reality’ is always influenced by the perceiver and therefore can only ever be partial and flawed. In line with these assumptions, my aim was to build a model of hospital transfers from care homes that was as close to reality as possible. In order to do this, I adopted qualitative, interactive research methods of data collection and used the Straussian approach to the Grounded Theory Method of data analysis. This chapter has provided justification for the methodological decisions that I made during the project. Further details about the practice of collecting and analysing the data are set out in the next chapter.

CHAPTER FIVE: Methods

In the preceding chapter, I provided a rationale for the methodological approach that I took to the project. This included a justification for my choice of research methods and my approach to data analysis. The methods I used were qualitative in nature: the first phase involved semi-structured interviews with 30 members of care home staff across six sites; the second consisted of more detailed ethnographic work at three care homes that had taken part in the earlier interviews. In this chapter I provide more details as to how these methods were used in practice.

5.1. Phase 1: Interviews with care home staff

5.1.1. Development of an interview guide with vignettes

Drawing on themes in existing literature and on preliminary stakeholder engagement with four care home managers, an interview guide was developed and used flexibly to inform the topics discussed. An introductory question was used to gather information about the participant's job title, the scope of their role and their experience of working in the care sector. This enabled me to build a rapport with interviewees, allowing time for participants to become comfortable. Participants were then asked to discuss an occasion in which a resident was transferred to hospital whilst they were on shift. This provided participants with an opportunity to focus on a concrete example of a resident transfer. The remainder of the interview focussed on the process of transferring a resident, the factors that staff consider during the transfer process, situations that would or would not require a transfer, and potential ways to reduce hospital transfers. Once questions were complete, staff were asked to work through a number of vignettes that had been designed to reflect situations that could occur in the care home. A full interview schedule is available in Appendix A. Vignettes are available in Appendix B.

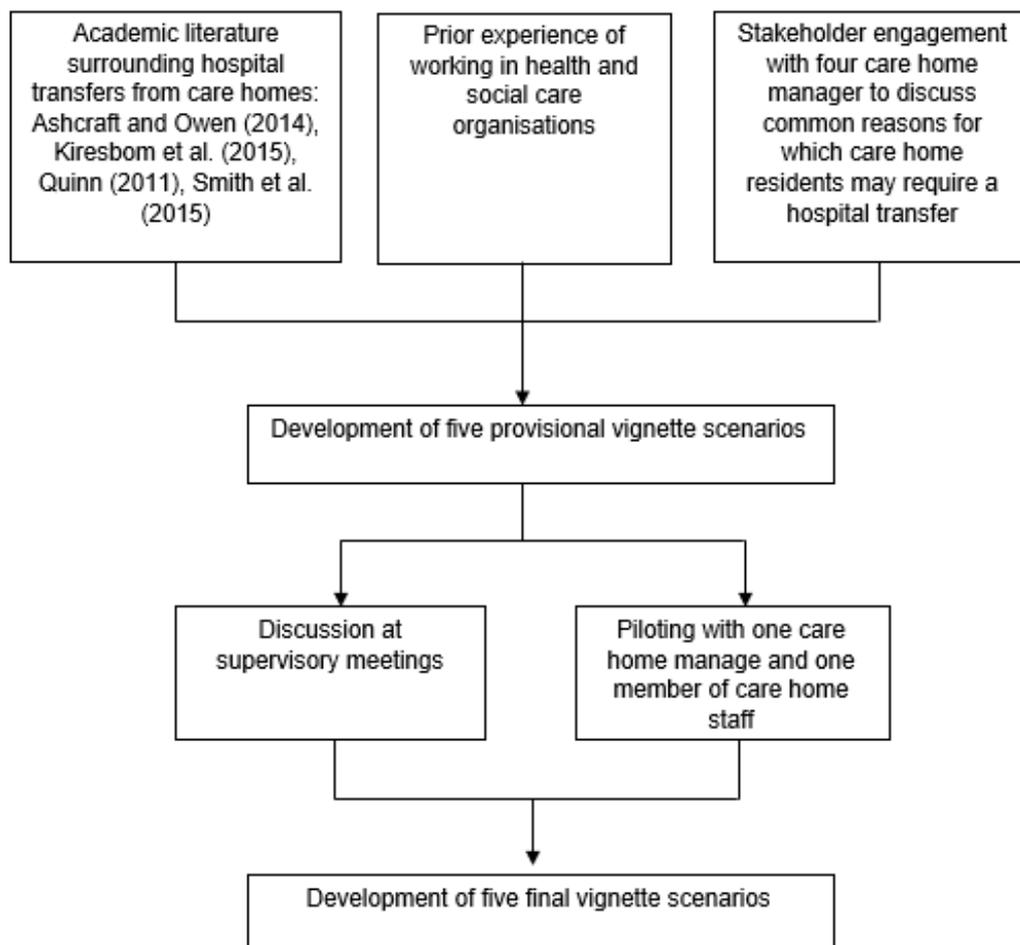
Several issues were considered when designing the vignettes. A discussion of many of these issues and a justification for using vignettes within the current study can be found in section 4.3.1. Vignettes can be based on 'real' events, be fictional or a combination of both. However, whatever the source of information, it is important that vignettes are "context-sensitive, realistic and familiar" (Schoenberg and Ravidal, 2000, p67). In the current study, the aforementioned process of stakeholder

engagement with four care home managers informed the content of the vignettes. In order to ensure that vignettes were realistic and authentic, care home managers were asked questions about common reasons for which hospital transfer could occur. The information provided was supplemented with existing academic literature surrounding hospital transfers from care homes (Ashcraft and Owen, 2014, Kirsebom et al., 2014, Quinn et al., 2011, Smith et al., 2015), my own experiences of working in health and social care roles and discussions with my supervisors.

As well as being realistic, another key requirement was to ensure that each vignette was somewhat unclear, partial or open to interpretation, so as to prompt further discussion. The reason for this was two-fold: firstly, during stakeholder engagement care home managers suggested that staff often have to make transfer decisions based on whatever information they have to hand, which is often ambiguous and incomplete; secondly, a vignette with a definitive answer may have produced shorter, closed responses and may have implied that the purpose of the vignette was to 'test' the care home staff and their knowledge.

Both the interview questions and accompanying vignettes were subject to a period of piloting prior to data collection. A care home manager and a member of care home staff read through each vignette and discussed: i) the appropriateness of the language used within the questions and vignettes and ii) the extent to which each vignette scenario was likely to occur in their care home. This process was essential, as vignettes that appear too hypothetical and implausible may elicit similarly implausible responses (Hughes and Huby, 2002). The flowchart, presented below in Figure 8, describes the process of developing the vignettes.

Figure 8: A flowchart to describe the development of vignettes



5.1.2. Site selection and access

Potential care home sites were identified in collaboration with the ENRICH East Midlands team and through my involvement with care homes that are signed up to ENRICH West Midlands. Each local ENRICH team, operating as part of their respective Clinical Research Network, had a database of local care homes that had expressed an interest in taking part in research.

Care homes (as research sites) were sampled purposively. As discussed in section 2.1.2, existing research has identified considerable variation in acute and emergency care use between residents from different care homes. Much of this variation is associated with structural factors: residents from care homes with nursing services experience fewer emergency hospital admissions than those without nursing (Wolters et al., 2019) and lower levels of acute hospitalisations are observed in

homes that are larger in size and have a lower proportion of short-term beds (Graverholt et al., 2013). Similarly, care homes have lower emergency ambulance call out rates if they are a care home with nursing, do not specialise in dementia care, and fail the quality standard for suitability of management (Hancock et al., 2017). Furthermore, authors conducting research studies conducted outside of England have observed higher rates of transfers amongst residents living in care homes owned by for-profit (as opposed to not-for-profit) providers (Dwyer et al., 2015, Kirsebom et al., 2014).

In line with these findings I sought to include care homes that: did and did not provide nursing services on site; were different sizes (determined by the number of beds they have); were owned by providers of different sizes (determined by the number of care homes the company owned) and types (for-profit and not-for-profit); were and were not registered to provide specialist dementia care; did or did not offer short-term beds; and had a range of CQC ratings. Primary care data has suggested that patients registered at GP practices that are geographically closer to a hospital are more likely to attend hospital than patients registered at GP practices that are further away (Bankart et al., 2011). Therefore, I also sought to recruit care homes that were located in different geographical areas (as situated in a rural, suburban or urban area) and different distances to the nearest accident and emergency (A&E) department.

Given that multiple authors have found the presence or absence of nursing services to be an important influence on the use of emergency services, initially two homes that differed in this regard but were otherwise similar were contacted and recruited. Cedar Court⁹ provided nursing services on site (i.e. a nursing home) and Sycamore Gardens did not (i.e. a residential home). Both homes were of medium size (approximately 45 and 35 beds respectively), owned by small chains (approximately five homes in each chain), registered to provide dementia care and located approximately four miles from the centre of a city in the East Midlands. Both Cedar Court and Sycamore Gardens were invited to participate by a member of the ENRICH East Midlands team who sent an introductory letter and an information sheet to the registered managers. Both managers expressed an interest in taking

⁹ The names of individual care homes presented in this thesis are pseudonyms.

part in the project and, as a result, I carried out a further telephone call to introduce myself, discuss the project and arrange a date to carry out the first visit and interview with the manager.

The remaining four care homes, all located in the West Midlands, were initially contacted by myself, either by email or telephone, due to my employment in the ENRICH West Midlands team. Information sheets were sent to the manager and a date was set to carry out the first interview. The third site, Cherry Tree House, was chosen due to its small size. This home was a stand-alone, independent, care home that did not provide nursing services that catered for approximately 15 residents, located one mile from the centre of a city in the West Midlands. Cherry Tree House was not registered to provide dementia care and residents in this home generally had lower levels of dependency (for example lower levels of frailty and cognitive impairment). The fourth home, Goldfinch Lodge was located in a small town in the West Midlands. This home was chosen because it was part of a large chain, registered to provide care for both residents with and without nursing needs and offering a number of short-term beds as part of a 'Discharge to Assess' scheme¹⁰ with the local hospital.

All of the first four care homes were rated as 'Good' by the CQC. Therefore, the fifth home, Wren Grange, was chosen because it was rated as 'Outstanding' by the CQC and also because of its location in a rural village. This home was a stand-alone, independent home that was registered to provide nursing services, but not to provide specialist dementia care. The sixth and final home, Starling Manor, was chosen primarily because it was rated as 'Requires Improvement' by the CQC. This home was part of a large chain, registered to provide nursing care for people with advanced dementia and located in a suburban area approximately three miles from a city in the West Midlands. A summary of each home's key characteristics is provided in Table 2.

2_____

¹⁰ 'Discharge to Assess' provides short-term, funded support for people who have reached their clinical baseline in hospital but who require additional support before returning to their own home or another community settings. People who are accepted on to this scheme are offered an opportunity to be transferred to a care home setting, which often has additional NHS services attached, so that an assessment of their longer-term care and support needs can be undertaken in a more appropriate, non-hospital setting.

Table 2: A table to describe the characteristics of participating care homes
 (* offering a number of short-term beds through a 'Discharge to Assess' scheme with a local hospital)

Site		Type of service	Provider		Number of beds	CQC rating	Dementia Specialist	Location		
No.	Name		Type	Size (approx. number of homes)				County	Area type	Miles from nearest A&E department
1	Cedar Court	Nursing	Private for-profit	Small chain (5)	35	Good	Yes	East Midlands	Suburban	4
2	Sycamore Gardens	Residential	Charitable not-for-profit	Small chain (5)	45	Good	Yes	East Midlands	Suburban	4
3	Cherry Tree House	Residential	Private for-profit	Independent (1)	15	Good	No	West Midlands	Urban	3
4	Goldfinch Lodge*	Dual registered	Private for-profit	Large chain (120)	60	Good	Yes	West Midlands	Suburban	6
5	Wren Grange	Nursing	Private for-profit	Independent (1)	40	Outstanding	No	West Midlands	Rural	13
6	Starling Manor	Nursing	Private for-profit	Large chain (300)	35	Requires Improvement	Yes	West Midlands	Suburban	2.5

5.1.3. Recruiting individual participants

Once permission had been obtained from the care home manager, individual members of staff were invited to take part in an interview. Individual members of care home staff were also sampled purposively to ensure a range of staff voices were heard (Robson and McCartan, 2016). In particular, I sought to include staff in a range of different roles (e.g. carers, nurses etc.) that worked across different time periods (i.e. days, evenings and nights). All potential participants were given a Participant Information Sheet (see Appendix C) and were given the opportunity to ask questions and have them answered before signing a written Consent Form (see Appendix D). A total of 28 interviews were carried out with 30 members of staff across six care homes. Interviews took place between May 2018 and February 2019. On two occasions participants requested that they completed the interview in pairs. In both cases the participants were employed in the same role. In one instance, at Cherry Tree House, two participants were both managers and in the other, at Starling Manor, both were registered nurses that only worked night shifts.

Of the 30 members of staff that took part in an interview, 28 (93%) were female. This largely reflects the gender balance of the wider care home workforce in England, in which 82% of all staff are female (Skills for Care, 2017). All managers worked during office hours throughout the week (i.e. usually 9am to 5pm from Monday to Friday). Of the 23 staff members who were not managers, six (26%) exclusively worked night shifts and one worked a mixed pattern of days and nights. Participants had worked at their current care home between 18 months and over 30 years. Most but not all of the participants had worked in a similar environment prior to working in the care home and many had worked in a range of health and social care settings. 14 members of staff (46%) reported being born and previously working outside of the United Kingdom, seven of which were countries in the European Union.

A summary of the interview participants is presented below. Some participants had multiple roles in the home, e.g. as both a deputy manager and nurse. The term 'primary role' is used to reflect the job title they were employed in for the

majority of the time. In addition, in some homes certain job roles did not exist. This is indicated by a grey shaded field.

Table 3: A table to show the distribution of participants and their job roles across each of the six research sites

Site		Total number of participants	Primary job role within the care home				
No.	Name		Manager	Deputy Manager	Registered Nurse	Senior Carer	Carer
1	Cedar Court	5	1	1	1	1	1
2	Sycamore Gardens	7	1	1		3	2
3	Cherry Tree House	4	2				2
4	Goldfinch Lodge	7	1	1	3	2	0
5	Wren Grange	3	1	0	1	1	0
6	Starling Manor	4	1	0	2		1
Total (N):		30	7	3	7	7	6
Total (%):		100	23	10	23	23	20

Interviews lasted an average of 38 minutes, ranging from 18 to 75 minutes. Interviews with members of staff in more senior positions tended to last longer than those with staff in more junior positions. The use of vignettes varied across each interview. The number of vignettes used ranged from zero to three. Vignettes were used flexibly in response to the issues that participants had or had not covered throughout the interview. This was due to the main purpose of utilising vignettes as a means to encourage conversation, rather than to 'test' participants or to seek out a definitive answer. Vignettes were less likely to be introduced for longer interviews and in interviews in which more information had been gathered during the interview questions.

5.2. Phase 2: Ethnographic fieldwork in three care homes

5.2.1. Site selection

Ethnographic fieldwork took place in three of the six care homes that had participated in Phase 1. A purposive approach to sampling was used, which required a decision to be made about which homes would be invited to participate in Phase 2. Data that had been collected during Phase 1 was used to advance conceptual thinking and to determine the sampling of care homes in Phase 2. Therefore, based on analysis of data gathered in Phase 1, two characteristics were identified as important when choosing homes to invite to

participate in Phase 2. These were: i) the home's registration status as a care home with or without nursing services and ii) the degree to which the staffing structure was hierarchical (which emerged as a potential source of variation during phase 1).

As a result, I sought out: i) at least one care home that provided nursing services on-site and one that did not, and ii) at least one home with a well-defined, hierarchical staffing structure and at least one home with a less well-defined, more flattened staffing structure. The following three sites were therefore chosen to take part in Phase 2: Sycamore Gardens, Cherry Tree House and Goldfinch Lodge. When approached, all three homes agreed to take part in the second, ethnographic phase of data collection. Table 4 below describes the staffing structure and roles in each home.

Table 4: A table to describe the staffing structure and roles at each care home

Name	Sycamore Gardens	Cherry Tree House	Goldfinch Lodge
Service type	Residential	Residential	Dual-registered
Size	45 beds	15 beds	60 beds
Staffing structure	Manager Deputy Manager Senior Carers Carers A large team of auxiliary staff consisting of an administrator, catering staff, cleaning staff, laundry staff, a full-time maintenance person and regular volunteers	Business Manager Care Manager Carers A small number of auxiliary staff employed as cleaners and one part-time maintenance person	Manager Deputy Manager/Clinical Lead Unit Managers (Nurses) Registered Nurses Senior Carers Carers A large team of auxiliary staff consisting of an administrator, receptionist, catering staff, cleaners, laundry staff, several maintenance people, activity workers and regular volunteers

5.2.2. Data collection during ethnographic case studies

The main method of data collection used during the ethnographic phase of the project was direct observation. This included observations of: i) the ways in which staff managed residents' health conditions, ii) interactions between members of staff, residents, family carers and visiting healthcare professionals, iii) the decision-making processes that care home staff undertook when

initiating or avoiding a transfer to hospital and iv) the work that care home staff undertook to maintain residents' health and to prevent hospital transfers.

The primary participants were care home staff and as such observations were focused on staff activity, interactions and documentation that occurred within the care home. Observations occurred at different times of the day (mornings, afternoons, evenings and nights) across all days of the week. This allowed for an examination of temporal patterns in the care home and the possible influence of these patterns on staff decision-making regarding hospital transfers. In total, across all three care home sites, 113 hours of ethnographic fieldwork were carried out during 26 visits which occurred over an eight month period from April 2019 to November 2019. The length of each visit ranged from two to ten hours. In addition, informal, unstructured conversations took place with care home staff, residents, family carers and visiting healthcare professionals. Data collection also involved documentary analysis, for example of policies and procedures relevant to hospital transfers, the way in which staff documented transfer decisions, and information used to assist a resident transfer.

It is noteworthy that at no point during data collection did I witness a hospital transfer first-hand, although one planned hospital transfer for a routine appointment did occur. Instead, there were several occasions in which residents were transferred to hospital on days in between my visits to each care home. In total, during ethnographic data collection, I was aware of seven occasions in which a resident was transferred to hospital. The primary reason for these transfers were due to a fall and/or suspected injury (two falls with a possible head injury and one potential injury requiring x-ray to rule out a fracture) or a sudden deterioration in health (one resident was suddenly short of breath, one resident appeared to be hallucinating, two residents suddenly became unconscious). In all of these occasions I was able to discuss the transfer with a member of staff and for five of the transfers I was able to obtain a copy of the resident's care notes.

Prior to completing ethnographic data collection, consideration was given to how to gather and record data prior to analysis. Observations were recorded in

field notes. Although there is no universally agreed way to document field notes, Silverman (2011) suggests that researchers should aim to produce field notes that contain descriptions of what happened rather than their impressions. In keeping with this suggestion, detailed descriptions were recorded manually using a pen and paper during each visit. In addition, at the end of each visit, an audio recording was created to summarise thoughts, experiences and the events that had occurred. These were later transcribed and used during data analysis.

5.3. Ethical considerations

Ethical approval for the first phase of the project, in which care home staff were interviewed about transfer decisions, was obtained from University of Leicester's Research Ethics Committee on 13th April 2018 (see Appendix E). Ethical approval for the second, ethnographic phase of data collection was obtained from the Social Care Research Ethics Committee. Favourable opinion was given on 12th November 2018, on the basis that the consent process and associated documents would be altered and resubmitted as a minor amendment (see Appendix F). The amendment was given favourable opinion on 20th February 2019 (see Appendix G).

A number of ethical issues were identified and managed throughout both phases of the study. This included reporting concerns, maintaining privacy and confidentiality, risks to myself as a researcher, appropriately rewarding care homes for their participation, and the nature of care homes as 'home' to the people that live there. Each of these issues is discussed in turn below.

5.3.1. Reporting concerns

During both phases of data collection, participants were made aware that although their interview data was confidential, any information that they disclosed that led to concerns about the welfare of residents would be shared with a relevant body. Depending on the nature of the concern, it could have been appropriate to share information with the care home manager or, if there were more serious concerns, the Care Quality Commission or police. Due to differing regulatory requirements, during the second phase of the study

approved by the national Social Care REC, a protocol for reporting concerns was developed and is included in Appendix H.

During the second (ethnographic) phase of data collection, I observed a series of minor events at one care home which caused me some concern. At this care home, I saw fewer residents in communal areas than I would have expected based on my visits to other sites and on several occasions I overheard staff referring to residents by their room numbers rather than by their names. I also observed what I felt was an excessive focus on documentation, which was greater than I had expected and witnessed at other care homes. I felt that these actions reflected a broader ethos of care, in which the evidencing of particular tasks was prioritised over more interactional tasks – for example spending time and building relationships with residents.

I discussed these concerns with my supervisors and we considered possible responses. We agreed that it would be appropriate to highlight these concerns to the care home manager. I wanted to ensure I did this in a way that was proportional and not confrontational so I set up a feedback meeting to allow me to raise my concerns and to allow the care home manager to comment on the ways in which I had been carrying out data collection as part of a 'two way' process. During this meeting, I emphasised some of the things I had been impressed by, for example by describing an instance in which an Activity Worker had supported a resident to eat their meal, by highlighting the way that their reporting system enabled staff to quickly see which tasks had not been done and the way staff had made me feel welcome in the home. I then mentioned that I had been surprised at the amount of time staff were involved in documenting care tasks and that staff referred to residents by their room number and suggested that perhaps others visiting the home (particularly the family carers of existing and prospective residents) may feel the same way. The manager responded positively and stated that she had recently received similar feedback during a routine CQC inspection and planned to address this by talking with staff.

5.3.2. Risk to myself as a researcher

There were a number of possible risks to myself as a researcher. These included the potentially upsetting content of interviews and observations (research involving care homes can elicit emotive topics such as illness and end-of-life care), risks associated with lone working and potentially experiencing aggressive, agitated or distressed behaviour from residents whilst in the care home, as a result of behavioural disturbance, which can be a feature of advancing dementia. Prior to starting the project, I had both personal and professional experience of working with vulnerable adults, such as people with dementia and learning disabilities. However, based on guidance provided by other care home researchers (Luff et al., 2011), I kept a reflexive diary and discussed any issues at regular supervision sessions. I also used a 24/7 lone working mobile phone app that enabled me to seek assistance at any time without making a phone call. To ensure safety, I took my mobile phone on all journeys and visited the care home by car, retaining control over when to leave the premises.

5.3.3. Maintaining privacy and confidentiality

A number of steps were taken to ensure the privacy and confidentiality of participants and their data. During the first phase of data collection, all interviews took place in a private room or, if this was not possible, a separate area of the home, away from other colleagues and care home residents (so that interviews could not be overheard). Each interview was audio-recorded and transcribed and no identifiable data was stored with the original transcript. Participants were assigned a participant number, which was used to label each audio file and written transcript. During later stages of the project, participants were referred to by their job title (e.g. Nurse 1, Carer 2). A list of participant numbers and corresponding job titles used to refer to participants was stored securely on the University of Leicester's computer network.

Once transcribed, original audio files were destroyed and the written transcripts were stored securely on the University of Leicester's computer network. Consent forms, field notes and research documents (for example, anonymised residents' care notes) were stored in a locked filing cabinet at the University of

Leicester in a locked room that can only be accessed by people with the appropriate swipe card access. All data sources were treated as confidential and I was careful not to record any data that would enable people outside of the research team to identify individual participants. Any data that could potentially be used to identify participants or third parties, such as residents or particular care providers, was removed during the transcription and analysis process.

5.3.4. Appropriately rewarding care homes

In line with general guidance from NIHR INVOLVE¹¹ and specific care home related guidance documents (Luff et al., 2011, Twiddy et al., 2013), care homes that participated in Phase 1 of the project received a £50 multi-store gift card. Care homes that also participated in Phase 2 received an additional £100 multi-store gift card. The purpose of the payment was to thank homes for their involvement and to provide a token of appreciation for their time.

5.3.5. The care home as home

Whilst it is important to ensure participants' privacy, dignity and autonomy are paramount throughout the research process in *all* studies, the need to consider these issues is particularly pronounced in the context of research in care homes because, as well as being a place where people work and visit, care homes are, first and foremost, home to the people who live there (Luff et al., 2011). With this in mind, it was especially important that I caused minimal disruption in the home and that I complied with residents wishes at all times (see the information regarding consent in section 5.3.6 for more information).

Care homes can be considered to be both private and public spaces, which in turn have both private and communal areas within them. Although it is not unusual for care homes to receive multiple visitors each day (including healthcare professionals, family carers, friends and community groups), there is also an emphasis on ensuring only appropriate people enter the care home, in order to keep residents safe. The large majority of data collection occurred in communal areas of the care home. I only entered private areas of the home (for example residents' bedrooms) when: the purpose of doing so was to observe

¹¹ INVOLVE is a national advisory group, operating as part of NIHR, that supports greater public involvement in NHS, public health and social care research.

something directly related to the research study; I was accompanied by a member of staff; and the resident had given me their permission to do so.

5.3.6. Consent

In addition to the aforementioned ethical issues, further consideration was given to obtaining appropriate consent.

5.3.6.1. Consent from the care home manager

Hagerty-Lingler et al. (2009) suggest that informed consent in research conducted in long-term care settings such as care homes should be a two-tier process. Researchers need to first obtain consent from the care home manager, before undertaking a consent process for individual participants. Goodman et al. (2011) suggest that when preparing to undertake research in a care home, researchers need to understand the care home's broad approach to care, including the home's formal and informal staff hierarchy, staff views on dementia, capacity and the way in which staff view their role as "mediators, protectors and gatekeepers" (Goodman et al., 2011, p480). In light of these suggestions, prior to any data collection, a discussion was held with each care home manager. In addition, throughout all instances of collecting consent, particularly the consent of residents, I sought to identify any discrepancies between their own views on capacity and the views of others.

As a result of requiring consent at an institutional level prior to approaching individual participants, in the current study each care home manager represented a potential gatekeeper. Recognising that the use of a gatekeeper could lead to coercion (Hagerty-Lingler et al., 2009), as individuals may have felt obliged to participate, it was made clear to all participants that their involvement was voluntary. Individuals were reminded that although the manager had given permission to approach staff in the home, staff were not obliged to participate, would not experience any repercussions if they declined, and could withdraw from the study at any time.

5.3.6.2. Determining whose consent was required

In their 'Methods Review' of care home research, Luff et al. (2011) state:

“One might also consider who is the ‘target’ of research. If the topic is focussed on staff yet the researcher spends time observing the performance of care work, are they then obliged to seek consent from residents even if residents will not in and of themselves be providing data?” (Luff et al., 2011, p14)

The primary participants in this study were care home staff. However, due to the ethnographic nature of the project’s second phase, it was recognised that people living in the care home (i.e. residents) and visiting healthcare professionals may also be observed during ethnographic fieldwork. As a result, a consent process was developed that included care home staff (as the focus of observation), external healthcare professionals and residents (recognising that I would be observing staff actions related to their care at times of vulnerability and potentially temporary loss of capacity).

5.3.6.3. Consent of staff and visiting healthcare professionals

Individual members of care home staff were provided with a Participant Information Sheet and asked to sign a written Consent Form. At times where it was appropriate to do so and I had been given their permission I accompanied healthcare professionals during their time in the care home. When visiting healthcare professionals entered the home, I approached the healthcare professional to introduce myself and to explain the project rationale. The healthcare professional was given a Participant Information Sheet and asked to sign a Consent Form, which included details about how to withdraw their data if they wished to do so. A copy of the Participant Information Sheet for staff and visiting healthcare professionals and the accompanying Consent Form can be found in Appendices I and J, respectively.

5.3.6.4. Determining the capacity of residents

A significant proportion of care home residents experience some form of cognitive impairment (Alzheimer's Society, 2013). However, the presence of such impairment does not equate to lacking capacity to make specific decisions, such as consenting to take part in a research study. In the current project, I wished not to exclude people who lacked capacity. Practically, excluding all people who lacked capacity to consent to research would

automatically exclude a large proportion of residents. Ethically and scientifically (and related to the first point), although people who lack capacity are often excluded due to a desire to protect them, this practice not only denies people the opportunity to partake in research but also leads to research findings that may not be applicable to this group (Crabtree, 2013, Shepherd et al., 2019).

Whilst preparing to undertake ethnographic fieldwork I worked with care home staff to identify people who may lack capacity to consent. Capacity judgements were initially led by the care home staff team, with the manager and staff making recommendations about which people may lack capacity. Information from staff contributed to the first stage of capacity assessment. Capacity was then assessed by having a conversation with each resident in which the two-stage capacity assessment was undertaken, in line with the Mental Capacity Act (MCA) (DoH, 2005) and the MCA Code of Practice (DoH, 2007). This involved firstly establishing if there was an impairment or disturbance in a person's mental functioning (for example due to illness, disability or side-effects of medication) through discussion with care home staff, before considering whether or not the disturbance was sufficient enough for the person to be unable to make a decision at that specific moment. A resident was considered to lack capacity if they were unable to: understand the purpose and nature of the research; weigh up the benefits and risks of taking part; retain the information long enough to make a decision; and communicate their decision (acknowledging that it was my responsibility to ensure that all residents are fully supported to communicate their decision).

5.3.6.5. Residents with capacity

Residents with capacity were given a copy of the PIS for Residents (see Appendix K). Then, during the first few visits to the care home, I spoke with residents about the study, allowing them the opportunity to discuss the study and ask questions. Residents were asked about their willingness for observations to take place *in the event of* a deterioration. This was a deliberate decision, both in recognition that residents are more likely to be able to make their own decisions (and have adequate time and freedom to do so) while they are well and not in the immediate context of an acute clinical deterioration and

to avoid any possibility of treatment delay in the event of a deterioration. Therefore, by holding discussions and obtaining verbal consent in advance, I was better able to understand each resident's wishes prior to any deterioration.

Throughout the study, consent was conceptualised as an on-going process rather than a singular event (Dewing, 2002). This approach to consent has been highlighted as particularly useful in care home research (Luff et al., 2011). Verbal consent was sought both at the beginning of the fieldwork and again at the beginning of each observation (e.g. "Is it OK if I observe you for a moment?"). This was especially important because hospital transfers can be associated with reduced and fluctuating levels of capacity.

5.3.6.6. Residents without capacity

In the early stages of the research project, in anticipation that consultees would almost certainly be required in some cases, I attended a 'Relatives Meeting' in a care home registered to provide nursing care for people living with advanced dementia. Here, discussions were held with 10 family carers, which provided an opportunity to receive feedback about perceived acceptability of the study, the information that consultees would like to receive and the format in which they would like to receive this information.

In cases where it was determined that a resident did not have the capacity to consent to taking part in the study, a suitable Personal Consultee was sought. Personal Consultees were given an Information Sheet and supplementary information about the role of a consultee (Appendix L) and asked to complete a written Declaration Form (see Appendix M). Consultees were asked about their knowledge of the resident's preferences and wishes and their opinion about whether or not the person would consent to the project if he/she had the capacity to do so. Consultees were also asked about any advance directives that were in place.

Where no suitable Personal Consultee could be found, I worked with the care home to identify a suitable Nominated Consultee, in line with the code of practice and relevant guidance (DoH, 2007; DoH and Welsh Assembly Government, 2008). Nominated Consultees were also provided with an Information Sheet and supplementary information about the role of a consultee

(Appendix N) and asked to complete a written Declaration Form (see Appendix M).

During data collection, I considered both the discussion with the resident's consultee, the nature of the observation, the presentation of the resident at the time of the observation and any guidance from care home staff. Consistent with advice provided by Luff et al. (2011), I used my personal and professional experience of working with vulnerable adults and guidance from care home staff (who personally knew the resident) to assess whether or not I was complying with a resident's wishes. This included looking for verbal cues (such as shouting, making loud noises) and non-verbal cues (facial expressions, pacing, avoiding me, wringing hands etc.) that could suggest that my presence was unsettling the resident.

5.3.6.7. Additional capacity issues

When a resident experienced a hospital transfer, I sought to access the relevant sections of the resident's care notes in order to understand what information staff had documented about this event. When this happened, separate written permission to access the notes was sought from the resident, providing they had capacity to consent at that time. In cases where a resident lacked capacity, written advice was sought from an appropriate consultee. The resident or consultee was asked to sign a Consent Form prior to me accessing the resident's care notes. A copy of the consent form can be found in Appendix O. All residents' notes were anonymised so that they did not contain personal identifiable data prior to leaving the premises.

5.4. Data analysis

Data analysis involved intensive engagement with a range of data sources collected throughout both phases of the project. This included transcripts, field notes, documentary analysis notes and audio files of my own thoughts recorded during the research process. Data analysis, in line with the Grounded Theory approach, was based on the constant comparative method (Bryant and Charmaz, 2007b), which involves coding segments of data and comparing each

segment with other segments, both within the same source and across sources, in order to identify similarities and differences.

Although ethnography is primarily concerned with exploratory research and the discovery of new data, the codes that were developed during analysis of the interview transcripts (collected during the first phase of data collection) were used as 'sensitising concepts' to inform the second, ethnographic phase of data collection. However, rather than being used as a fixed framework to structure and code subsequent data, such sensitising concepts were used only as points of interest (Bowen, 2006). This is in keeping with the conceptualisation of sensitising concepts put forward by Herbert Blumer who described: "Whereas definitive concepts provide prescription about what to see, sensitizing concepts merely suggest directions along which to look" (Blumer, 1954, p7).

In line with the Straussian approach to grounded theory, a three-step approach to coding occurred, with analysis becoming progressively more focussed over time (Singh and Estefan, 2018). Firstly, each transcript was read in order to code each section of text according to the phenomenon or concept that was being discussed, thus each transcript was compartmentalised into a number of 'open codes'. Secondly, once a number of open codes were identified, each code was compared against other codes. This allowed for an exploration of relationships between codes to produce 'axial' codes. This process, which has been described as "weaving the fractured data back together again" (Glaser, 1978, p116), involved the use of computer software MindView (which enables users to create mind-maps of their ideas) and data analysis software NVivo. Step one and two then continued to occur concurrently until the later stages of data collection and analysis in which 'selective codes' - core categories to which all data related – were identified. This approach to analysis enabled me to develop an in-depth understanding of how care home staff make transfer decisions within the context of care homes in England.

Throughout the analysis process, both of my academic supervisors contributed to data analysis. During the early stages of the project, both supervisors independently analysed and coded five interview transcripts, before comparing their codes with my own. This also provided an opportunity to reflect on my

style of questioning and to seek and receive advice on improving conversational flow. At later stages of the research project, preliminary findings were discussed at regular supervisory meetings. Furthermore, preliminary findings were also presented to a range of audiences. This included: clinical academics interested in the care of older people and care home residents; researchers specialising in qualitative sociological health and social care research; and care home managers and staff working in care homes that had not taken part in the project.

Data collection and analysis occurred concurrently throughout the duration of the research project until theoretical saturation was achieved. Bryant and Charmaz (2007b) describe theoretical saturation as a 'judgement' that further data collection is not required. During Phase 1, theoretical saturation was not conceptualised as a total understanding of hospital transfers and therefore an end-point of the overall study. Instead, theoretical saturation was understood as the point at which I was confident that the findings could be used to guide sampling and to guide data collection in the second ethnographic phase. In Phase 2 theoretical saturation was understood as the point at which no new themes emerged from subsequent data collection and a point at which I felt confident that my analysis and findings fully represented the decision-making of care home staff during hospital transfers from care homes.

5.5. Reflections on data collection and analysis

During data collection I reflected on the relationships between myself and research participants. In several ways I shared characteristics with many of the participants. Like the majority of care home staff, I am female and consider myself to be from a working-class background. I have personal and professional experience of care work and have several friends and family members who work in caring roles. However, many of the care staff were older than me, many were migrant workers and very few were educated to degree level with the exception of registered nurses and managers with a nursing background. Such similarities can be advantageous, particularly in ethnographic research in which there is a need to 'blend in' to the research setting (Silverman, 2011). The similarities between myself and the research

participants enabled me to build a rapport with care home staff and to develop a sense of trust during data collection. This was reflected in discussions with care home managers that occurred at the end of data collection. When asked about their experiences of taking part in the project, all of the managers noted that I had “fitted in well” at the care home and with the staff team.

Although developing a rapport with participants is advantageous, there is a danger that identifying too closely with participants could result in the researcher ‘going native’ and losing the necessary distance required to objectively study the community in which they are involved (Silverman, 2011). The necessity of creating an appropriate distance between the researcher and participants is discussed by Barbara Tedlock who suggests that “ethnographers are expected to maintain a polite distance from those studied and to cultivate rapport, not friendship; compassion, not sympathy; respect, not belief; understanding, not identification; admiration, not love” (Tedlock, 2000, p457).

Due to my prior experiences of care work, I was concerned that I would identify too closely with care staff and find it difficult to objectively observe and interpret data. During the first year that I was registered for my PhD, the year in which I developed my ideas and obtained ethical approval for the first phase of data collection, I occasionally worked as a Healthcare Assistant on an NHS mental health inpatient unit for people living with dementia. However, in order to create a ‘polite distance’ between myself and the research participants, I decided that during data collection and analysis I would not undertake any external paid employment in roles in which I would be involved in direct care work.

In addition to refraining from undertaking any paid care-related employment during data collection, whilst at each research site, I also made deliberate decisions about the types of interactions and activities I would and would not become involved in. Whilst I spent time engaged in conversations with residents and staff and I took part in individual and communal activities, for example laying the tables at mealtimes and making drinks for residents, I was not involved in personal care tasks, for example washing and dressing. This decision was partly related to ethical considerations around the appropriateness of me undertaking particular tasks in my capacity as a researcher, but it was

also a deliberate attempt to create some distance between myself and the staff teams that were to be studied.

Despite taking deliberate steps to create a “polite distance” from the people who were to be studied (in this case, the care home staff), during the times that ethnographic data collection took place, my Nan (who was living at home with a diagnosis of dementia) experienced a fall and a subsequent deterioration in her health. As a result, I found myself involved in the search to find a suitable care home for my Nan at the same time ethnographic data collection took place. Whilst none of the care homes involved in the study were ever considered as a suitable home for Nan due to their geographical location, during fieldwork I was acutely aware that a member of my own family would soon spend almost all of their time in a setting similar to the ones in which I was conducting research. As such, I found my attention drawn towards the experiences of care home residents, for whom the care home was ‘home’. Whilst watching staff provide care, I imagined how care might be experienced or felt by my own Nan, and how I too would feel if she were to receive the care that I observed. This increased focus on the lived experiences of residents may have influenced the ways in which I read and interpreted the actions of staff.

After data collection was complete, during the time this thesis was written, my Nan passed away following an acute deterioration in her health. As her registered Lasting Power of Attorney for health and welfare, during the final days of her life I was involved in deciding whether or not a hospital transfer would be appropriate for her. Knowing she died in her own room, in a care home that had effectively been her home for some time was comforting. This experience provided me with a personal, first-hand experience of what it is like to be a relative tasked with deciding whether or not a hospital transfer would be in a resident’s best interest. This experience could not have influenced the way that I approach the project or collected data (as her death occurred during the final ‘writing up’ phase), however it will have influenced my overall perception of hospital transfers from care homes.

During data collection, at times I witnessed practices that did not fit with my own views of what ‘good’ care ought to be. The way that I dealt with this issue is

described in section 5.3.1. However, for me, deciding how to reflect this aspect of what I had observed within my thesis presented an ethical dilemma. Whilst I felt that this was an important aspect of staff behaviour that I wished to document, I was wary of producing and publishing data that could further add to the 'broken' image of care homes (Hockley et al., 2017). Ethical dilemmas like these are not uncommon in qualitative research: Barbour (2014) suggests that ethnographers are likely to face feelings of (dis)loyalty when making sense of and writing up the data they have collected. Throughout analysis and through the writing of this thesis, rather than to portray staff as 'saints or monsters' (Foner, 1994, p245), I have sought to present a balanced and well-rounded account of staff behaviours by considering the contextual factors that influence staff decision-making.

5.6. Summary

In summary, I carried out data collection across two phases. The first phase consisted of 28 semi-structured interviews with 30 members of staff across six care homes; the second consisted of 113 hours of ethnographic observations, documentary analysis and informal conversations (with staff, residents, family carers and visiting healthcare professionals) at three of the care homes that had taken part in phase one. Data analysis was based on the Straussian approach to grounded theory and consisted of a three step approach to coding.

A number of ethical issues were considered and addressed. This included: when and how to report concerns; risks to myself as a researcher; maintaining privacy and confidentiality and appropriately rewarding care homes for their participation. It also included acknowledgement that as well as being a place where people work and visit, care homes are home to the people who live there. Although the primary participants in this study were care home staff, it was recognised that people living in the care home (i.e. residents) and visiting healthcare professionals may also be observed during ethnographic fieldwork. As a result, for the second phase of data collection, a consent process was developed that included care home staff, external healthcare professionals and residents.

CHAPTER SIX: Staff views of hospital transfers: Perceptions of risk and uncertainty

In this chapter, the first of three findings chapters, I explore the ways in which care home staff perceive and conceptualise hospital transfers from care homes. I begin this chapter with a case study to provide an 'intact' example of a real occasion in which care home staff were involved in decision-making about a potential hospital transfer. Then, throughout the chapter, I discuss this case study in relation to specific themes raised in the chapter.

Case Study A: Introducing Alice

Alice, a woman in her 80s living with advanced dementia, had been living at Sycamore Gardens for approximately two years. On arriving at Sycamore Gardens, Alice moved into a bedroom upstairs. However, as her dementia progressed and she required more assistance, Alice moved on to the home's specialised dementia unit. On the first day of data collection at Sycamore Gardens, the deputy manager described Alice as experiencing 'terrors' – she appeared frightened, had become uncharacteristically aggressive towards others, and had been calling out for several days. The staff team had contacted the local GP practice for support but the GP, who regularly visited the home and knew the residents well, could not identify a physical cause for the change in Alice's behaviour. As a result, the GP advised staff to continue to monitor Alice to see if her terrors would subside.

Alice's terrors did not subside and for three more days staff continued to witness and attempt to relieve Alice's distress using several non-pharmacological approaches. This included sitting with Alice, giving her space to relax on her own, playing music and bringing in family members. The deputy manager and the GP discussed whether altering Alice's anxiety-related medication might relieve some of her 'terror'. However, staff were concerned that increasing Alice's medication could "take her off her feet" by decreasing her mobility and balance. As a result, the deputy manager described the decision as being "between a rock and a hard place".

In order to increase the dosage of Alice's medication, an electrocardiogram was required to check Alice's heart. However, it was not possible to perform an electrocardiogram at the care home, so the manager brought in two additional members of staff to accompany Alice to the GP surgery. On receiving the results of the ECG, it was decided that altering Alice's medication would not be a suitable option. Alice's 'terrors' continued.

During the following two data collection visits to Sycamore Gardens, Alice continued to scream. By the third visit, 12 days after data collection commenced, the following interaction occurred between two carers and a senior carer in the staff office.

Carer 1: "Alice is sweating buckets in there."

Carer 2: "Could we call 111?"

Senior Carer: "But they will just section her."

Carer 1: "That's what they said up there [on the dementia unit]."

There was no further discussion after this point. The two carers left the room and the senior carer resumed her work in the office. During the time that these observations took place, care home staff were in regular contact with Alice's son, who was registered as her next of kin. He also believed that a hospital transfer would be a negative experience for Alice. Alice continued to scream for two more weeks, until her behaviour began to subside. During one of my last visits to Sycamore Gardens, approximately six weeks later, the deputy manager noted that Alice had been recognised as being at the end-of-life and that the staff team intended to care for her at Sycamore Gardens until she passed away.

6.1. Staff preference for keeping residents within the care home

Staff consistently described and demonstrated a preference for keeping deteriorating residents in the care home. Staff understood the burdens associated with hospital transfers and suggested that avoiding hospital transfers where possible was an aspect of good quality care. A preference for caring for residents within the care home, where possible, was evident in the case of Alice described above. Staff tried various non-pharmacological approaches aimed at minimising Alice's distress and contacted the GP to

assess her physical health. Furthermore, when Alice required a test that was not available in the home (an ECG), a decision was made to bring in two additional members of staff to support Alice to visit the GP practice, rather than to a transfer Alice to hospital so that the ECG could be performed.

At any point in time, staff could have called the NHS 111 service to seek additional advice or 999 to request an ambulance and further support from paramedics. However, during the discussion amongst two carers and one senior carer, staff expressed concern that calling 111 may lead to Alice being 'sectioned' and taken to the local mental health unit. Staff were concerned that transferring Alice to an unfamiliar environment would only exacerbate her symptoms and, as one participant described, "make her worse". The suggestion that a call for additional support may have resulted in Alice being 'sectioned' (and therefore transferred out of the care home) may at first appear implausible but appears to reflect a concern from staff that calling for help might trigger a chain of events that they considered undesirable. During an interview, the deputy manager at the same home stated:

"The problem is with 111, they quite rightly have to safeguard themselves as well. So, you've got to be aware that when you ring it could quite easily escalate quickly."

(Deputy Manager, Sycamore Gardens)

Therefore, in not calling an ambulance, staff were deliberately and knowingly acting in ways that minimised the likelihood that Alice would experience a hospital transfer.

A strong preference for keeping residents in the home was also evident in participants' responses to interview questions. Staff consistently described the benefits of avoiding transfers and were able to provide examples of occasions where they had advocated for a resident to remain in the home. Staff suggested that this was particularly important for residents with cognitive impairment, who may find an unfamiliar hospital environment confusing and distressing, and for people nearing the end of their lives as staff wanted to ensure the resident was at the care home at the time of the death. The use of bold text in the extracts below is used to show emphasis in participants' voices.

*“A lot of people we support have sensory impairments as well as dementia so it’s **fundamental** that we keep them here rather than send them to hospital.”*

(Manager, Sycamore Gardens)

*“People who live in a care home, especially with dementia, it’s not good for them to go to the hospital... it’s a completely different environment and people with dementia, they don’t like change... if they go to the hospital, it makes everything changed... So, it’s better for to stay here. Unless they **have** to go.”*

(Senior Carer 1, Goldfinch Lodge)

“We had a gentleman that was dying. Clearly dying... We said, ‘we just want to keep him here, keep him comfortable’.”

(Nurse, Cedar Court)

Although participants unanimously preferred to care for residents in the care home, they acknowledged there were some situations in which avoiding a hospital transfer was not possible. The use of the phrase “unless they **have** to go” in the second extract of the set above emphasises that staff make judgements between situations in which avoiding a hospital transfer is or is not necessary. Further consideration of this distinction is outlined in section 6.6.

6.2. Concerns about care, outcomes, and inappropriate discharges

The strong preference for caring for residents within the care home where possible was influenced by concerns about the ways in which residents might experience a visit to hospital. Staff suggested that residents may become distressed at being transferred to an unfamiliar environment and spoke of the potential for residents to have a poor experience of care in hospital as well as the potential for them to experience cognitive and physical deteriorations.

“I really don’t have a lot of respect for the way they are treated in hospital. It’s not their fault – at the end of the day it is staff shortages, but it’s just a body in a bed, not an individual. To us they are very individual people... My experience of anybody going into hospital that is elderly or at various stages of dementia is that they don’t get

better, they get worse... that sounds really derogatory but it's true – there is nobody there to support them with meals, there is not enough time given to them and its very rare that they respond to treatment because they are in the wrong environment.”

(Manager, Sycamore Gardens)

“You send someone with dementia into hospital and it makes them a million times worse... they don't recognise anybody, they are scared, everything is just 10 times magnified with what they were feeling in the first place. And they are restricted a lot in the hospital because you have only got your bed. It's not like they would be able to get up and walk like some of them do here.”

(Carer, Cedar Court)

“Our concern is when we transfer residents and they come back with bed sores or they have lost weight. We have one... she always comes back with a bedsore and the last bedsore she came back with we had to treat for nearly a year... That is our main concern - they always come back with a problem.”

(Nurse, Wren Grange)

Staff often attributed the perceived shortcomings of hospital care to organisational factors beyond the control of individual members of hospital staff (e.g. “staff shortages” and being “restricted” due to the physical environment). Nevertheless, concerns about the potential to experience poor quality care and negative outcomes as a result of a hospital transfer were mentioned by two thirds of all participants that took part in a formal interview. The remaining participants did not comment and although several participants described situations in which they felt hospital care was *necessary* (see section 6.6 for more detail), all participants suggested that caring for residents within the care home where possible was preferable. Returning to the case of Alice, described at the beginning of this chapter, staff were concerned that a transfer to hospital would exacerbate her symptoms and leave her vulnerable to experiencing poor care and outcomes.

Staff made comparisons between the level of care that could be provided in hospital and in the care home. For example, in the above extracts the manager at Sycamore Gardens suggests that within a hospital environment “there is not enough time given to [residents]” who are treated as “a body in a bed, not an individual”. This is mentioned in contrast to the more personalised care that staff felt they could provide. In another interview, a participant stated:

“If we have someone who is end-of-life and they are going to die... they get special attention. In hospital you won’t get special attention. Because they are so busy and they want to cure people.”
(Manager, Wren Grange)

This contrast was also evident in one participant’s reflection on an occasion in which a hospital transfer was considered but the resident remained at the care home:

*“We’ve got more one-to-one time to help feed her, make sure she is getting fluids, better rest, we can maintain her skin care while she is in bed... The GP said that half the time, keeping residents at home, they get better care, more one-to-one. Because hospital is rammed at the minute. I mean, as a home in general we do like to keep them home unless we really **need** to. Because we see deteriorations when they come back.”*

[Interviewer: Does that happen often?]

“It has happened a few times. You feel like you are starting at the bottom and building them back up again from when they first came in. Sometimes it’s a bit of a shock and they come back, and you are like ‘woah’. You can see the weight loss, you can see their skin is breaking down and it’s just like, wow, yeah.”

(Carer 1, Cherry Tree House)

Again, the participant suggests that the lack of “one-to-one time” in hospital is due to structural and organisational pressures rather than a result of unkind or uncaring hospital staff. Interestingly, the perception that a hospital environment may not always be the most appropriate place for residents to receive care appeared to be shared by some of the healthcare professionals who visited the

care homes. The extract below is reproduced from field notes as Sycamore Gardens.

A GP visited the home today to see a number of residents. The GP said that her visit was part of protected, scheduled time she has been allocated to work with the care home. She felt that these regular visits allowed her and the staff team to “keep on top of things” so that illnesses or symptoms did not progress too far. She also stated that without this regular protected times, she felt that there would be more occasions in which residents’ symptoms progress and require an admission, which could have otherwise been prevented. She said “acute is not the best place for them”, noting that residents often “sit around” and “pick stuff up”.

Although care home staff often attributed the perceived shortcomings of hospital care to organisational issues, a topic of conversation that elicited more emotional responses from staff was that of resident discharges (i.e. when a resident is transferred from the hospital to the care home). Although not included within the interview questions, when asked if they would like to raise anything that they felt was important, over half of all interviewees spoke of their concerns about resident discharges. For example, in the extracts below both participants describe a concern that residents may be returned from the hospital too soon or without adequate investigation.

“For me, I think sometimes residents really need help and they go into hospital and they are not looked into properly. They just send them back with a UTI or chest infection diagnosis. They don’t do any further checks in the hospital... Like a gentleman we had, a few hours later he came back without any other tests done.”

(Nurse, Cedar Court)

“It’s just, you know, it’s just a circle. The care home call the hospital, the hospital send them back to the home because the hospital are busy, so they want to discharge as soon as they can... They try to push you to go.”

(Nurse 3, Goldfinch Lodge)

In addition, the extracts below highlight some of the frustrations that care home staff felt with regards to the level of care provided for residents during this process. Staff were concerned about how residents' physical and emotional needs were being met (or not) during the discharge process.

"The times we have discharges from hospital at two and three o'clock in the morning in little green hospital gowns, in the middle of the night with cannulas in and no discharge notes – nightmare!... Where is the dignity in that? There isn't any. I find it appalling."

(Manager, Sycamore Gardens)

"I have concerns with them coming home... I always feel there's a bit of neglect... Coming home in a nighty, no blankets. It could be 10 o'clock at night and it's like, 'hold on a minute, this is a vulnerable lady'... It's awful. You can have someone with pneumonia and they're coming back wrapped in a sheet and it's like 'do you want her back in?'... It's awful, absolutely awful. You think, 'where is your duty of care?' These are elderly people. That's somebody's Nan!"

(Carer 1, Cherry Tree House)

In the excerpts above, participants describe the discharge process as "awful", "appalling" and a "nightmare". Although this may, at first, appear dramatic, the aforementioned participants were not alone in voicing concerns about what they perceived to be an inadequate discharge process. Concerns of this kind were raised by numerous participants, despite resident discharges not being included as a specific interview question. It would be reasonable to suggest that the spontaneity of the responses, coupled with the depth of feeling expressed, highlights the salience of the discharge process to the overall perceptions of resident hospital transfers that staff held.

6.3. Staff perceptions of their role in preventing hospital transfers

In keeping with their preference for caring for residents in the care home where possible, much of the work undertaken by care home staff focussed on the prevention of hospital transfers. Staff gave examples of things that they felt able to do in their work that would prevent hospital transfers and an analysis of each

care home's policies identified several policies centred around preventing specific scenarios that could lead to a resident transfer (for example, preventing falls). The prevention work that staff described could be grouped into three categories: monitoring residents to detect potential deteriorations; maintaining residents' existing health and functional abilities; and being 'proactive' by anticipating future health needs and responding appropriately to potentially deteriorations in residents' health in a timely manner.

Staff perceptions of how they could prevent transfers - monitoring residents, maintaining health and functional abilities, and being 'proactive' – were bound up with broader views about their role as care home staff and what constituted 'good' quality care, rather than being related exclusively to the issue of preventing transfers. Therefore staff perceived their role in preventing hospital transfers as beginning much earlier than the point at which residents' health deteriorates. Given the focus of this thesis, which seeks to understand the wider contextual issues that influence staff decision-making, each of these themes will be discussed in turn below.

6.3.1. "Monitoring residents": Detecting potential deteriorations

When asked if there was anything they could do to prevent hospital transfers, several members of staff made reference to carefully monitoring residents in order to detect signs or symptoms that, if left unmanaged or untreated, may escalate into the need for a hospital transfer. Much of the monitoring work that staff undertook was evidenced in various forms of documentation. For example, each care home had systems in place to monitor residents' diet and fluid intake, urine output, bowel movements, sleep and medication usage. In addition, staff were required to make notes about each resident at the end of each shift. This often included information about the activities the resident had been involved in, the help they had received from staff and information on their health and well-being.

Whilst some monitoring work occurred routinely, additional monitoring could be completed if a resident was perceived to be at risk of becoming unwell. For example, staff completed turning charts to document when they had repositioned residents who were less mobile – a task that was completed to

reduce the risk that the resident would develop a pressure ulcer. Furthermore, what was considered to be routine monitoring differed across care homes. For example, in some care homes, staff were required to periodically record structured nursing observations for each resident. This included measures of the resident's respiration rate, oxygen saturation levels, systolic blood pressure, pulse rate, level of consciousness and temperature. However, in other care homes, observations were only recorded in response to an event such as a fall or a resident appearing unwell.

6.3.2. "Pushing fluids" and "preventing falls": Maintaining residents' existing health and functional abilities

During interviews, several members of staff suggested that they could prevent hospital transfers by encouraging residents to have an adequate intake of fluids and, to a lesser extent, food. Similarly, during ethnographic data collection staff placed importance on encouraging residents to eat and drink as a way of maintaining their health. In two of the three care homes where ethnographic data collection took place, additional staff were available at mealtimes. At Goldfinch Lodge, three Activity Workers, who worked 9am until 5pm daily, supported residents during mealtimes. At Sycamore Gardens, two members of 'Nutritional Support' staff were employed each day to cover mealtimes - one person from 8am until 2pm and another from 2pm until 8pm. Across the two care homes the staff who assisted during mealtimes were involved in supporting residents who required help to eat and drink and encouraging residents who were able to do so independently.

Returning to the case of Alice, at the beginning of this chapter, staff were particularly concerned about Alice's health and wellbeing because during the 'terrors' she was experiencing she had eaten and drank very little. As a result, staff were concerned that Alice was at risk of becoming dehydrated and malnourished. In addition to perceiving eating and drinking to be general markers of well-being, several members of staff made links between the lack of adequate fluid intake and an increased prevalence of urinary tract infections.

“We try to encourage the drinks of course... If there is only one thing [they will drink] then we will try to encourage them with more fluids and give it more time... In the [handover] the nurses can say ‘this person has a very low output today on their fluid chart so encourage him to drink more’ and staff will be going in to him to encourage.”
(Senior Carer, Wren Grange)

Staff also suggested that they could maintain residents’ existing health and functional abilities by preventing people from falling where possible. Participants made reference to the potential for residents to experience serious injuries and to struggle to recover as a result of a fall. A carer at Cherry Tree House made reference to a previous resident who had fallen, fractured her hip and subsequently struggled to walk. Because staff felt the residents’ needs could no longer be managed at Cherry Tree House, the resident moved out of Cherry Tree House and into a care home which provided nursing services. The extracts below show the responses of two care home staff when asked how they might prevent hospital transfers

“If there is no falls then [residents] won’t be going to hospital. So we can prevent injuries and we can prevent [transfers] by looking after them, by making observations. So if someone is at risk of falls, they are always one-to-one, so someone is with them all the time. So that’s what we can do for them to keep them safe.”
(Senior Carer, Cedar Court)

“What we do at this care home is try to prevent the reasons why people are going to hospital. Like the lady I was telling you about, she had a fall yesterday and the thing is, like times, we were discussing to see what time of day those falls occur... If a fall keeps occurring, at the same time we try to work around that and make sure that something is in place to prevent them falling.”
(Senior Carer 2, Goldfinch Lodge)

6.3.3. “Being proactive”: Anticipating future needs and responding in a timely manner

Staff also suggested that they could prevent hospital transfers by being “proactive”. Staff discussed being proactive in terms of anticipating residents’ future health needs and responding to potential deteriorations appropriately, in a timely manner.

*“If you are proactive as a nursing home - If a UTI isn’t picked up they could become septic... They might go into a delirium – well, you would **have** to go into hospital then because it is too late. As long as you are being proactive you are actually stopping hospital admissions.”*

(Manager, Goldfinch Lodge)

Although responding to a potential deterioration in a timely manner could involve calling an external healthcare professional for help, staff suggested that, where they felt it appropriate, they could implement a range of practical actions to prevent residents’ health from deteriorating further. For example, in response to a vignette in which a resident had a high temperature after choking on their food, participants suggested that they could: *“give the resident paracetamol”* (Senior Carer 1, Sycamore Gardens) *“put on a fan, open a window and check [the resident was] wearing appropriate clothing”* (Senior Carer 2, Goldfinch Lodge); ensure that the resident was *“hydrated... sitting comfortably and being watched, checked and repositioned”* (Carer, Cedar Court).

In reference to being ‘proactive’, staff discussed the importance of recognising when a resident was nearing the end-of-life. Staff suggested that being aware of and prepared for a potential end-of-life situation could help to prevent hospital transfers. Participants discussed the need to ensure advance care planning discussions had occurred and advance care plan documents were in place.

“Our GP is really proactive. He wants to see [advance care plans] in place so we don’t get to the stage where somebody is very poorly and the family are saying ‘we don’t want them to go into hospital’ and paramedics are saying ‘we have a duty of care to take this person to hospital’ because there’s nothing in place that tells them the person

doesn't want to go."

(Manager, Sycamore Gardens)

[Interviewer: Can you think of a time where you have been able to prevent someone from going to hospital?]

"We have done lots of end-of-life work... When I say we I mean ourselves, the families and the doctors. We make that decision that someone has come to the end of their journey and what is the benefits [of further treatment and transfers] really?"

(Manager, Starling Manor)

The role of advance care plans during transfer decisions will be discussed in more detail in Chapters 7 and 8 of this thesis. However, being proactive and preparing for the end-of-life also involved practical arrangements, such as ensuring appropriate anticipatory medications were in place.

[Interviewer: Can you think of anything care staff can do to prevent hospital transfers?]

"We have these 'thoughtful Thursdays'. When it is going to be the weekend, we have to think about who may need the GP... We make sure that on a Friday, if somebody is poorly, we get the doctor out just to avoid calling out-of-hours at the weekend or we will get anticipatory medication."

(Nurse, Wren Grange)

During her interview, the nurse in the extract above explained that staff wanted to ensure they had anticipatory medication delivered to the home during the week because they anticipated that it would be more difficult to obtain the medication during the weekend when the regular GP was not available. She suggested that without anticipatory medication, if a resident became distressed during the dying process, staff too may be distressed at witnessing them suffer. This in turn could increase the likelihood that staff would call an ambulance for support, which could result in a resident being transferred to hospital.

6.4. Hospital transfers as an infrequent occurrence

Due to the preference for keeping residents in the home, care home staff across all six sites reported that hospital transfers occurred “rarely”. Staff believed that hospital transfers were not a frequent occurrence, as is evident in the responses below.

[Interviewer: Can you think of a time recently where a transfer has happened whilst you were on shift?]

[Silence]

[Interviewer: Where someone has had to go to the hospital?]

“Erm, [5 second pause] not whilst I’m on shift no! [laughs]”

(Carer 2, Cedar Court)

[Interviewer: Can you think of an occasion where someone was transferred to hospital recently whilst you were on shift?]

“When I was around? [3 second pause] Hmm.... It’s got to have been, erm, a death. Where somebody died unexpected. But no, we very, very rarely now have people admitted to hospital.”

(Deputy Manager, Sycamore Gardens)

*“We rarely send a resident to the hospital unless they really **need** to go and their condition will be reversible.”*

(Nurse, Wren Grange)

Although staff suggested that hospital transfers occurred infrequently, a nurse who worked night shifts at Goldfinch Lodge, suggested that there could be variability in the number of transfers that occurred.

[Interviewer: How often do you think you transfer someone to hospital?]

“Sometimes it is very quiet, and you can go one month, and you don’t send anyone. Sometimes it’s busy [laughs] you can call the ambulance twice in a night. It is quite variable, it depends on the residents.”

(Nurse 3, Goldfinch Lodge)

The above response suggests that the frequency with which hospital transfers occur may be variable. What is of interest is that Goldfinch Lodge provided a number of short-term beds under the 'Discharge to Assess' scheme (see section 5.1.2. for more information). The residents in these beds changed frequently as each person's bed was funded for a maximum of six weeks. Throughout interviews and ethnographic data collection at Goldfinch Lodge, several members of staff suggested that the health of residents in these beds was less stable and that these residents were more likely to be transferred to hospital than permanent residents.

Throughout the project, staff made comments about how *their* care home was 'good' at avoiding hospital transfers. These comments were often made in reference to 'other' care homes. Interestingly, the discussion of 'other' homes was seldom related to a concrete example of a specific home and instead appeared to be more often based around an abstract concept of 'other' care homes.

"I am not a happy 999-er you see [laughs] so we would always put it through the doctor if we can."

[Interviewer: "Why is that?"]

"Because we don't want them admitted – Sometimes, back in the day when you could just ring 999 and they would come out and fly them in, we used to do that. But then we were taught to think about the options, what we can do... I think it's 'I can't be bothered, let's just get them in'. I think that sometimes happens."

(Manager 1, Cherry Tree House)

In the extract above, the participant refers to staff in other care homes transferring residents to hospital because they "can't be bothered" to manage their condition(s) in the home. Throughout data collection across all homes, there were no instances in which this appeared to form part of the decision-making process of staff. Popular discourse around hospital transfers from care homes in England is often focussed on 'inappropriate' hospital use and 'bed blocking'. In addition, care homes have historically been, and frequently continue to be, represented negatively in lay media (Hockley et al., 2017).

Existing literature into how people manage risk highlights the moral aspects of risk practices (Alaszewski, 2018, Brown and Gale, 2018b, Douglas, 1992), and research into help seeking behaviours has highlighted the moral work patients undertake to present their help seeking as legitimate (Turnbull et al., 2019). As a result, it could be suggested that these comments may have been borne out of a desire to portray themselves and their organisation favourably and to depict the transfers from their own organisation as legitimate. However, staff reports aligned with my own ethnographic observations, which are less subject to this desirability bias.

6.5. Hospital transfers as a series of escalations

Based on staff descriptions, hospital transfers can be conceptualised as a series of escalations. When faced with a situation in which a resident's health could be deteriorating, staff made a series of decisions. Firstly, the staff member who identified the potential deterioration was required to decide whether they could manage the situation alone or whether they should escalate to someone else. To some extent, this was influenced by the ways in which care was organised in the specific care home and the responsibilities assigned to different staff groups. In some care homes responsibilities were clearly demarcated and staff referred to certain tasks as being a "nursing job" or "senior job". The roles and responsibilities of different staff groups tended to reflect the type of home (i.e. whether or not it provided nursing services) and the extent to which there was a hierarchical staffing structure. Common tasks that were assigned to specific staff groups included the monitoring of vital signs (such as blood pressure and temperature) and the completion of specific documentation. In addition, the task of calling external healthcare professionals (e.g. a GP or emergency service) was assigned to different staff groups across different care homes.

[Interviewer: Can you think of an example where you might call a GP rather than an ambulance?]

"Well mostly it's the nurse taking the decisions. We are just reporting when something is wrong. They are trained so they are making the decision who is going to hospital, when they should ring the

ambulance, when they should ring the GP. It's not for me to decide.

In a residential home it's different because there are no nurses.

Seniors will make the decision, but here there are nurses.”

(Senior Carer, Cedar Court)

At Goldfinch Lodge, a dual registered home providing care for people with and without nursing needs, different members of staff were responsible for residents with different types of needs. Nurses were responsible for escalating concerns about residents who had nursing needs and senior carers were responsible for residents who did not.

“[The nurse] is responsible for the nursing residents. If anything happens with anyone from the residential setting, it is our responsibility.”

[Interviewer: Can the care staff call too?]

“It would only be the seniors making those calls. A senior can call the GP or out of hours whenever we think they need to be called.”

(Senior Carer 1, Goldfinch Lodge)

In total, in five of the six care homes, roles and responsibilities of different staff groups were clearly demarcated. The exception was Cherry Tree House, which employed two managers and approximately 12 carers. No formal distinction was made between carers of different levels and any member of staff was able to escalate a potential transfer situation to an external healthcare professional.

Despite the differences in the specific escalation pathways at each care home, a closer look at the data revealed a pattern of escalation. As previously noted, once a member of staff detected a change that could signal a resident's health was deteriorating, they were required to decide whether they could manage the situation or whether they should escalate to someone else. If deciding to escalate, then they were also required to decide *who* they should escalate to. Escalations at first occurred internally within the care home. For example, where a staff member chose to involve another person within the same staff group (e.g. a carer to carer) or to escalate to someone in a more senior position (e.g. carer to senior carer). As additional members of staff were brought into the decision-making process, they too were required to choose between attempting

to manage the situation or continuing to escalate. As a result, multiple internal escalations could occur, particularly if there were multiple layers within the staffing hierarchy.

Staff described the potential responses to potential deteriorations in residents' health. If staff felt comfortable and able to manage the situation within the care home they could choose to implement practical interventions (for example, providing paracetamol to a resident with a temperature) and to "continue to monitor" the resident in the care home. For example, in response to a vignette in which a resident was not eating or drinking, one participant stated:

"It sounds like she is dehydrated so I would give her plenty of fluids. We would do a fluid chart, monitor the ins and outs of the fluids, and offer her snacks throughout the day because she had a poor appetite... I wouldn't call an ambulance, I would just monitor for the next 24 hours".

(Senior Carer 2, Sycamore Gardens).

Eventually, if staff did not feel able to manage the situation, an escalation would reach a member of staff who was perceived to have the authority to decide whether or not an escalation should be made to external healthcare services. As discussed previously, this person could differ depending on the individual home, however it tended to be more senior members of staff, for example senior carers, nurses or members of the management team. Returning to the case of Alice, care staff at all levels tried to implement several strategies to minimise Alice's distress prior to the deputy manager making an external escalation to the GP.

This pattern, of escalating first internally and then externally, was evident across all six care homes. During interviews at Cherry Tree House, where there was a flattened staffing structure, staff suggested that they did not need to escalate internally, and all staff were able to escalate externally for help. However, during ethnographic fieldwork the aforementioned pattern of escalation was observed but without a formal hierarchy. When faced with a potential deterioration, staff often chose to approach a member of staff who was deemed to be more experienced. This was not determined by job title, since all

staff were employed as 'carers'. Instead, seniority was associated with length of time in the job and the number of hours worked each week. Staff who were relatively new to the home often approached more experienced members of staff and staff who worked fewer hours per week often sought advice from staff who spent more time at the care home. Therefore, the same pattern of escalation occurred at Cherry Tree House, albeit more informally.

6.6. "Unless they **have** to go": Perceptions of need

In deciding whether or not to escalate a situation and who to escalate to, staff made judgments about situations which they deemed to require a hospital transfer and those situations that did not. This was evident in a number of phrases that care home staff used, such as "*it's better for [residents] to stay here. Unless they **have** to go*" (Senior Carer 2, Goldfinch Lodge). Staff identified a number of situations in which a hospital transfer was considered necessary regardless of the individual circumstances surrounding the situation. This included potentially life-threatening situations, for example heavy bleeding, loss of consciousness or possible stroke or sepsis. In addition, situations likely to require a hospital transfer included those in which there was no immediate risk to life, but where they believed a resident required tests or treatments to prevent further deterioration in their health or quality of life. Therefore, although hospital transfers often occurred as a series of escalations, there were certain conditions that supplanted the internal escalation process and automatically trigger an external escalation.

[Interviewer: Are there any occasions where you would always need to send somebody to the hospital?]

*"Yes! A fall with a head injury or a fracture... So, we might think 'yeah they **need** to go'."*

(Manager, Cedar Court)

[Interviewer: In your experience, are there any common reasons why residents are sent to the hospital?]

"It's mainly a bump to the head, breaks and things like that. Normally we do try and keep residents at the home... I don't think we really have many admissions other than breaks that can't be dealt with

*here, they **need** to be going to the hospital when they need scans and things.”*

(Senior Carer 1, Sycamore Gardens)

“Sometimes it can be difficult to decide if it is an emergency or not. Unless it is an injury to the head or something like that.”

(Manager 1, Cherry Tree House)

Staff made a distinction between ‘emergency’ and ‘non-emergency’ situations to justify the actions they might take.

*“If their obs [structured nursing observations] are **really** bad they will call for an ambulance. But if the obs are bad, but not really bad, they will call for a doctor.”*

(Nurse, Wren Grange)

“If it is something that has happened gradually, for example, somebody having a chesty cough or somebody with an infection, we usually call the GP. But if somebody has a fall or something happens suddenly, then we call 999.”

(Senior Carer 2, Goldfinch Lodge)

Although staff identified some situations that they felt clearly warranted a hospital transfer, in other situations staff suggested it was more difficult to accurately interpret the severity of the situation, which in turn made it more difficult to determine the most appropriate course of action. Staff identified a number of uncertainties that made it difficult to accurately assess whether or not and to whom an escalation should be made. This could include: residents not being able to accurately report symptoms; staff being uncertain about their assessment of the severity of residents’ symptoms; and finding it difficult to weigh up the potential benefits and possible harms of a hospital transfer to determine the most appropriate course of action. During ethnographic data collection at Cherry Tree House, a member of staff described the difficulties they faced when supporting a resident who could not accurately report their symptoms. She stated, “*you don’t want to over-react, but you also don’t want to under-react if they **really** need to go*”. When faced with situations that were

particularly uncertain, participants suggested that they were more likely to choose to escalate (either internally or externally) than to attempt to manage the situation.

6.7. “Weighing up” risks: Deciding when to escalate

In addition to staff perceptions of need, the decision to escalate was also influenced by staff perceptions of a number of negative consequences that could be associated with their decision-making. One participant stated, *“the decisions that we make can have long term implications”* (Deputy Manager, Goldfinch Lodge). Staff described several types of risk which could be associated with their decision-making. These risks could be conceptualised as falling into five categories: risks to the resident, to themselves (as decision-makers), to their social relationships (for example with colleagues, residents, their family carers, or external healthcare professionals), to the care home as an organisation and to wider health and social care systems.

6.7.1. Risks to the resident

Throughout data collection staff spoke fondly of residents, in ways that emphasised their personhood and social ties. For example, staff used phrases such as *“if that was your mum, if that was your dad”* (Manager, Sycamore Gardens), *“that’s somebody’s Nan”* (Carer 1, Cherry Tree House) and *“if it were my mum”* (Deputy Manager, Sycamore Gardens). As discussed in section 6.2, staff were aware of the potential for residents to experience deteriorations in their physical health, cognitive abilities, and well-being whilst in hospital. Staff also voiced concerns that care provided in hospital may not sufficiently meet residents’ needs.

Despite preferring to care for the resident in the care home where possible, there were occasions where the decision to do so was perceived to carry possible risks. In some instances, for example where residents exhibited life threatening symptoms or required tests or treatments that were not available in the care home, avoiding a hospital transfer was neither possible nor desirable. In addition, there were also instances in which staff felt that all of the options available to them (to initiate a transfer, to call an emergency or non-emergency service) could potentially result in undesirable consequences.

“It’s a bit trite to say you are looking at a person holistically, but you do. You have got to weigh up the pros and cons... It’s not just straight-forward ‘this person is going to hospital’. You have really got to think about it.”

(Manager, Goldfinch Lodge).

“You question yourself - by going into hospital what can they do any more than we can do here?... So, you weigh up that, you weigh up how distressed a person would be. But you are all the time having to weigh that up against your duty of care to make sure they are going to be OK.”

(Deputy Manager, Sycamore Gardens)

Staff described this experience as being “between a rock and a hard place” and used phrases such as “damned if you do and damned if you don’t”. This was evident in the case study of Alice, presented at the beginning of the chapter, when the deputy manager described the benefits and burdens of increasing Alice’s anxiety-related medication. Whilst increasing her medication had the potential to reduce some of Alice’s ‘terror’, doing so could have the potential to “take her off her feet” by decreasing her mobility and balance. Therefore, both options available to staff were perceived to hold potential negative consequences for Alice.

6.7.2. Risks to the staff member as decision-maker

Staff also described potential consequences that they, as a decision-maker, may face because of their actions. Like the final extract in the set above, several participants referred to their “duty of care” for residents. Staff were motivated by an intrinsic desire to act in residents’ best interests. Therefore, decision-making carried potential personal consequences for the staff members, who were concerned that they had ‘done the right thing’ or ‘done enough’ for the resident. That different stakeholders may hold different perceptions of what is considered the ‘right thing’ to do will be discussed in more detail in Chapter 8. Staff also discussed the potential professional and legal consequences that could occur due to their decision-making and the associated need to ensure they were ‘covered’ and able to ‘justify’ their actions.

“What happens if I keep them in place and keep them clean and comfortable, what if it is not enough?”

(Nurse, Starling Manor)

“It is a very sobering thought that you and your career, especially as a nurse, you can be suspended and scrutinised, you can face legal ramifications ... You have to bear that in mind and have the experience and the wisdom to say - if I were going to be reprimanded, would I be able to justify?”

(Manager, Goldfinch Lodge)

During ethnographic data collection at Cherry Tree House, a carer reflected on an occasion in which a resident had fallen and, believing the resident was uninjured, she had not called external services or initiated a transfer. The following day it was clear the resident had fractured her hip.

“And you think about the fear and the blame – because whatever happens you blame yourself, because you are supposed to be looking after them... I felt awful and then I got a bollocking from the managers”.

(Carer, Cherry Tree House)

6.7.3. Risks to social relationships

Decision-making was associated with the potential to damage several social relationships. This could include damaged relationships with residents and their family carers or healthcare professionals, for example if staff made decisions that did not align with their wishes, preferences or own subjective view about what was the ‘right’ or most appropriate course of action. Staff anticipated the reactions from others and sought to make decisions that would avoid conflict, thus preserving social relationships. Therefore staff highlighted several ways in which their decision-making could be influenced by and embedded within social relationships. Each of these relationships, and their influence on staff decision-making, will be discussed in more detail in Chapter 8 of this thesis.

“The straightforward [transfer decision] is when the nurse uses their clinical judgement, their professional judgement, but in addition to

that it is working with people.”

(Deputy Manager, Goldfinch Lodge)

6.7.4. Risks to the care home organisation

The need to be “covered” and to be seen to make the right decision, also extended to the wider care home in which the individual member of staff worked. In the same way staff described being aware of the potential for them, as individuals, to experience potential negative consequences as a result of their decision-making, staff were also aware that their decisions could have repercussions for the wider care home organisation. Furthermore, staff suggested that their actions could have implications for the ways in which other people (family carers and external healthcare professionals) viewed care staff as a profession.

Staff described this form of risk in the same way they described risks to themselves as an organisation, however when discussing risks to the wider team and organisation often they would use the plural pronoun ‘we’ rather than the singular ‘I’ or ‘me’.

“Today, with allegations and safeguarding issues... I think sometimes ambulances are called because we need to cover our backs.”

(Manager, Starling Manor)

6.7.5. Risks to the wider health and social care systems

To a lesser degree, staff also referred to risks to the wider healthcare system when discussing the factors that influenced their decision about whether or not to transfer a resident to hospital. For example, staff described the healthcare sector as “*under stress*” (Carer 2, Sycamore Gardens), “*rammed*” (Carer 1, Cherry Tree House) and “*very busy*” (Deputy Manager, Cedar Court). Care home staff were aware that their decision-making could have implications for the wider healthcare system and sought to ensure that they only requested support from healthcare services when they perceived it to be necessary and appropriate. In the two extracts below, the desire to avoid “wasting” resources was discussed in relation to both GP appointments and ambulance call outs.

“I don’t want to waste people’s time because I know people call [999] for really silly things.”

(Carer 2, Cherry Tree House)

“We don’t waste the GP’s time... yesterday a gentleman was more confused, and he had increased urine frequency, so we tested his urine. I emailed the doctor, described the symptoms, and said, ‘according to my view it is not necessary that the doctor visits, but shall we prescribe something?’ I didn’t say ‘prescribe an antibiotic’ but I was sure he had a urine infection because we know him very well. The GP said OK. So, we didn’t waste his time and the patient is already better.”

(Manager, Wren Grange)

Reflecting on a local ‘rapid response’ service that had recently been de-commissioned, in which a healthcare professional would attend the care home by car prior to calling an ambulance, one participant stated:

“I think the car worked great because then you can make an assessment... And then it’s not wasting an ambulance... because you are very conscious of that now.”

(Deputy Manager, Sycamore Gardens)

Staff were aware that healthcare resources (e.g. GP time, ambulance call outs etc.) were limited. Therefore any resources they requested could have implications for others. For example, if an ambulance were called to the care home, staff were aware that that ambulance could not then have been sent elsewhere. Similarly, whilst discussing hospital transfers with the wife of a resident during ethnographic fieldwork at Goldfinch Lodge, the resident’s wife stated *“that’s what we are trying to avoid where possible, we don’t want to be taking a place from somebody else who might need it”*.

Staff also discussed the potential for their decisions and actions to potentially contribute to broader perceptions of care homes, the social care sector and of staff working within it. For example, several participants suggested that they believed the healthcare professionals that they contacted when a resident

potentially required a hospital transfer could hold negative views of care home staff. Participants suggested that external healthcare professionals may not recognise the skills of care home staff and therefore may believe that care home staff are not able to assess a resident and to determine which service would be most appropriately placed to respond. The participants who made these comments related this back to a broader public perception of care homes as a negative place to live and work and expressed concerns that the decisions they made could further contribute to this negative perception. This will be discussed in more detail in section 8.4.2.

6.8. Summary

Staff unanimously preferred to care for deteriorating residents within the care home where possible due to concerns that residents may experience poor care and poor outcomes in hospital. Staff believed that they could prevent hospital transfers by: monitoring residents to detect deterioration; maintaining residents' existing health and functional abilities; and by being 'proactive' which staff described as a process of anticipating residents' future health needs and responding to potential deteriorations appropriately and in a timely manner. Across sites, staff held a shared perception that hospital transfers were not a frequent occurrence.

Based on data collected throughout the project, in the context of care homes in England, hospital transfers can be conceptualised as a series of escalations. Despite differences in the specific escalation pathways of each care home, a pattern occurred across homes in which escalations first occurred internally (within the layers of staffing hierarchy in the specific home) prior to external escalations to healthcare services. Therefore findings suggest that with the exception of situations that staff perceive to be urgent enough to warrant an immediate external escalation, staff undertake a substantial amount of work 'in house' prior to calling external services for support. Based on this process of decision-making, staff may choose to manage and monitor a resident within the care home or to escalate to an emergency (i.e. paramedic) or non-emergency service or healthcare professionals (i.e. GPs or district nurse).

When deciding whether each escalation was appropriate and to whom an escalation should be made, staff made judgements about perceived clinical need (i.e. whether a resident medically required support from external services). In addition, staff considered a number of potential risks associated with their decision-making. Therefore, in the context of care homes in England, hospital transfers can be conceptualised as a series of escalations in which staff make complex, multifactorial decisions about the perceived burdens and benefits for residents, themselves as a decision-maker, their social relationships, the care home organisation in which they work and for wider health and social care systems.

Staff and visiting healthcare professionals suggested that a hospital environment may not be the “best place” for residents to receive care and raised concerns that a resident’s needs might not be met in a busy and unfamiliar hospital environment. Therefore, it could be suggested that care home staff perceived care home residents to be “out of place” in hospital (Douglas and Wildavsky, 1982, Douglas, 1966). However, although staff consistently described a strong preference for caring for deteriorating residents in the care home where possible, there were times when the perceived benefits of a hospital transfer outweighed the perceived burdens. Therefore whilst earlier sections of this thesis suggested that care home residents may be considered ‘out of place’ (Douglas and Wildavsky, 1982, Douglas, 1966) in a hospital environment, it could also be suggested that when residents experience deteriorations in their health, they could also be perceived as ‘out of place’ within the care home.

When faced with a potential transfer situation, staff were motivated by an intrinsic desire to ‘do the right thing’ for residents yet perceived a need to balance this with a desire to maintain relationships with others (residents, family carers and external healthcare professionals) and to ensure they were personally and professionally ‘covered’ and able to justify their actions. Therefore, the decision to escalate can also be conceptualised as a ‘moral act’ (Alaszewski, 2018, Brown and Gale, 2018b, Douglas, 1992) in which staff have to both “weigh up” a number of risks and subsequently account for the decisions and actions they take.

CHAPTER SEVEN: The decision-making process: Navigating through risk

In the preceding chapter I explored staff perceptions of hospital transfers. I suggested that hospital transfers from care homes can be conceptualised as a series of escalations in which staff make multifaceted decisions about potential benefits and risks. This includes risks to the resident, to staff (as decision-makers) and their social relationships (for example with colleagues, residents, their family carers, or external healthcare professionals), to care home as organisations and to wider health and social care systems. In this chapter, I describe the ways care home staff come to know these risks by exploring the different forms of 'risk knowledge' (Gale et al., 2016, see section 3.1.4 for more details) that staff draw upon. Within this chapter I also explore the ways that staff navigate tensions within and between forms of risk knowledge.

I begin this chapter by presenting the case of Bilal. Bilal was transferred to hospital during the time I was carrying out ethnographic fieldwork. Although I was not on site at the time of Bilal's transfer, I had witnessed some of the events that occurred in the preceding days. I was also able to access relevant sections of Bilal's care notes and to discuss the transfer with several members of staff who had been involved.

Case Study B: Introducing Bilal

Bilal, a gentleman in his late 70s living with advanced dementia and multiple health conditions, had been living at Sycamore Gardens for approximately 18 months. The day before Bilal's health began to deteriorate he received a scheduled visit from a district nurse to change the dressing on a hospital-acquired pressure sore on his sacrum. Bilal appeared his 'usual' self and staff did not report any concerns in his care notes. However, the following day, at 2:30am, whilst turning Bilal to maintain the integrity of his skin, a member of staff documented that Bilal had been hallucinating. The entry read: "He said he can see things in his room [and] people are walking around his bedroom." The staff member documented their actions which included spending time reassuring Bilal, getting him a glass of water and informing the senior carer who was in charge of the shift. Later that morning, at 11am, a senior carer working

on the day shift made reference to blisters on Bilal's skin "again", suggesting this was not the first time this had occurred.

No further entries expressed concern that day, however, at 2:00am the following morning another entry from a carer reported that Bilal had experienced another hallucination. Two hours later, at 4:00am, an entry made by a senior carer read "Called 111 for advice as [he] was very confused, shouting out and saying people were in his room. Very unsettled had not slept since the start of shift. After telephone assessment with a doctor it was advised that he be seen by a doctor". By 4:50am an entry reported that an Out-of-Hours GP "checked him over and said that his temperature, heart rate and blood pressure were normal, his hallucinations may be due to his dementia deteriorating and advised he has blood test from GP".

Bilal's hallucinations continued. An entry recorded just after lunchtime stated that Bilal was "seeing five different people in dining room". Later that day I observed two members of staff supporting Bilal to eat his evening meal. Both members of staff said that they felt he was "not quite right", which was reported in an entry by one of the staff members. The entry also stated that Bilal had spent much of the afternoon with his eyes closed, and that when his son had visited, Bilal uncharacteristically appeared not to recognise him. A third entry that evening also made reference to possible hallucinations.

The following day, four days after staff first recorded Bilal was hallucinating, an entry at 2:20pm reported: "Ambulance called due to [Bilal] being very agitated, uncomfortable and looks in pain. He's not eaten or drank for 24 hours and is hallucinating. [His] sons are here waiting for the ambulance." One hour later, a short entry reported that Bilal had been transferred to the hospital and a further entry, at 8:15pm, recorded Bilal's return to the care home. This entry stated: "He has a lower respiratory infection (chest infection) he's been given a five day course of antibiotics to take orally".

The remainder of the notes for the day indicated Bilal slept well and staff did not report any concerns. An increased tiredness was reported on the day

after Bilal's hospital transfer. In addition, in the early evening, a senior carer recorded that Bilal had "vomited at tea time. Not sure if it's his antibiotics or not. All procedures were taken and he was taken straight up to his room as a precaution. I think he should stay in his room tomorrow and monitor how he is due to his infection". Bilal was cared for in his bedroom that evening and on the following day. Entries after this point did not suggest anything unusual or alarming and, on speaking with staff, they reported Bilal had not appeared to experience further hallucinations.

7.1. Knowing residents: Identifying and interpreting change

Throughout data collection, one of the most prevalent themes discussed by staff was the importance of 'knowing' each resident. At first, knowing was described as an intuitive process and when asked how they might come to know that a resident's health was deteriorating, staff often responded with phrases such as "*you just know!*" (Carer 2, Sycamore Gardens). However, as staff elaborated, references were made to knowing individual residents' routines, behaviours and the ways in which they 'usually' presented on a day-to-day basis. Staff provided examples of a broad range of changes that might signal a resident's health was deteriorating. These included changes in mobility, appetite, fluid intake, consciousness, responsiveness, continence, behaviour, mood and physical appearance. Therefore for care home staff, knowing was grounded in their experiential knowledge of what was usual for each resident. Staff perceived this type of knowing to be a legitimate form of knowledge that they could use to identify subtle changes that could suggest a resident's health was deteriorating.

"It is very much that you would know that individual... particularly for us, because we work with people with very advanced dementia. They can't always tell you how they are feeling but because you know them so well, and the staff know them so well, you notice any changes."

(Manager, Sycamore Gardens)

[Interviewer: "How do you know when residents are unwell?"]

"Because they act differently. Perhaps their communication might not

*be as good, they might be showing some signs of distress. Erm, just, **we know them**. We know how they are, how they are acting.*

Residents who are normally very mobile might not be very mobile.

Residents who aren't very mobile might start to be mobile and you're like, that's not right for them. So it's just because we know them."

(Manager 1, Cherry Tree House)

Staff working in all roles discussed the importance of knowing each resident but it was described in particular as an essential part of being a 'carer'. Several members of staff referred to themselves as the "eyes and ears" of the home, responsible for reporting changes to staff in senior roles in order to "pick up anything that is a possible threat" to residents' health (Carer 1, Sycamore Gardens).

"We work with the residents every day. We know their routines, we know their characters and we know when there is something up with them. So we play our part with that. The nurses know a lot about the medical history and stuff like that but we work with the families and find out about their past."

(Carer, Starling Manor)

"As a carer you are there every day. You are on the floor. You see it, you hear it, you know what's what. You are getting this person up every single day and know something is not quite right."

(Carer 2, Sycamore Gardens)

As discussed in the previous chapter, care home staff believed that some situations always required a hospital transfer, almost regardless of the individual circumstances, for example when a resident exhibited potentially life-threatening symptoms or when staff felt that a resident required tests or treatments that were not available in the care home. In other situations, that did not meet the threshold for an immediate transfer, staff drew upon their experiential knowledge to make resident-specific judgements about whether or not a situation warranted a hospital transfer and to determine the likely benefits and/or burdens (i.e. risks) associated with initiating or avoiding a transfer. In particular, staff were more likely to interpret a situation as more serious (and

therefore more likely to potentially require a hospital transfer) when faced with something that was particularly unusual for the resident.

“We have one resident here who always eats breakfast, always eats lunch, again at tea-time and at supper. Say he went off his food, we would know there was something off.”

(Carer, Starling Manor)

“A lady here, we know when her mood changes, if she stays in bed and doesn’t want to get up there is a high risk that she has got an infection somewhere.”

(Carer 1, Sycamore Gardens)

Ethnographic observations supported the notion that care staff perceive unusual occurrences to be a cause for concern. During handover meetings that occurred at each shift change, the person leading the meeting often discussed each resident in reference to what was usual for them. For example, a phrase commonly used to signal that a resident had been their usual self was “no changes and no concerns”. Another example of a phrase that was often used was “[John] has been [John]”. Frequently when this was the case, the person leading the handover did not spend further time discussing the individual resident and instead utilised the time to discuss more unusual occurrences.

Staff recognised that what was considered usual varied across residents. For example, the extract below is reproduced field notes from ethnographic work at Sycamore Gardens.

*During a handover meeting staff reported that a gentleman had “kicked off” and smashed a table. A piece of table had hit him in the face, causing a small skin tear to the front of his nose. I asked “was anybody called when he ‘kicked off’ and injured himself?”, to which the staff replied “no because it is usual for him, this gentleman **does** get unsettled and we know how to manage it, even though it’s not nice”. The staff member talked about this incident in contrast to the case of Alice (described at the beginning of Chapter 6), suggesting*

that it was “really unusual for her to be aggressive”. The unusual nature of Alice’s actions had prompted concern.

However, staff also made reference to noticing patterns of change across residents. Staff referred to specific types of changes that they had seen across a number of residents that could be indicative of a potential deterioration. For example, staff suggested that if a resident were to ‘go off their food’ and ‘really go downhill’ they might consider the person to be reaching the end-of-life. In addition, staff made reference to ‘dark, foul-smelling’ urine to be indicative of a UTI. Although staff could learn these patterns of change through formal training, they suggested that their prior experiences informed their understanding of what was generally considered (un)usual for residents. This could include experiences of working in similar roles across health and social care organisations, or experiences of working with other care home residents.

“I think we are all quite experienced enough to know whether somebody needs a GP and can wait three or four hours, or whether we feel that somebody warrants a 999.”

(Deputy Manager, Sycamore Gardens)

“Experience will help them... Nurses and care workers... time can give them more examples of different situations. I have worked for hospitals, in different countries as well and in different situations. And actually through that I built myself as a real nurse.”

(Nurse 1, Goldfinch Lodge)

Staff suggested that what was considered normal for a specific resident could change over time, either due to normal fluctuations in a resident’s abilities or due to underlying disease progression. Therefore, when deciding whether or not to transfer a resident to hospital, often staff were trying to differentiate between changes that occurred due to normal fluctuations, changes that could be expected due to progressing illness trajectories and changes that signalled an acute deterioration.

“We have had times when families come and say [stern voice] ‘I want her to go into hospital’... She had gone downhill a lot in like, how she

was. But she, she had bone cancer. She had gone downhill but she was just normal for that kind of [illness] so I didn't think she really needed to go [to hospital]."

(Carer 2, Cherry Tree House)

"You know we have got one lady who has lived here for 12 years and she has been able to wash herself and get herself dressed and now all of a sudden she can't do that. Now obviously we are looking into it. Is she not doing that because something is happening? Or is it going to be a permanent thing?"

(Manager 1, Cherry Tree House)

In the same way that staff drew upon experiential knowledge to identify changes that could represent a potential deterioration in residents' health, staff also used their experiential knowledge to assess the *severity* of a specific situation and to determine the most appropriate course of action. As such, the experiential knowledge that staff developed and used could be conceptualised as a type of risk knowledge (Gale et al., 2016) through which staff identify and assess potential risks. In response to a vignette in which a resident with Parkinson's disease was described as sweating and having difficulty breathing, one participant stated:

*"OK, so I guess, the difficulty in breathing and sweating – it could be something **normal** for her, she could be asthmatic or she gets sweaty whilst moving."*

(Manger, Starling Manor)

Similarly, in response to the same vignette, another participant made reference to considering what was normal for the resident in order to determine the severity of a situation and to decide how to respond appropriately.

"I would call for assistance from the senior and take her obs (structured nursing observations). We've got obs machines and a chart in the office that lets us know what's abnormal. I would call 111 and just talk it through with, like, that professional over the other side... it doesn't say here she has asthma or anything. Sometimes

*they just need an inhaler or something. But if she was **really** bad then I would call 999 straight away. If she was visibly struggling, hmm. There is a difference when they are like [big gasp] you know? It's knowing, is it serious or not – and you can normally pick up if it's a bit off... It depends on - she might be out of breath and sweating because she's walked! She's got Parkinson's so she's going to find it a bit difficult. So it's knowing that individual, if this was out of sorts for her then you would be like 'something's not right, she is struggling to breathe, forget the doctor, ring 999' but if it was just, ahh, I don't know, it's one of them in the moment you decide!"*

(Carer 1, Sycamore Gardens)

In the extract above, the carer makes reference to her experiential knowledge of what is usual for the resident. This is evident in several phrases including “out of sorts”, “a bit off” and “knowing that individual”. Therefore, in the extract above, experiential knowledge is one of several sources of risk knowledge (Gale et al., 2016) that the carer is using to determine the severity of a given situation. However, the carer also appears to struggle to find the words to describe the process of using experiential knowledge during decision-making. Therefore although care home staff position experiential knowledge as a legitimate form of knowledge, which they can use to inform their decision-making regarding resident transfers, they simultaneously find it difficult to articulate their justification for decision-making based on this type of knowledge.

In addition to experiential knowledge, the participant in the above extract describes several other sources of information she could use to determine the severity of the situation at hand, which in turn would influence her decision-making about the most appropriate course of action. For example, she discusses: escalating to a more senior colleague (in the case a senior carer); the use of structured clinical observations (described as “the obs”, which will be discussed in more detail in section 7.2.2); and calling the 111 service for further support. Later sections of this chapter will explore the ways in which staff combine or ‘bricolage’ (Horlick-Jones et al., 2007) different forms of risk knowledge to assess risk

Due to the centrality of knowing each resident, when deciding whether or not a hospital transfer would be beneficial for a resident, certain situations were highlighted as particularly problematic by care home staff. Participants suggested that it could be difficult for new members of staff to identify and interpret changes in residents' health if they had not had sufficient time to come to know what is usual for them and new members of staff reported needing to ask colleagues who knew the residents well for help. In addition, staff also suggested that they found it more difficult to identify and interpret changes when new residents moved into the home.

“For a new member of staff like myself you would ask another member of staff – ‘is this normal behaviour?’ I would have to know the resident myself, I would have to be here for a good couple of months to know their routines.”

(Carer 2, Sycamore Gardens)

“You’ve got to know that person. If [a new resident] came in, we’ve got a new guy here at the moment... you err on the side of caution... we make them an appointment at the GPs... and it will be the GP’s decision where we go with it, not ours. And that is very important because we can’t be seen to shrug it off... we don’t know him well enough to do that if he’s only been here a week.”

(Manager, Sycamore Gardens)

The above extract suggests that care home staff take a more cautious approach when interpreting changes in situations in which they have limited experiential knowledge, which may increase the likelihood that an individual staff member may choose to escalate a situation, either internally within the layers of staffing hierarchy or to external healthcare services. In response to a vignette in which a new resident exhibited a poor appetite, reduced fluid intake and appeared to be drowsy and confused, one participant responded:

“It depends how well they know her. She had only been [living at the care home] for three weeks. If she had been there three years and staff felt that they knew her... They might speak with the family because she has only been there three weeks we don’t really know

her.”

(Deputy Manager, Cedar Court)

7.2. Beyond experiential knowing

7.2.1. Advance care plans

When faced with a potential deterioration in a resident's health, whilst deciding whether or not to escalate a situation and who to escalate a situation to, almost all members of staff made reference to advance care plans (see section 2.3 for a discussion of advance care plans in care homes). As a result, advance care plans can be conceptualised as a form of risk knowledge (Gale et al., 2016) through which care home staff come to know and assess the likely risks of transferring or not transferring a resident to hospital. Where advance care plans existed, it appeared that staff were using them in addition to their experiential knowledge.

Staff believed the process of creating an advance care plan was valuable as it provided an opportunity for staff and family carers to discuss potential deteriorations in residents' health prior to a crisis occurring. The ways in which family carers influenced staff decision-making about potential hospital transfers, and the role that advance care plans can play in reducing disagreement between staff and family carers, will be discussed in the next chapter. Staff also described the importance of the advance care plan document as an agreed upon plan to guide 'in-the-moment' decision-making. Therefore, the risk knowledge provided by advance care planning extended beyond the written care plan to encompass staff understandings of family wishes, preferences and potential reactions to the possibility of future hospital transfers.

Care staff provided examples of occasions in which the presence of an advance care plan enabled staff to keep deteriorating residents within the care home. They also provided examples of occasions where the lack of an advance care plan made decision-making more difficult.

“We lost somebody over the last few days actually... over the last month he stopped walking, his whole demeanour changed. We contacted the GP and the GP met with the family and put the

paperwork in place... His family didn't want him to go to hospital and he was treated here"

(Manager, Sycamore Gardens)

"We had a gentleman who was clearly dying... the ambulance crew were umm-ing and ahh-ing about whether to take him because his [oxygen] saturations were dropping and we were saying 'if we transfer him he will probably die'... there were phone calls between the ambulance and the GP and the GP turned up at the last minute and did all the paperwork"

(Deputy Manager, Cedar Court)

In the second extract of the set above, the participant describes a situation in which there was conflict about the 'right' thing to do. Staff felt a hospital transfer was not appropriate for the resident, due to them being at the very end of their life. However, the ambulance staff appeared to be uncomfortable leaving the resident within the care home until "the paperwork" (i.e. an advance care plan) was in place. The presence or absence of an advance care plan appeared to weigh heavily on the ambulance staff, their perceptions of the likely risks associated with decision-making and the most appropriate course of action. The potential for advance care plans to reassure decision-makers that they are doing the 'right thing' for the resident and, importantly, to provide decision-makers a means through which they can justify their actions, will be explored in the next chapter. Both of the extracts above make reference to several other people who may become involved in transfer decisions including family members, a GP and paramedics. Further discussion of the influence of other people on transfer decisions will also be discussed in the next chapter.

Although staff consistently advocated for the use of advance care plans, it is important to note that staff suggested that it was not enough to simply have a care plan in place. Instead, in order for advance care plans to be perceived as legitimate, particularly in the context of transfer decisions, staff suggested that written documents should be detailed, unambiguous, reviewed regularly and understood by families.

“[Advance care plans] are crucial. As long as it’s been made and it’s signed, sealed, dotted and delivered and reviewed – and that’s the important thing because people’s situations can change.”

(Manager, Sycamore Gardens)

“As long as it’s all been done correctly - the GP has been involved and everyone understands the risks.”

(Carer 2, Sycamore Gardens)

Staff described situations in which residents were transferred to hospital despite the presence of an advance care plan recommending against admission. If the care plan document was perceived to be inadequate or ambiguous, a hospital transfer would tend to follow.

“Most recently we had a gentleman who was breathless, and he was unresponsive and the care plan wasn’t clear. It didn’t tell us if he was for hospital admission or not... In the end I called the ambulance... it’s just tricky sometimes to understand what they wish.”

(Nurse 3, Goldfinch Lodge)

“the [transfer] I can think of was where there was actually a little break in communication with that emergency care plan and it didn’t actually state ‘not for hospital admission’... it was a technicality where the doctor hadn’t quite written it for the paramedics to be happy... It should literally, the paramedics tell me, say NOT FOR HOSPITAL ADMISSION... And if they are written really well, generally speaking that is the key.... Some will be a one to 20 guide of exactly what to do and others are a little bit wishy washy, which is what happened with the lady before.”

(Deputy Manager, Sycamore Gardens)

In both of the extracts above, the advance care plans in place were perceived to be unclear and ambiguous. In this situation, care home staff, and sometimes other healthcare professionals too, did not feel comfortable following the plan, which increased the likelihood that a resident might be transferred to the hospital.

7.2.2. Structured clinical observations

In addition to experiential knowledge and written advance care plans, approximately one third of all participants made reference to the use of structured clinical observations. Structured clinical observations were predominantly, but not exclusively, discussed by registered nurses and management staff that had a background in nursing, demonstrating how individual 'risk logics' can be bound up with an individual's professional identity and prior training. This form of knowledge, often described as "doing the obs", usually involved measuring residents' respiration rate, oxygen saturation levels, systolic blood pressure, pulse rate, level of consciousness and temperature. For example, returning to the case of Bilal introduced at the beginning of this chapter, on arriving at the care home the Out-of-Hours GP measured Bilal's temperature, heart rate and blood pressure.

A focus on clinical symptoms was also evident in a discussion between two registered nurses that worked night shifts at Starling Manor. When asked if they could recall an occasion in which a resident had been transferred to hospital during their shift they responded:

Nurse 1: "I send people to hospital only in case of emergency."

[Interviewer: "What kind of things might be an emergency here?"]

Nurse 1: "Like coffee ground vomiting."

Nurse 2: "Yes, if they fall and bang their head and have an injury. We take that decision to call for help or to monitor in the care home."

Nurse 1: "They might have a cough or become restless and you find that their temperature is high."

Nurse 2: "If their saturation of oxygen is low, less than 90 for example."

Some situations were perceived to be significant enough to trigger a structured set of clinical observations. Therefore, although it is possible to detect changes in a resident's health whilst undertaking routine clinical observations, and indeed several care homes routinely undertook structured clinical observations to monitor residents' health, more often staff discussed the ways in which they

would use clinical information to confirm or further investigate a concern that had arisen due to a change in what was usual for each resident.

Staff also used structured clinical observations to assess the *severity* of a situation, which in turn fed into their decision-making about whether or not a transfer would be beneficial for a deteriorating resident. When asked how staff might respond to a resident who was breathless and sweating another participant stated:

“I would ask Mrs West to sit down and then we are checking al her vital signs, and blood sugars and everything...if her vital signs are fine I would not ring 999. It depends on her levels - if oxygen levels are really low then I will but if they are above 90 then I won’t do it.”
(Nurse, Cedar Court)

Similarly, when provided with the same vignette, another participant replied:

“Straight away I would do blood pressure, pulse, oxygen saturations and just check to see whether it was anxiety or whether it was, erm, past medical history... If all her vital signs are OK and then she started to settle I would probably just call the GP. But if her blood pressure was in her boots and her vital signs were alerting that something was wrong, like the oxygen, then straight away I would call 999.”
(Deputy Manager, Cedar Court)

Furthermore, the process of “doing the obs” provided care home staff with risk knowledge that could be articulated more easily to external colleagues than their experiential knowledge. Completing structured clinical observations provided staff with objective, codified knowledge which could be used in combination with experiential knowledge. Interestingly, it appeared that this type of information was most likely to be requested by external healthcare professionals, in the event that staff made external escalations to these services.

[Interviewer: “What happens once the ambulance staff arrive?”]
“They want to see all information, the [medication] sheet, the past

history of the patient and to know what are the [diagnoses] of the patient. They want to know all of this, when was the last seen by the GP and things like that... And when we send someone to hospital we send a full history, medication sheet, even DNR we send it.”

(Nurse 2, Goldfinch Lodge)

7.3. Socially mediated risk knowledge

When making decisions about potential hospital transfers, the process of weighing up the potential benefits and risks of a transfer was socially mediated in a number of ways. This could occur at an interpersonal level (either through informal conversation or via formally organised interactions) or at a broader organisational level.

7.3.1. Informal interpersonal processes

Staff perceptions of what represented a change for each resident - and, by extension, to what extent the changes were a cause for concern and what an appropriate course of action might be – were often negotiated through interaction with others. This could include family carers, other members of care home staff, healthcare professionals from external healthcare services and to a lesser extent individual residents. The extent to which different stakeholders influence the decision-making of care home staff will be covered in more detail in the next chapter. Acknowledging that she had only recently started working at Sycamore Gardens, one participant stated:

“For a new member of staff like myself you would ask another member of staff – ‘is this normal behaviour?’”

(Carer 2, Sycamore Gardens)

Reflecting on a transfer that had occurred recently, one participant stated:

“His wife said he wasn’t well. He was twitching but I was thinking ‘this is normal’ but she said ‘this isn’t normal, he is twitching quite a lot’. So I thought ‘OK maybe she knows him more than I do’.”

(Carer, Starling Manor)

Staff perceptions of the likely risks and benefits associated with transferring a resident to hospital (for the resident, for themselves as a decision-maker, to wider social relationships and to wider health and social care systems) could also be influenced by the ways in which hospital transfers were socially constructed in different care homes. In turn, these shared constructions could influence staff decision-making.

At Wren Grange, the decision *not* to transfer a resident was often discussed in terms of doing everything possible to provide what staff perceived to be high quality care within the care home. In the previous chapter (see section 6.2), the manager at Wren Grange made reference to being able to provide residents with “special attention” that would not be possible in a hospital environment. In keeping with this suggestion, all three members of staff who worked at Wren Grange who took part in an interview made reference to only transferring to residents to hospital for conditions that were “reversible”, suggesting that they would prefer to keep a resident in the home wherever possible if a resident’s health condition was not thought to be reversible. In the extract below, the manager at Wren Grange describes the death of a resident that was managed in the care home.

“If a resident dies we ask the carers ‘what do you think? how was the death? was it good? was it bad? could we do more?’ and we are very honest. For example, a person who died here two weeks ago... I felt very good. I will tell you why. The evening before she died I went in, just to see how she was. I said to her daughter ‘I think [she] will die tonight, I can see it’ you know, ‘be prepared’. Then I checked her and she was very calm. I looked at her and she was looking beautiful... the next morning they said ‘she died’ and I felt good because I really saw her until the end and I said goodbye.”

(Manager, Wren Grange)

For the manager at Wren Grange, that the resident was ‘calm’ and comfortable before her death was perceived to be evidence of ‘good’ care. In contrast, although staff at Starling Manor discussed a preference for caring for residents

in the home where possible, hospital transfers were often discussed in relation to concerns about being accused of 'not doing enough' for the resident.

"Sometimes I am unsure. If something happens, you ask, 'what happens if I keep them in place and keep them clean and comfortable, but what if it is not enough?' Because most of the time [external healthcare professionals] can do other things, other checks and they can make a decision."

(Nurse 1, Starling Manor)

Interestingly, there were key organisational differences between Wren Grange and Starling Manor which may have influenced the staff's wider perceptions of hospital transfers. Whilst both homes provided nursing services, staff at Starling Manor cared for people with advanced dementia, whereas staff at Wren Grange did not. Therefore it is possible that staff at Starling Manor were involved in decision-making about situations that were more uncertain, as the majority of residents were not able to report their symptoms accurately. In addition, at the time of data collection Wren Grange was rated as 'Outstanding' by the CQC, whereas Starling Manor was rated as 'Requires Improvement'. It is difficult to make associations between a homes' CQC rating and the specific perceptions and practices of staff. However, it might be reasonable to suggest that working in a home that had been rated as Outstanding may have increased staff confidence in their approach to providing care, which in turn could have mitigated against concerns about being accused of 'doing nothing'.

7.3.2. Formal interpersonal processes

The ways in which individual members of staff come to know and understand the likely risk associated with their decision-making also appeared to be socially mediated through interactions that were structured and formally organised. For example, two of the six care homes held regular sessions in which staff reflected on recent events, such as hospital transfers or deaths, as a team. Whilst discussing hospital transfers that had occurred staff were encouraged to reflect on whether or not the hospital transfer had been necessary and to consider the potential benefits and burdens for the resident. Staff reported that these sessions provided a valuable opportunity to consider whether a different

course of action may have been 'better' and to anticipate how they may respond to similar situations in the future. Therefore, scheduled reflection sessions provided a means through which individual understanding of risk could be shaped, through formally organised interaction with colleagues.

"We reflect on everything that has happened in the past month... who needs more attention, what needs do the residents have now... It's helped us improve our practice."

(Nurse, Wren Grange)

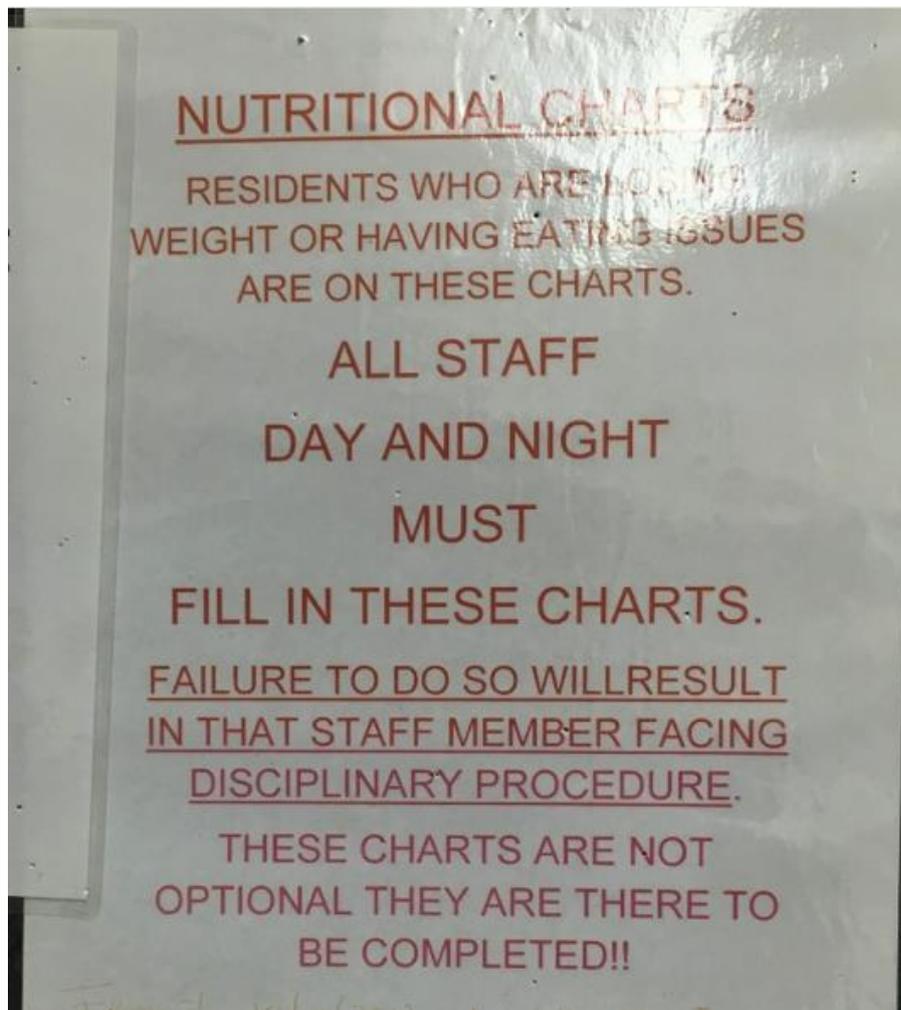
"It helps because it is peer-learning. We ask - What could we do? Why did it happen? Can we prevent it? Can we take a different approach? So there is a lot of communication... it boosts nurses' confidence."

(Deputy Manager, Goldfinch Lodge)

7.3.3. Organisational level processes

Although all staff across all care homes discussed the potential risks associated with initiating or avoiding a hospital transfer, risk were prioritised differently across care homes. At Goldfinch Lodge, there was an emphasis on avoiding instances in which staff could be seen as potentially responsible for deteriorations in residents' health, for example through not identifying deteriorations in a timely manner, for inaccurately assessing residents' symptoms or for failing to respond appropriately. Signage in staff areas, an example of which is reproduced below in Figure 9, reiterated the importance of undertaking different tasks.

Figure 9: A photograph of a notice displayed in a staff area at Goldfinch Lodge



In other homes, whilst staff were aware of professional risks, these types of risks were discussed less frequently, were less 'visible' in the home environment and featured less heavily in the day-to-day work of staff. Therefore, whilst all care homes had procedures in place to assess, manage and mitigate against risk, the specific ways of 'doing risk' varied significantly across care homes. To some extent, the prioritisation of particular tasks could be imposed upon staff by the organisation (care home) in which they worked. The extract below, reproduced from field notes from Goldfinch Lodge, demonstrates the ways in which one staff member at Goldfinch Lodge appeared to prioritise particular risks over others.

During a night shift, a carer showed me a form that was used to record hourly resident checks. He said that it could be difficult to complete the paperwork accurately when other residents needed

help at the same time that checks were due to be completed. I asked "What happens then - do you fill it out or do you leave it?" He replied that he would still complete the paperwork, stating "if anything happens, this is what they will look at and use". He said that if it was not completed he would "get in trouble". I asked if it was acceptable to be honest and explain why a check was not carried out on time, to which he replied "no".

It appeared that, for the carer in the extract above, the risk(s) associated with having to document that a resident had not been checked on time were prioritised over the risk(s) associated with inputting inaccurate information into the form. The carer related this back to the priority of the care home, as an organisation, placed on making sure all paperwork was completed on time, stating that he would "get in trouble" if a resident had not been checked (even if this had happened because he had been busy helping another resident). Therefore the ways in which he prioritised risk was, at least to some extent, imposed by the organisation in which he worked.

The prioritisation of particular risks, and the ways in which organisations influenced the process of prioritisation, could be seen within potential transfer situations. For example, staff who took part in formal interviews at Goldfinch Lodge described the need to be 'covered' more frequently than staff at other homes and during ethnographic data collection, the ways in which risks were prioritised could also be felt by myself as a researcher. At Goldfinch Lodge, much of the day-to-day work that staff undertook was tied into staff perceptions of professional risk. In this home, care appeared to be more regimented, focussed on the completion of specific tasks and forms of documentation. At times, it felt as if a focus on avoiding particular risks (in this case, to individual staff as decision-makers and to care homes as organisations) could overshadow other aspects of care. The extract below is reproduced from field notes at Goldfinch Lodge.

I have seen very little sitting and chatting at this home. Whilst the residents look as if their health is well managed - and indeed the home has records of everything they do - there is less dialogue

*between residents and staff here in comparison to the other two homes I have been to. And there is **so** much documentation. I wonder if sometimes the documentation might become more important than the actual care work.*

The above extract makes reference to documentation. As discussed in the previous chapter (section 6.3.1), when asked how they could prevent hospital transfers, staff made reference to carefully monitoring residents, which was often evidenced in various forms of documentation. In addition, when responding to a potential transfer situation, staff placed importance on documenting their actions, even when attempting to manage a deteriorating resident within the care home. For example, when presented with a vignette in which a resident had a high temperature, a participant at Goldfinch Lodge said that she would attempt to manage the situation by undertaking a number of practical actions (including putting on a fan, opening a window and removing layers of clothing) and that she would “*document all those things for handover with the day staff*” (Senior Carer 2, Goldfinch Lodge).

During transfer decisions, staff also documented *who* had been involved in decision-making, which could include members of the staff team, family carers and external healthcare professionals.

“I always say to the staff, if you’ve got any doubt at all, phone a GP and get some advice. Use the services we have got and document it. And then you’re covered.”

(Manager, Sycamore Gardens)

“You can speak to other seniors, other staff members, and management if you need to... Obviously document it. As long as I’ve documented it I’m covered. I have told younger staff as well, if you have involved a senior put who you have informed, put the initials or whatever. You know, just to cover your own back basically and to support the service user the best way you’re supposed to.”

(Carer 2, Sycamore Gardens)

Documentation was often discussed in reference to ensuring staff were 'covered' by providing a means of demonstrating the actions staff had taken to detect and respond to potential deteriorations in residents' health. As a result, the process of documenting the work staff undertake could be conceptualised as a 'risk intervention' – a strategy thought which staff seek to minimise and mitigate against risk (Gale et al., 2016).

Although each care home had structures and processes to document the work and decision-making processes that staff undertook, these structures and processes varied significantly across homes. In Cherry Tree House, staff made hand written notes in each resident's individual diary at specific times of the day. At Sycamore Gardens, staff used hand-held electronic devices which connected to an online recording system, so that staff could document their work in real time. At Goldfinch Lodge, staff recorded their work on an online system at the end of each shift.

At both Goldfinch Lodge and Sycamore Gardens, the online systems were able to flag particular tasks or documentation that had not been completed – for example if a resident's blood pressure had not been taken or a care plan had not been updated. For example, at Sycamore Gardens, tasks that had not been completed appeared in red. When this happened a warning would appear on the screen, prompting staff to prioritise this task. This provides a further example of the influence of organisational processes on the ways that individual staff members understand risk and carry out day-to-day risk practices.

7.4. Navigating tensions within and between sources of risk knowledge

7.4.1. Working with fallible risk knowledge

Staff suggested that residents often displayed vague or atypical signs and symptoms of ill-health and, due to high levels of cognitive impairment, were not always able to report their symptoms reliably and accurately. As a result, although staff understood objective criteria for different illnesses, at times it was difficult to apply this knowledge to individual residents with whom they worked. Because of the uncertainties surrounding the applicability of population level information to individual residents, staff were more likely to rely on experiential knowledge of what was usual for each resident. However, there were occasions

when staff found it difficult to assess the likely risks of (not) transferring a resident to hospital, even when they had developed detailed experiential knowledge of what was normal for each resident. In the extract below, a participant describes a situation where she found the process of assessing risk especially difficult. Although she knew the resident well and possessed objective risk knowledge about the symptoms of a stroke, she was unable to use this information to assess the resident in front of her because she was unsure if the resident's inability to follow her instruction was indicative of a stroke or due to dementia.

“One time a lady was hunched over ... I couldn't tell if she was [having a stroke]. She had dementia, and I was asking her “smile for me” and she wouldn't, she wouldn't lift her hands over her head... [I rang 111] because I couldn't do all the other things to check if she was having a stroke or not.”

(Carer 2, Cherry Tree House)

There were also occasions in which staff were using forms of risk knowledge that they perceived to be inadequate. This was evident in the ways staff discussed the use of urinalysis strips (referred to as 'dipsticks') as an indicator that a resident may have a urinary tract infection. Staff across several care homes made reference to the inadequacy of dipsticks, due to the likelihood of a false positive result. The following extract is reproduced from field notes created during a visit to Sycamore Gardens.

Whilst in the office I noticed a form designed for staff to record occasions where they suspected a resident had a urinary tract infection and to document their decision-making process regarding the appropriateness of antibiotics. The form, titled 'UTI Care Home Assessment Form' appeared to be designed by a local NHS organisation. I asked a member of staff about the form and she said “it's probably not used as much as it should be” and that it was introduced alongside training in which “they told us not to dip the urine and instead to focus on symptoms, because 99% of the time something will show up [on the dipstick]”.

Despite acknowledging the limitations of urinalysis strips, there was often a tube of dipsticks in the staff office on the main staff desk. The following extract is reproduced from my final visit to Sycamore Gardens.

Last time I visited the home staff had obtained a urine sample from a resident who had been particularly confused. I asked what had happened to that sample. The carer had taken it to a senior carer so that the senior carer could 'test it' using a dipstick before requesting antibiotics from the GP. In response, the GP requested another urine sample so that they could test it themselves before prescribing antibiotics. I thought this was strange given that the staff had received training and openly acknowledged the limitations of using dipsticks. The UTI Care Home Assessment Tool was not completed for this referral.

The practice of using dipsticks despite being aware of their limitations was not limited to staff at Sycamore Gardens. In all three of the care homes where ethnographic observations took place I witnessed staff advocate for the use of dipsticks despite also discussing the limitations of using them as a tool to diagnose possible urinary tract infections. Furthermore, despite a national emphasis on the limitations of using dipsticks (NICE, 2018, NICE, 2019a), staff across all six care homes that took part in formal interviews discussed using dipsticks when they suspected a resident had an infection.

In most cases where a dipstick was used, staff had previously noticed a change in what was considered usual for a resident. For example, in the extract above, the carer had noticed the resident was more confused than usual. Therefore, the staff were using the results from the dipstick in combination with their own experiential knowledge of what was usual for each resident, rather than as a stand-alone diagnostic tool, as a way of confirming a suspected urinary tract infection. This practice provides further support for the notion that staff combine or 'bricolage' (Horlick-Jones, 2005) different forms of risk knowledge in order to assess risk.

The extracts above refer to a clinical proforma that had been introduced by a local NHS organisation and was intended to assist staff with determining

whether a resident had a urinary tract infection (reproduced below in Figure 10). However, it appeared that staff were not consistently making use of this form. When I asked staff about the form, specifically why the form was not being used, staff gave two different suggestions. Firstly, staff noted that the form asked about the onset of new symptoms, yet staff felt many of the symptoms listed “didn’t apply” when assessing many of the residents with whom they worked. For example, three of the symptoms listed on the form (need to pass urine urgently, need to urinate more often than usual and new onset urinary incontinence) were either difficult to identify or not valid for residents who were already known to be incontinent. Furthermore, three symptoms (pain whilst urinating, pain in the lower tummy / above pubic area and lower back pain) relied, to some extent, on residents being able to communicate their pain.

Figure 10: The UTI Care Home Assessment Tool introduced at Sycamore Gardens

Leicestershire Medicines Strategy Group

UTI CARE HOME ASSESSMENT TOOL
Older patients (>65) with suspected UTI (urinary tract infection)- Guidance for care home staff

- Complete 1) to 4) and patient details and send to GP by NHS email/fax if no email (Add copy to patient care plan). Template also available on SystmOne for Care homes
- **Contact GP to ensure tool received and agree response time**
- **DO NOT PERFORM URINE DIPSTICK** – No longer recommended in pts >65 years. CLEAR URINE - UTI highly unlikely

1) Has the resident recently developed any of the following (please use “Y” to indicate YES for all that apply)?

Cough	Shortness of breath	Sputum	Falls
Abdominal pain	Diarrhoea	Vomiting	Nausea
Medication changed (Specify below)	Red Skin (specify area)	Warm skin (specify area)	Swollen skin (Specify area)

2) Please complete the information below as much as possible:

New onset sign/symptom	Type “Y” if present
Pain on urinating	
Need to pass urine urgently	
Need to urinate more often than usual	
Pain in lower tummy/above pubic area	
Blood in urine	
New onset urinary incontinence	
Lower back pain	

3) Does the patient have a catheter?

Sign/Symptom	Delete as necessary
Please record current Temperature:	
Is there visible blood in the urine?	Yes / No
Is this New onset or sudden worsening confusion or agitation (please circle as appropriate)	Yes / No
Is the resident eating and drinking as usual?	Yes / No

YES / NO
If YES: Reason for catheter
Temporary / Permanent
Date changed:

4) Has the patient had any recent antibiotic course? YES / NO **If yes, what antibiotic, when was this prescribed and for what duration?**

GP Management Decision - circle all which apply: Prescribing guidance available on LMSG and diagnosis tool on system1/EMIS

- Provide safety netting advice and care home staff to monitor resident for 72 hours and contact GP if any further deterioration
- Uncomplicated lower UTI likely (use UTI diagnosis template in >65 years on the system). **Take MSU before administering empirical antibiotics prescribed**
- Pyelonephritis
- Other

GP TO TASK DECISION BACK TO THE CARE HOME
 Antibiotic prescribed: Signed: Date:

Adapted by LLR CCG Antimicrobial Pharmacist Working Group for LLR Prescribing Guidance Template from Nottingham CCG Care Home Tool and SIGN guidelines V6.1 Review due September 2023

In addition, staff suggested that they often forgot or chose not to complete the form because they were “already doing a lot of the work in our heads or on the [online care notes system]” (Carer, Sycamore Gardens). Staff suggested they were already undertaking the same process, albeit in a different format and therefore could not see value in completing an additional form.

The UTI Care Home Assessment Form was introduced by an external, NHS organisation. A previous section of this chapter (see section 7.3) explored the ways that care homes, as organisations, can influence the ways individual members of staff understand and assess the likely benefits and risks associated with transferring a resident to hospital. It could be suggested that the introduction of the UTI Care Home Assessment Form was designed by an external healthcare organisation to influence individual staff members understanding of risk. Although the form was designed to impose a particular way of assessing risk upon staff, by requiring staff to make notes about new symptoms, the form was not able to achieve this in practice. Staff did not perceive the form to be a valuable source of risk knowledge because they believed it did not align with the work they were already doing or the context in which they were working.

7.4.2. Weighing up contradictory forms of risk knowledge

In some situations, different sources of risk knowledge contradicted one another and led to conflicting ideas about the most appropriate way to respond to a given situation. The most frequently discussed example of this, which was discussed across all care homes, was related to resident falls. Throughout data collection a number of staff described the difficulty of deciding whether or not to transfer a resident to hospital following a fall in which there was no obvious injury. Several care homes had a policy in place that advocated for sending residents to hospital following *all* falls and staff understood the importance of ruling out a possible break or fracture as a result of a fall. However, staff were also aware that transferring the resident to hospital for an x-ray was likely to result in them spending several hours in hospital, often unaccompanied. Therefore, when their experiential knowledge suggested that the resident was unlikely to be injured (and therefore to be less likely to benefit from an x-ray), staff were reluctant to transfer a resident to hospital.

Staff positioned experiential knowledge as a legitimate form of knowledge through which they could come to 'know' what was normal for residents and, by extension, what was unusual and therefore representative of a potential threat to the residents' health and wellbeing. However, it appeared that staff also felt a

sense of unease at relying on this form of knowledge when presented with contradictory forms of risk knowledge. In some instances, like in the extract below, staff suggested they would transfer the resident to hospital, even if this did not align with their experiential knowledge, as the decision to work outside of the guidance provided in written policies was perceived to be too 'risky', both for the resident and for the decision-maker. This is evident in the extract below in which a carer decided to align their actions with the home's written policy, despite her experiential knowledge suggesting that a transfer may not be necessary.

"Sometimes I know they're gonna be fine but... there is always a part of me that thinks 'what if they are not?' and then I think 'well I have to [call for help] because it says in the policy'."

[Interviewer: "Is that the risk?"]

"Yeah, that I thought they were fine and later it turns out to be something... But what I don't like thinking of - I know how busy hospitals can be and are they gonna be in a corridor all night? I think - sometimes if they go into hospital they come back more sick than when they went in... So I am thinking, do I really want to send them in?"

(Carer 2, Cherry Tree House)

However, in other instances, like in the extract below, when faced with such dissonance, staff might choose to draw on their own subjective, experiential knowledge to assess risk and inform their decision-making.

"If someone falls we will call 999."

[Interviewer: "Do you call 999 every time someone falls?"]

"It all depends because we was told by a GP if somebody has had a fall to do that - to call 999 - but not really no. We check them over. If they are in pain, if it is the hip or anything like that then we do."

(Senior Carer 2, Sycamore Gardens)

This 'bending of the rules' was common across participant responses to interview questions and vignettes and during ethnographic observations. Whilst this behaviour allowed staff to draw on other sources of risk knowledge, doing

so introduced new risks. If, based on their experiential knowledge, staff decided not to transfer a resident to hospital who later appeared to have an injury, then new risks could occur. For example, the resident may experience pain and not receive treatment in a timely manner which may impair the healing process. In addition, 'bending the rules' could introduce new risks to the staff member as a decision-maker. For example staff may face professional risks (i.e. being reprimanded), emotional risks (i.e. "feeling awful") and social risks (i.e. through damaged relationships with colleagues, the resident, their families and external healthcare professionals).

7.5. Summary

Care home staff placed great importance on 'knowing' each resident. Although staff initially described their knowing as intuitive, further exploration of how staff came to know residents suggests that within the context of care homes in England, 'knowing' is: predominantly experiential (grounded in carers' experience); longitudinal (acquired gradually over time); socially mediated (influenced by the individuals staff interact with and the organisations in which they work) and dynamically evolving (staff adjust their perception of what is 'normal', and by extension what is unusual and representative of a threat to each resident's health, over time). Staff perceived this type of knowing to be a legitimate form of knowledge that they could use to detect changes that could signal a deterioration in residents' health.

Staff believed they could use their experiential knowledge to make resident-specific assessments about what a change might mean for an individual resident and to weigh up the likely benefits and burdens associated with initiating or avoiding a hospital transfer. However, staff faced a number of difficulties when assessing risk. Some of these difficulties were related to working with risk knowledge that they knew to be fallible – for example, when trying to apply population level risk knowledge to an individual resident or situation. In addition, staff faced difficulties in navigating tensions between different sources of risk knowledge, which at times led to conflicting ideas about how best to respond to a deterioration in a resident's health.

Despite positioning experiential knowledge as a legitimate way through which they could assess risk, staff often described feeling vulnerable when doing so. This sense of vulnerability seemed to be related to difficulties in articulating and justifying their decisions and actions from experiential knowledge due to its subjectivity, especially in the presence of other contradictory forms of risk knowledge. A lack of experiential knowledge could be problematic, particularly when new residents or new staff entered the home.

In addition to experiential knowledge, staff also drew upon other forms of risk knowledge when weighing up the likely benefits and risks associated with a hospital transfer. Advance care planning was perceived to provide staff with an opportunity to understand the wishes of residents and their family carers in the event of a potential deterioration in health. In addition, staff suggested the written advance care plan document could guide 'in-the-moment' decision-making. Therefore, the risk knowledge provided by advance care planning encompassed both the written care plan and knowledge of family wishes, preferences and potential reactions to possible hospital transfers. In addition, staff drew upon structured clinical observations (completed as part of their routine practice but also as a means of further investigating concerns that were triggered by experiential knowledge). These observations provided staff with a different form of risk knowledge that was objective and codified. Where additional forms of risk knowledge were used, staff appeared to be combining, or 'bricolaging' them with their experiential knowledge (Horlick-Jones et al., 2007).

Individual understandings of risk were socially mediated in a number of ways. This could happen at an interpersonal level, for example through one-to-one interaction with others or through group discussion. Individual conceptualisations of risk could also be socially mediated at an organisational level, for example through written policies, normative working practices and shared conceptualisations about the likely benefit and burdens of a hospital transfer at each home. Whilst all care homes had procedures in place to assess, manage and mitigate against risk, the specific ways of 'doing risk' varied significantly across care homes.

CHAPTER EIGHT: Roles and responsibilities: Risk, power and influence in transfer decisions

In Chapter 6 I argued that, in the context of care homes in England, transfer decisions can be conceptualised as a series of escalations in which staff make multifaceted decisions about perceived burdens and risks – to the resident, to themselves (as a decision-maker) and their wider social relationships, to the care home as an organisation and to wider health and social care systems. Building on this premise, in Chapter 7, I explored the ways care home staff come to know and understand these risks by investigating the different forms of risk knowledge that staff draw upon and by exploring the difficulties that staff face when there are tensions within and between these knowledge sources.

The focus of this thesis is the decision-making of care home staff when faced with residents who potentially require a transfer to hospital. However, staff decision-making can be influenced by and occurs within the context of multiple social relationships with other stakeholders. This can include the resident, family carers, colleagues within the care home and external healthcare professionals. For example, this chapter begins with the case of Cora. As was the case with both Alice (Chapter 6) and Bilal (Chapter 7), the process of deciding whether or not to transfer Cora to hospital required input from others – in this case, a GP. Therefore, this chapter will explore the power, influence and perceived responsibilities of different stakeholders in staff decision-making.

Case Study C: Introducing Cora

Whilst working on a Sunday morning, a carer at Goldfinch Lodge noticed that Cora, a woman in her 80s living with advanced dementia and nursing needs, had a rash-like mark on the inside of her upper arm. The carer documented the mark in Cora's care notes and contacted the GP to request a visit. The GP who visited suggested that the mark on Cora's arm could be due to a possible skin infection. However, whilst Cora was unable to report her symptoms accurately, she appeared to be in pain when the GP examined her. As a result, the GP prescribed antibiotics (for the possible skin infection) but also scheduled a hospital appointment for an x-ray two days later to rule out possible injury.

After the GP left the care home the nurse reported the outcome to the manager. The manager was not satisfied and raised further concerns that the mark on Cora's arm may have been due to a potential fracture. The manager referred to the care home's policy which stated that all residents should be transferred to hospital immediately in the event of a suspected fracture. As a result, an ambulance was called, and Cora was taken to hospital. She returned five hours later after an x-ray confirmed there was no fracture.

The following day I spoke with the nurse and asked her about her decision-making. In particular, I asked why she chose to call the GP rather than an ambulance in the first instance. She said that she was particularly uncertain about what had caused the mark on Cora's arm and she was unsure if it was an injury or a skin infection. Therefore, in an attempt to avoid "over-reacting" she decided to call the GP for further assessment. She also stated that she had considered Cora's advanced dementia and described the physical environment of the local hospital x-ray department as "a long corridor where people are expected to wait" and said that she felt this would be a "stressful experience" for Cora, adding that if Cora were to spend a long period of time in hospital she believed it was likely she would "get a pressure sore because no-one will be asking her to move".

I asked the nurse whether or not she agreed with the GP's chosen course of action - to prescribe antibiotics and to schedule an appointment for later in the week. The nurse stated that she did not agree, yet she felt that once the GP became involved, the decision to transfer Cora (or not) was "passed to them" and therefore "taken out of [her] hands". When asked if she could 'override' a GP's decision, she said she could not. When I asked why she said, 'because I need to be covered'. She discussed 'being covered' in relation to her decision to call a GP. The nurse suggested that in calling a GP she felt she had fulfilled her responsibility to seek appropriate help (in this case she had chosen to call a GP due to being uncertain about the nature of the mark on Cora's arm). As a result, she felt she was 'covered' and able to justify her actions to others. She also suggested that, since she had requested support and the GP had made their recommendation, she would find it difficult to justify acting in a way that contradicted the GP's recommendation.

Although the nurse felt she was personally and professionally covered (due to escalating the situation to a GP and following their advice), the manager was concerned that the decision to wait two days for an x-ray could have potentially negative consequences for her as an individual and for the care home, particularly if the x-ray identified an injury such as a fracture. If this happened the manager was concerned that she would struggle to provide justification (to family members and/or to professional regulatory bodies) for waiting two days for an x-ray. The manager made reference to Cora displaying signs of pain that was suggestive of a fracture and suggested that the only way to ensure that both she (as an individual) and the care home (as an organisation) were legally and professionally 'covered' was to transfer the resident immediately for further investigation.

8.1. Experiential knowledge as a source of power in decision-making.

In the preceding chapter, I described the importance care home staff placed on 'knowing' each resident. For care home staff, 'knowing' was predominantly (but not exclusively) rooted in their experience of what was usual for each resident. Staff were more likely to interpret a situation as more serious (and therefore as more likely to require a hospital transfer) when faced with something that was particularly unusual for the resident.

Staff suggested that other healthcare professionals (who perhaps may not 'know' the resident well) could make greater use of the experiential knowledge that care home staff held when making decisions about whether or not to transfer a resident to hospital. Staff believed that the experiential knowledge they held, of what was usual for each resident, provided them with a means through which they could influence the decision-making process to advocate effectively for residents. For example, the extract below, reproduced from ethnographic field notes, describes a 'GP round' at Sycamore Gardens - a weekly visit in which a regular GP visited the care home to see up to six residents. During this GP round, a senior carer sought to persuade the GP that a resident required further treatment.

The GP was visiting Helen - a woman in her 80s who was able to communicate well but who had an impaired short-term memory due

to a form of dementia. The GP had been asked to look at Helen's eye. As the GP and the senior carer walked towards Helen, the GP asked, "Has she been seen before?". The senior carer provided details of previous GP visits and the medication Helen had been prescribed to date. She noted that Helen had had problems with her eyes for a long time, but she had been "asking for her eye drops more than usual". As they approached Helen, the senior carer said, "Hi Helen, this is the doctor and she is here to see you about your eye". The GP asked, "Have you ever been to the eye clinic?" to which Helen responded, "No, I don't think so." The GP glanced at the staff member who quietly said "no" to confirm this was correct. After looking at Helen's eye, the GP decided she would prescribe eye drops and refer her to an eye clinic at the hospital.

The ability for staff to use their experiential knowledge in order to influence others was perceived to be particularly important on occasions in which there was disagreement about the appropriateness of a hospital transfer. In the two extracts below, participants discuss the ways in which they might navigate such a potential disagreement.

*"[Ambulance staff] know more about stuff than I do so I trust their decision. But I feel like, if I did [disagree], I would say. I would **really** try and make sure they went [to hospital]."*

[Interviewer: "How would you go about that?"]

*"I'd just say that, you know, I **know** them a lot more than they know them. That their behaviour is not like it normally is. And I would say why I thought that and try to back it up with whatever I could find."*

(Carer 2, Cherry Tree House)

[Interviewer: Do you ever disagree with the decisions that GPs or paramedics make?]

*Manager 1: "Sometimes when we **really** think they should go in."*

[Interviewer: "Ok, what kind of situations are they?"]

Manager 1: "Hmm, I am going back some time..."

Manager 2: "It's been a while hasn't it? But we know them well and"

*we **know** when they are not right. So they have been took in.”*

[Interviewer: “Is it possible for you to almost overrule a paramedic or GP or is their say kind of final?”]

Manager 1: “With a paramedic you can talk them round, you can talk them round.”

Manager 2: “I know before, going back, we have felt that they should [go to hospital] and I remember the [paramedic] saying ‘well they are not very happy with us at the hospital’. But I know my residents and I know that something is not right, and they did take them in.”

(Manager 1 and 2, Cherry Tree House)

Taken together, the quotes above and earlier extract provide examples of times where staff were able to draw on their knowledge of what was (un)usual for residents to influence the decision-making of healthcare professionals.

However, there were also instances in which staff felt unable or unwilling to do so. For example, some staff suggested that they felt unable to challenge or “overrule” healthcare professionals and/or family carers during decision-making about potential hospital transfers. The extent to which healthcare professionals and family carers were perceived to be able to lead or influence decision-making about potential resident transfers will be discussed in more detail in later sections of this chapter.

8.2. Decision-making amongst colleagues: Trust and layers of assurance

As described previously, in section 6.5, when faced with a resident who was potentially experiencing a deterioration in their health, staff described their responsibilities as a process of deciding whether they could manage the situation or whether they should escalate to someone else. Initially, these escalations tended to occur internally within the care home (i.e. amongst the staff team), prior to external healthcare services. As a result, staff decision-making about potential hospital transfers was influenced by relationships between staff members. For example, participants talked about being able to consult their colleagues and to draw on the knowledge of others within the home.

“We have a good rapport and working relations. They will ask the management and say, ‘can I check this with you, I’m not happy about this’ like when the resident’s condition changes drastically.”

(Deputy Manager, Goldfinch Lodge)

“In [difficult] conditions you could ask the nurses for their opinion, if you are not really sure of what decision to make.”

(Senior Carer, Cedar Court)

The extracts above suggest that being able to consult colleagues, particularly those in senior positions, was valued by care home staff as a way of managing uncertainties. In turn, consulting colleagues could assist staff in decision-making about the most appropriate way to respond to a change or deterioration in residents’ health. Therefore, for care home staff, being able to escalate in-house amongst the staff team and to involve others in decision-making could be conceptualised as a ‘risk intervention’ (Gale et al., 2016) - a strategy through which staff sought to manage and minimise risk and uncertainty. In some care homes transfer decisions were described as a shared responsibility, enacted by several members of the care team. Conversely, staff in other care homes described decision-making as an individual responsibility.

“I’ve said to them ‘never make a decision on your own’. We all live around here. And then we talk. Someone must always be on call.”

(Manager, Wren Grange)

“I would let the nurse decide. We’ve got qualified nurses. They can do observations. I am not a nurse so I would rely on the nurse to make that decision.”

(Manager, Starling Manor)

The two quotes above demonstrate a marked contrast in how transfer decisions were approached in two different care homes. The individual participants’ responses may have been related to each manager’s own professional skill set. Although both care homes provided nursing services, the manager at Wren Grange was a registered nurse, whereas the manager at Starling Manor was not. However, for care home staff, the extent to which decision-making was

conceptualised as an individual or shared responsibility had important implications, as it tended to reflect the extent to which they (as a decision-maker) were likely to accept the personal, professional and social risks associated with decision-making.

Although consulting others within the staff team was a common way for care home staff to minimise risk, particularly risks to themselves as an individual, this strategy required those in senior positions to take on some of the responsibilities and professional risks associated with decision-making. In the extract below, a manager, describes this process as providing “reassurance” for staff.

“They want the reassurance. If we have an accident here, you hear the emergency bell. They don’t switch it off until they have a member of management or a nurse... Even though their colleagues are there, you would think they would switch that off because they know what to do. They want some reassurance... an element of ‘well it’s your responsibility at such a high level’. It takes you back to nights and weekends, I don’t work nights and I am on call at weekends, but I am not around.”

(Manager, Goldfinch Lodge)

Later, the same participant suggested that the presence of management staff in the home during the week provided “an extra layer of insulation” for staff, shielding them from some of the personal, professional and social risks associated with decision-making. Although all homes had an emergency ‘on call’ system in place during the evenings and weekends that would enable staff to contact a member of the management team, management staff were rarely present on site during these time periods. Several members of staff described decision-making about potential hospital transfers during these periods as especially difficult due to less support being available on site.

“In the evening there is only one nurse... It makes a difference because you haven’t got anyone.... In the morning there is two or three nurses and the manager. In the evening, when management

has gone you are on your own, so all the pressure is on you.”

(Nurse, Starling Manor)

“During the day you can ask the manager if you need some help but during the night-time, sometimes I am on my own as the only nurse.”

(Nurse 2, Goldfinch Lodge)

The extract suggests that at nights and weekends, the strategy of escalating to someone in the home became less effective because fewer senior members of staff are on site. As a result, staff felt increased ‘pressure’ to manage multiple and at times conflicting risks, increasing the likelihood that a resident would be transferred to hospital. Therefore, the above extract provides further support for framing the process of escalating a situation to colleagues as a strategy care home staff employ to minimise risk and uncertainty. However, in order for this ‘risk intervention’ to provide an effective way for care home staff to minimise risk, staff needed to trust that their colleagues could accurately identify and interpret changes in residents’ health. This participant in the extract below suggests that this trust develops over time.

“Sometimes it is difficult if I don’t know personally what is happening...I will ask the other nurses... I trust their judgement. And I think that is important - to have that trust amongst your nurses.”

[Interviewer: Is the importance of trust the same for care staff as well? And what about newer staff?]

“I would say, the longer they are here, the more you have trust in them. It’s the same thing for me and the GP. If a new nurse does the GP round, he is not, erm, what do you call it, he’s not so lenient to the new nurse because he doesn’t know if the new nurse is able to... it’s the same with me and the carers. The new ones I find it very difficult because I don’t know if what they are telling me - if they observe it the correct way.”

[Interviewer: Like if they interpret a situation the same way as you?]

“Yes! You see like [staff member who had worked at the home for a long time] if she says something then I will say ‘alright’, or sometimes I will ask her because she is working on the floor. So, she knows the

residents better than me so I will ask her. I will say 'do you think there is really a deterioration in Mrs X' and she might say 'hmm no sometimes she has episodes like that' and I will believe her."
(Nurse, Wren Grange)

In the extract below, another participant reflects on a situation in which two members of staff disagreed about a potential transfer.

"We had a bank nurse who joined us who was not that confident. There was another nurse on shift that said 'look this is the situation' but the bank nurse felt pressure... The bank nurse said, 'it's my PIN [professional registration], I will be the one that was looking after her' and the other colleague backed off."
(Deputy Manager, Goldfinch Lodge)

In the extract above, one member of staff (the 'bank nurse' who worked in the home sporadically), felt susceptible to the personal and professional risks associated with decision-making. As a result, it appears that the bank nurse wished to take a more risk averse approach to managing the situation by initiating a transfer to "be on the safe side". Therefore, it could be suggested that individual members of staff may choose to implement more risk averse practices when working in a staff team that has not had the opportunity to develop trust amongst colleagues.

8.3. Residents' best interests and the power of family carers

The most obvious social relationship surrounding transfer decisions is the relationship between the care home staff and residents. As described in section 6.7.1, staff spoke fondly of residents, emphasising their personhood and social ties to others. Staff almost always made reference to making decisions that were in the best interest of residents (i.e. that would improve or retain their health and/or quality of life), yet residents were less frequently described as being involved in the decision-making process. This was largely due to a high proportion of residents lacking or having fluctuating levels of capacity to make these decisions. More frequently, staff described the involvement of family carers in decision-making. Staff suggested that the level of involvement differed across families, dependant on the extent to which family carers wanted to be

involved. Whilst some families wished to be actively involved and consulted about transfer decisions, others wished only to be kept informed.

“Some of [the families] would like to go with [the resident to the hospital] but some just want to be informed of what’s going on.”

(Carer, Cedar Court)

“I know our main job is to look after, protect and help the resident but it is a package these days, it’s not just an individual.”

(Manager, Goldfinch Lodge)

The reference to residents’ families being part of a “package” (quote above) highlights the key role that families play during transfer decisions. The involvement of family carers was particularly pronounced when decision-making concerned a resident who was considered not to have the mental capacity to contribute to the decision-making process. Throughout data collection there appeared to be uncertainty amongst staff about their ability to act in ways that conflicted with family wishes, especially if the family carer was registered as the resident’s Lasting Power of Attorney (LPOA) for health and well-being¹². Whereas some staff members described having to “consult” “consider” or “involve” family carers who were registered as LPOA, other members of staff described a stronger sense of being unable to disagree with a person holding LPOA, with the exception of instances where they felt they had a legal duty to do so.

“The daughter had LPOA... So, when they have LPOA for health and wellbeing we have to consult with them with regards to making any decisions... you have to consider their wishes because they are making the decision for the best interest of their loved ones.”

(Nurse, Wren Grange)

“If the resident is compos mentis then we have [the discussion] with them but we would always invite the family. If they do not have mental capacity and the family have LPOA for health and welfare we

²_____

¹² Lasting Power of Attorney – a Lasting Power of Attorney is a legal document that enables an individual to appoint one or more people (known as “attorneys”) to help make decisions on their behalf, if the individual loses the ability to do so.

discuss it with them.”

(Manager, Wren Grange)

“If a family member has got LPOA for welfare then yes, they can make the decision for the resident. Because the residents here have advanced dementia and they can’t make that decision so it would be a team decision – it would be us, family, GP, nurse to make that decision. If they are LPOA then it would be their relative full stop, nobody else needs to be involved.”

[Interviewer: What happens if you disagree with the relative and they are LPOA?]

“Erm, I don’t think that we can disagree. It is a legal document... If it was a safeguarding issue, then we could get involved that way. For instance, a resident needed a new pair of glasses because his vision had changed but a family member had got a LPOA and had refused the glasses. I raised it with a social worker to say, “look the resident is entitled to glasses”. So, if it is that sort of situation, we can challenge it.”

(Manager, Starling Manor)

In the second extract of the set above, the participant suggests that even when a resident is “compos mentis” (i.e. has capacity to make decisions about whether or not they would want to be transferred to hospital), staff would still involve family carers. This was predominantly the case across all data collection. For residents who had capacity, whilst staff placed importance on making decisions that aligned with their wishes (particularly if these were documented in an advance care plan), staff also made reference to the involvement of family carers.

“If the person has got capacity then you really need to go with whatever they say. It depends on the family as well... you’ve got to really respect the service user’s wishes if they’ve got capacity.”

(Senior Carer 3, Sycamore Gardens)

“I think some of it falls down to capacity. Do they have capacity in that specific moment to make that decision? I think if it was

something serious then you would have to get the family involved as well. Erm, get the family to have a chat with them and also join in with the decision-making.”

(Carer 1, Cherry Tree House)

Although family carers without LPOA technically did not hold any legal power over decision-making, involving family carers in decision-making was often described as a ‘courtesy’ and a way in which staff built and maintained good relationships with family carers. In addition, even when families did not hold LPOA, staff were concerned that acting contrary to family carers’ wishes could result in legal and/or disciplinary procedures which could have severe and long-term consequences for them as an individual. This was highlighted as a source of power for families in decision-making.

“It is a very sobering thought that you and your career, especially as a nurse, you can be suspended and scrutinised, you can face legal ramifications, families can sue. So, you have to bear that in mind and have the experience and the wisdom to say - if I were going to be reprimanded, would I be able to justify?”

(Manager, Goldfinch Lodge)

Because families were seen to have a powerful influence on decision-making, staff anticipated the likely responses of family members. This anticipation fed into their understanding of the likely risks associated with initiating or avoiding a hospital transfer. Therefore, ensuring family carers were involved in decision-making about potential transfers could be conceptualised as a ‘risk intervention’ (Gale et al., 2016) - a strategy through which staff could reduce the likelihood a relative might disagree with their actions and later make a complaint, which in turn minimised risks to them as an individual.

Staff reported that relationships with family members were predominantly positive and acknowledged the importance of talking to family carers as part of getting to ‘know’ each resident and in understanding their preferences. Families could shape staff perceptions of what was ‘normal’ and ‘unusual’ for each resident as well as provide information on any known wishes or preferences of the resident.

“The wives and the husbands obviously know them better, what they want, and they don’t want.”

(Manager, Starling Manor)

“Sometimes they give you that clear guidance to say, ‘while my mum was in her senses, she wouldn’t have liked that’.”

(Deputy Manager, Goldfinch Lodge)

However, staff acknowledged that for many family carers, supporting their relative in a care home was associated with a mixture of complex emotions. In particular, staff suggested that family carers could be upset and struggle to accept that a resident was nearing the end-of-life, particularly if there was a rapid or unexpected deterioration in a resident’s health. This natural emotional response could lead to unrealistic expectations of the potential benefits of hospital care.

“For a lot of relatives, if you say they are on end-of-life medication – which is the terminology used in health – it sends shockwaves into them... We’ve had people who are reluctant to talk about [end-of-life] ... a lot of it is a fear.”

(Manager, Sycamore Gardens)

“Families have unrealistic expectations [of hospital care], you know? Their expectations are not realistic...they don’t want their loved one to die.”

(Manager, Wren Grange)

Although staff reported that most interactions about the appropriateness of hospital care were characterised by agreement, situations in which staff and family carers disagreed were a significant source of difficulty. Staff described experiences of residents being transferred to hospital due to pressure from family carers, even when staff felt a transfer was not appropriate.

“There are occasions where relatives are demanding for their loved ones to go in to hospital even when it is not needed. And it is quite difficult to manage. We all know that we need to avoid unnecessary hospitalisations... but it happens. What can I say? I need to be

honest.”

(Manager, Cedar Court)

“Some of the [families] will say that [residents] should go to the hospital, even at the end-of-life... I think it is the feeling of guilt or whatever, wanting to clear their conscience.”

(Deputy Manager, Goldfinch Lodge)

In Chapter 6 I suggested that when deciding how best to respond to a potential deterioration in residents' health, staff made decisions based on their perception of clinical need and their perception of potential negative consequences (i.e. risks) associated with their decision-making (see section 6.7.2). This could include potential risks for the staff member as a decision-maker, for example the risk that they may feel as if they made the 'wrong' decision, or that they had not 'done enough' for the resident'. The second extract in the set above refers to family carers being motivated by a need to "clear their conscience". Therefore, it could be suggested that family carers were also motivated by an intrinsic desire to do the 'right thing' for their relative and to avoid feeling as if they had not done enough.

Transfer decisions could be particularly difficult if care home staff and family carers held different views about the 'right' thing to do. The extract below describes a disagreement between care home staff and a resident's daughter:

“We have got one daughter here who thinks she has a duty to her Dad. He has got end-stages Parkinson's. He is having trouble swallowing, having lots of chest infections, so it's not going to be long and she has had a massive argument with the doctor. Both the doctor and ourselves are saying he is end-of-life... but she doesn't think she is doing her daughterly duty unless he is treated in hospital and he will die in hospital. She needs to be seen to be doing something for her dad. She told the doctor 'if you don't do anything, I will ring treble nine' – so what can you do? He is already on thickened fluids from a teaspoon, he's already on pureed food, his weight is stable, so we are doing a good job! He hasn't got any pressure sores, he's up in the lounge most days. But this is the

daughter's decision, and he will die in hospital. There is nothing we can do. Although we don't think it is the right place [for him] to be."
(Manager, Starling Manor)

The participant above makes reference to several things she believed were indicative of good quality care in the care home – providing appropriate foods and fluids, ensuring the resident spent time in communal areas of the home, and avoiding pressure ulcers. As such the participant believed the 'right' thing to do would be to care for the resident in the care home, yet the daughter felt that a hospital transfer would be in her father's best interests and was therefore reluctant to allow the GP to create an advance care plan that would advise against a hospital transfer.

Although, as in the extract above, family carers were viewed as holding a position of power in transfer decisions, there were limits to this influence. Staff suggested that family carers might successfully push for a hospital transfer, even when staff and healthcare professionals thought this was not necessary or appropriate. However, staff suggested that families could not prevent a hospital transfer in instances where staff and healthcare professionals felt that it was required. During interviews with care home staff, a vignette was introduced in which a resident with advanced dementia experienced a fall (see Appendix B). Staff were informed that although the resident did not hit his head, his arm was warm and swollen – symptoms that are indicative of a possible fracture. A probe included in the vignette suggested that that on calling the resident's family, the family stated that they would prefer for the resident did not attend the hospital. On reading the probe, several participants suggested that they would "overrule" the family and seek further support from either a GP or ambulance staff.

"If the family are saying that they don't want him admitted to hospital, I would overrule that if I think there is a fracture there and I would call the paramedics anyway and get them to check him over and potentially take him in."
(Senior Carer 3, Sycamore Gardens)

Nurse 1: “Well I have to explain to them that if I do not send them to hospital that will be neglect because obviously a fracture in the care home, which I know it is possible, then it is proper neglect.”

Nurse 2: “We would definitely have to let the patient go because if he can’t explain the pain and if you are mobilising it could worsen the situation so it is best to let the patient go for help.”

(Nurse 1 and Nurse 2, Starling Manor)

Therefore, although staff generally sought to act in ways that aligned with family wishes, there were times where seeking appropriate care for the resident, being ‘covered’ and able to justify their actions were prioritised over the desire to maintain relationships with family carers.

8.4. Healthcare professionals: Reactions, relationships and responsibilities

8.4.1. External escalations as risk minimisation

When care home staff felt unable to assess or manage the likely risks associated with transferring a resident (or not), they often chose to escalate the situation to external healthcare professionals. This strategy was apparent in the case study of Cora, described at the beginning of this chapter. When the nurse faced difficulty in determining whether the mark on Cora’s arm was due to a rash or indicative of a fracture, she decided to call a GP for further support. Like the nurse in the aforementioned example, there were many instances in which staff reported they would escalate to another service, for example to a GP or an emergency service, in the face of uncertainty. This could include uncertainty about the nature of a resident’s illness or uncertainty about the likely benefits and burdens of either initiating or avoiding a transfer.

Furthermore, whilst staff described their role in transfer decisions as a process of deciding *whether* or not to escalate a situation and deciding *who* to escalate a situation to, staff described the decision to *transfer* a resident (or not) as ultimately the responsibility of an external healthcare professional such as a GP or member of ambulance staff. Staff suggested that external healthcare professionals might have skills and knowledge that would enable them to better assess and manage a situation. For example during an interview, one participant stated “*I am not a doctor*” and later, when discussing paramedics,

said “*they know more about stuff than I do so I would trust their decision*” (Carer 2, Cherry Tree House). The knowledge of external healthcare professionals was highly regarded and described as “*professional advice*” (Deputy Manager, Cedar Court) and “*high-level knowledge*” (Nurse, Starling Manor).

However, when discussing the role of external healthcare professionals, as being responsible for deciding whether or not to transfer a resident to hospital, staff also described this process as a means through which they could shift responsibility away from themselves (as an individual) and from the care home (as an organisation) and on to external healthcare professionals.

“It is the GP’s judgement call, or the Out-of-Hours’, as to whether they should be coming to see that person and whether they should advise us to send for the emergency services. It takes away quite a lot of responsibility, especially from the senior carers.”

[Interviewer: Is that intentional – moving responsibility to the GP?]

*“Erm, it is intentional because of a lesson learnt earlier this year because we had to justify to a family that a person **can** and did walk on an injury without discomfort... I think it is spreading the load as such, erm, it’s not a way out, it’s not a cop out. I think what it’s doing is just giving people an opportunity to discuss it with a medical practitioner. Yeah.”*

(Manager, Goldfinch Lodge)

“With people with advanced dementia you just never know. If you’ve got people with an injury you can have safeguarding involved and all sorts... I think really, even if they don’t take them to hospital for an x-ray, we are covered, and the paramedics have been out to say there is no injury. It is not a nice feeling these days, to have that hanging over your head about whether you should have rang an ambulance or not. And I think the nurses are, they are worried about PIN numbers [i.e. their professional registration], and their responsibility and allegations and all that.”

(Manager, Starling Manor)

The extracts describe the process of contacting external services as providing staff with a means to “justify” their actions (for example to family carers) and to avoid “allegations”. Therefore, although staff believed external healthcare professionals had skills and knowledge that would enable them to provide additional support to residents, the process of escalating to an external healthcare professional (and allowing them to decide whether or not a transfer was required) provided a way for staff to minimise risks to themselves as a decision-maker. Contacting external healthcare services was repeatedly described as “erring on the side of caution” or acting to “be on the safe side”.

“[If a new resident appears to be unwell] you err on the side of caution.... And the safest bet – call it covering your back... we make them an appointment at the GPs... and it will be the GPs decision where we go with it, not ours. And that is very important – because we can’t be seen to shrug it off.”

(Manager, Sycamore Gardens)

“I would say to give the ambulance a call. You know, to be on the safe side, you call the ambulance.”

[Interviewer: The safe side for yourself?]

“Yeah. The safe side for myself but also the resident. Because family, if something happens later, they can turn round and say, ‘my mum had a fall, you said it was fine but the day after she wasn’t OK’.”

(Nurse 3, Goldfinch Lodge)

The language used in these extracts provides further support for the notion that external escalations could be conceptualised as a ‘risk intervention’ (Gale et al., 2016) - a process that staff use to minimise risks. Furthermore, although the second extract in the set above makes reference to reducing risks to the resident, the content of the response is more strongly related to reducing risks to themselves as an individual, ensuring they have a suitable way to defend and justify their actions in the event of a complaint. Therefore, although staff may have a moral and professional responsibility to seek appropriate help for residents, which could reduce risks to the resident, the practice of escalating to

an external healthcare professional also provides a means through which they could minimise risks to themselves as an individual.

In the case of Cora, at the beginning of this chapter, staff escalated the situation externally by seeking the advice of a GP. The GP decided to prescribe antibiotics for Cora (believing the mark on her arm could be due to possible cellulitis) and to schedule a hospital appointment for an x-ray two days later to rule out possible injury. The nurse suggested that she did not agree with the GP's decision, but that once the GP became involved, the decision to transfer Cora was "passed to the GP" and therefore "taken out of [her] hands". When questioned about this further, the nurse made links between the positioning of healthcare professionals (as being the person responsible for deciding whether or not to transfer a resident to hospital) and the need to ensure she was 'covered'. In calling a GP she felt she had fulfilled her responsibility to seek appropriate help and was therefore 'covered' and able to justify her actions to others. However, she also suggested that acting in a way that contradicted the GP's recommendation would be particularly difficult to justify. Throughout data collection, there were occasions where similar comments were made, for example one participant stated:

"I always say to the staff, if you've got any doubt at all, phone a GP and get some advice. Use the services we have got and document it. And then you're covered."

(Manager, Sycamore Gardens)

"The GP is a higher level from me, his duty is different to mine in some ways and I think that it's his decision. I ask the GP because he is the doctor, and I am the nurse, and I am responsible to the doctor... I give my concerns, I document everything, I call the GP, inform the next of kin, then if they take another decision that is their responsibility."

(Nurse 1, Goldfinch Lodge)

Whilst the participant in the first extract refers to being "covered" due to fulfilling their responsibility to seek support, the participant in the second extract seems to take this further, suggesting that as long as she raises and documents her

concerns she will be “covered”, even if the GP’s final decision is at odds with what the nurse perceived to be the best approach to managing the resident. These comments could suggest that some care home staff are happy for decision-making to be led by external healthcare professionals, regardless of whether they agree with the healthcare professional’s assessment and subsequent decisions. However, during data collection there were also instances where care home staff were willing and able to challenge the decisions of healthcare professionals. This was evident in some of the extracts presented in section 8.1, in which staff suggested they could use their experiential knowledge, of what was usual for each resident, to advocate on residents’ behalf.

There were also instances in which, as a result of not agreeing with a healthcare professional’s assessment or decision, care home staff sought out further support, usually from a different service or different healthcare professional. This usually occurred when a healthcare professional had assessed a resident and concluded that no further action was needed. For example, in the case of Bilal (see Chapter 8), staff called the Out-of-Hours service because Bilal appeared to be hallucinating. On visiting Bilal, the GP suggested that his hallucinations may be due to a progression in his dementia. However, staff reported feeling that the Out-of-Hours GP had not “got to the bottom of it” or provided an adequate explanation. Therefore, when Bilal’s hallucinations continued, staff decided to call an ambulance for further assessment. It appears staff felt more able to challenge a healthcare professional’s opinion, or to seek a second opinion, when they felt a greater degree of action was required. Whilst staff felt able to push for a hospital transfer, they felt less able to push for the resident to remain in the home when a healthcare professional had deemed this necessary.

“If the nurses think that it could be dealt with outside the hospital, they will ring the Out-of-Hours... and sometimes we have found, occasionally, that it is not necessary for the resident to go in but [Out-of-Hours] say to call 999.”

[Interviewer: So when they suggest you call 999 and you don’t feel it is appropriate, is there anything you can do in that situation?]

“In that situation it becomes difficult because the nurses have their PIN number [professional registration], and it is their accountability... it could put a bit of a pressure on the nurse. Because she has asked for advice because it was not within her scope and the [doctor] has advised, so the [Nurse] is saying ‘this is what [Out-of-Hours] have said, I should do that even I don’t think it is necessary’.”

(Deputy Manager, Goldfinch Lodge)

In the extract above, the participant provides an explanation for why staff found it especially difficult to push for a resident to remain in the home when they felt a hospital transfer was not necessary but where a healthcare professional thought it was required. Acting against the advice of a healthcare professional, particularly when they had contacted a healthcare professional because they had required additional support, would be especially hard to justify.

Framing escalations to external healthcare professionals as a ‘risk intervention’ (Gale et al., 2016) through which staff seek to reduce the share of risk that they (and their care home as an organisation) hold could provide further insight into a belief widely held by care home staff, that decision-making can feel particularly ‘risky’ during periods of time that these people are not available to be consulted, namely evenings and weekends. In addition to a lack of management staff available internally (i.e. within the care homes) during these time periods (see section 8.2), it is during nights and weekends that care home staff are also unlikely to be able to contact their regular GP, a source of external support which they perceive to be particularly valuable. Instead, during these periods of time, care homes reported having to contact an Out-of-Hours GP or, if the Out-of-Hours GP was not available or unwilling to visit the home (and to take on some of the risk associated with decision-making), to contact ambulance staff.

Staff found this problematic on two accounts. Firstly, staff across all care homes reported experiences of these services ‘refusing to come out’ and secondly, staff recognised that healthcare professionals from these services were much less likely to have an existing relationship with the resident and therefore lacked the experiential knowledge of what was (un)usual for that resident. As a result,

staff suggested that whilst the support of Out-of-Hours services and ambulance teams were necessary, the support of a regular GP was preferable.

“It is nights or weekends where emergency services are called out to care homes... it is not staffing, there is no difference of the staffing level... its - they know that the GP is not the normal GP who knows the resident. They know when they ring up that it can be a problem. Out-of-Hours are notoriously bad for coming out or it takes them three or four hours. I can understand that a fall that you are just reporting is not a priority but you know, that’s fine as long as the staff are happy, but I have always said to the staff ‘you can notify but if you think there is a problem always call 999’. I don’t care what it is, it is better to err on the right side like that than not.”

(Manager, Goldfinch Lodge)

“I think we are just very lucky because our doctor is very willing to help... Because if we don’t get the GP and it goes to Out-of-Hours then we will have more residents going to the hospital. It cannot work without the GP; nurses can’t just make all the decisions. There are things that a doctor must decide.”

(Nurse, Wren Grange)

“When we call the Out-of-Hours and the GP will say ‘we’re not coming out’... I’ve said ‘are you refusing to come out? I am going to document that you are not coming out’ and then they usually come but it gives the staff no assurance at all.”

(Manager, Sycamore Gardens)

Throughout data collection, staff described the importance of having regular and reliable support from a GP, preferably from a GP that could visit the care home regularly in order to get to know what was (un)usual for residents and to develop trust between the GP and the staff team. Therefore, framing escalations to external healthcare professionals as a risk intervention through which staff seek to minimise risk and uncertainty could provide further insight into why this relationship is particularly valued by care home staff. It could also provide new insights into the variation in hospital transfer rates between care

homes. Based on the data presented in this chapter, it could be possible that in care homes where staff feel unable to obtain support from a GP, the only way to stay “on the safe side” is to call for an ambulance, which may in turn increase transfer rates.

8.4.2. Anticipating the reactions of healthcare professionals

When deciding whether or not to escalate a situation to an external service, care home staff anticipated the likely reactions of healthcare professionals. For example, staff noted that whilst their interactions with ambulance staff could be polite and professional, at other times they found these interactions challenging. During an interview, one participant stated:

“You get grumpy ones, you get lovely ones, you get people who make you feel this big [gestures small], you get others that have nothing but praise for you.”

(Deputy Manager, Sycamore Gardens)

Furthermore, the text below, reproduced from ethnographic field notes, describes the experiences of staff at Goldfinch Lodge.

*“At 11:00pm I spoke with two carers. They stated that if they suspected a resident’s health was deteriorating they would always report to a nurse or senior carer and they would never call an ambulance themselves. They said ambulance staff can be “quite rude” and that it is difficult for staff making the external call because if they **don’t** call an ambulance they might be asked ‘why didn’t you call?’ - especially if someone deteriorates further or develops a new symptom. But often when they **do** call an ambulance the paramedics question whether the call out was needed and ask, ‘why did you call?’”*

It is possible to draw parallels between the field note, reproduced above, and a quote provided in Chapter 6 in which a participant described decision-making about deteriorating residents as being “between a rock and a hard place”, with staff feeling that there could be consequences, either for the resident or for them as an individual, regardless of the actions they chose to take.

Staff suggested that their interactions with external healthcare professionals were influenced by broader perceptions of care homes as a negative place to live and work. Staff believed that external healthcare professionals viewed their knowledge and skills as secondary, or lesser than, the knowledge and skills of healthcare staff.

“If I think a patient is not well and they need to be in hospital, I contact my colleague to make a decision and we say ‘let’s call 999’... But there is a lot of questions... If we call 999 it means we need quick action! I know it is routine to ask about the condition, but it is a lot of questions... And [ambulance staff] judge us. I think that they think that because we work in a nursing home, we don’t know anything... We are educated people... We work in a nursing home, but we know what we are doing.”

(Nurse 2, Goldfinch Lodge)

“[The out-of-hours service] should realise that when the care home calls them, we have already done an assessment and it does not warrant hospital admission, it just warrants a doctor... And when the ambulance people come, some of them, the attitude that they give the staff! They talk down to the staff, they raise their voices... Care home staff are looked down on. [Healthcare professionals] think it is sub-care that the nurses that work in a care home are not as bright as the hospital nurses. But what they are forgetting is the nurse in the care home has to take decisions, nurses in care homes they take a lot of responsibility and they can assess situations completely and comprehensively... They don’t realise that a care facility is on par and we should just integrate across at the same level [meshes hands together].

(Deputy Manager, Goldfinch Lodge)

In both of the extracts above, the participants described a belief that external healthcare professionals may not recognise the skills of staff working in a care home setting. The participants suggested that external healthcare professionals might not trust care home staff abilities to assess a resident and to determine

which service would be most appropriately placed to respond. It is important to note that both the two quotes presented above and the preceding extract were all gathered from the same care home, albeit from different members of staff, on different days and via different forms of data collection. Therefore, it could be suggested that interactions with healthcare professionals were more problematic in some care homes than others. However, across all care homes, staff anticipated the reactions of healthcare professionals whilst making decisions about potential hospital transfers.

Although staff thought carefully about the likely reactions of external healthcare professionals, no member of staff made explicit statements to suggest that these interactions would deter them from seeking help when they felt it was required. Therefore, it is not possible to determine whether staff perceptions about the likely reactions of healthcare professionals could prevent staff from contacting external services.

8.4.3. GP involvement in advance care planning discussions and documentation

In addition to providing care home staff with advice and shouldering some of the personal and professional risks associated with decision-making, staff across all care homes suggested that external healthcare professionals (particularly GPs) played a crucial role in building and maintaining relationships with family carers. Staff suggested that the presence of a supportive GP increased family carers' confidence in the care home staff's ability to care for residents, especially during the end-of-life. In particular, staff reported calling on the support of a GP when there was disagreement amongst the staff team and family carers about the appropriateness of hospital care. Participants suggested that family carers often felt 'reassured' by talking to a GP, which they believed was linked to the professional status of medical doctors. This provides further support for the notion that decision-making about potential transfers is influenced by and occurs within the context of a broad range of social relationships.

*“And if families need, something to, what do you call it – sometimes it's not **enough** that nurses will give their explanations, sometimes it*

is better if the doctor will tell them. I can't find the word for that, to describe it, but our families always want to talk to the doctors."

[Interviewer: "That they want the doctor's opinion or value the doctor's view? Is that the type of thing you are talking about or not?]

"Yes, that reassurance. Families, when they hear the doctor say the same thing that we are saying then they are reassured."

(Manager, Wren Grange)

"When [the GPs] see that someone is going down they approach the family to talk with them. In that way it becomes easier for the nurses... you will find that the family are calmer and reassured."

(Manager, Goldfinch Lodge)

In addition, staff highlighted the vital role that GPs played in discussing potential end-of-life situations with family members and in creating advance care plans. Staff felt that advance care planning should predominantly be led by GPs, who were perceived to have overall responsibility for advance care planning. Some staff felt comfortable in initiating and supporting these conversations but recognised that some people may be more comfortable with and competent in these supporting discussions than others. Care home managers saw this as a skilled task that not all staff could perform, and some described offering informal support to develop the skills and confidence of new colleagues. Again, when discussing the use of advance care plans during transfer decisions, the need to maintain relationships with family carers was again emphasised.

"It would be a doctor's decision to put the [advance care plans] in, not ours... We are having the first part of the discussion. We are explaining it - prioritising comfort, even at the expense of sustaining life. So, we talk through that before the doctor comes in."

(Manager 1, Cherry Tree House)

"If a nurse is new, we will not let them do [advance care planning discussions] but we pressure them to do it with another member of staff because you have got to get more confident. And it is difficult to talk about it, but you have got to do it... If you do it in a nice way then

[families] are OK.”

(Manager, Wren Grange)

As discussed in the preceding chapter, see section 7.2.1, staff valued both the *process* and *output* of advance care planning. Staff believed the *process* of advance care planning provided an opportunity to have early discussions with family carers about the appropriateness of hospital care. In doing so, advance care planning was perceived to have the potential to minimise the chance that a disagreement would occur between staff and family carers about the most appropriate course of action in the face of a deterioration in a resident's health.

“We do the advance care plans for everyone...we try to get the family on board as quickly as possible on board because they can make it very difficult for you”

(Manager, Wren Grange)

“We have a care plan - wishes for end-of-life..... If I have the paperwork in place... then it's OK. Because for me, I am already covered.”

(Nurse, Starling Manor)

In addition, staff suggested that the *output* of advance care planning – the written advance care plan document – was valuable an agreed upon plan to guide ‘in-the-moment’ decision-making. For example, the second extract of the set above suggests that having a written care plan in place provides a means through which staff are ‘covered’ and able to legitimise their decision to not transfer a resident to hospital. It appeared that without an advance care plan in place, staff could feel obliged to initiate care and/or treatments that they felt would not be in the best interest of a resident (e.g. initiating a hospital transfer of performing cardio-pulmonary resuscitation in order to avoid being accused of not fulfilling a duty of care.

“I know GPs are very pressured, but if we had more support from the GP that would prevent people going into hospitals... If a resident stops breathing and we haven't got a DNR in place... we would just do CPR until the paramedics arrived and they would end up in

hospital.”

(Manager, Starling Manor)

“Our GP is really proactive. He wants to see things in place so we don’t get to the stage where somebody is very poorly and the family are saying ‘we don’t want them to go into hospital’ and paramedics are saying ‘we have a duty of care to take this person to hospital’ because there’s nothing in place that tells them the person doesn’t want to go.”

(Manager, Sycamore Gardens)

The previous chapter (section 7.2.1) suggested that advance care planning could be thought of as a source of ‘risk knowledge’ through which care home staff come to know the likely risks of transferring a resident to hospital. However, findings presented in this chapter suggest that both the *process* of creating an advance care plan and the *output* (in the form of a written advance care plan) can be conceptualised as a ‘risk intervention’ (Gale et al., 2016) which can potentially minimise and mitigate against perceptions of risks and uncertainty.

For staff, advance care planning is perceived to be useful because the process of creating a plan moves the decision about the potential benefits and burdens of care temporally, so that staff are not required to make a decision in the ‘heat of the moment’ whilst a resident’s health is deteriorating. In addition, the presence of a written document, providing it is perceived to be robust and therefore legitimate, can allay fears that the decision *not* to transfer a resident would be perceived as a failure to fulfil a duty of care. However, although advance care planning can reduce the likelihood of a disagreement amongst different stakeholders, even clear and seemingly robust plans could be challenged by family members when faced with the reality of an acute deterioration. In these situations, the family’s view would tend to hold sway, even in the presence of an advance care plan. As such, care planning did not remove all the challenges at the time of deterioration.

“The [advance care plan]... it was written by the daughter ‘not for hospital admission’. But the patient’s condition was severe, so we

called 999 and the paramedics said, 'no it's not for hospital admission'. We contacted the daughter... she said, 'if my mum is going to die due to this infection, I am going to sue the home'. It means she wanted active treatment to save her life."

(Nurse 2, Goldfinch Lodge)

8.5. Summary

When faced with residents who are potentially experiencing deteriorations in their health, staff described their responsibilities as a process of deciding whether they could manage the situation or whether they should escalate to someone else. Decision-making about potential hospital transfers can involve several people, including residents, family carers, other members of staff from within the care home and external healthcare professionals. When other people were involved in decision-making, there was potential for different stakeholders to disagree about the most appropriate course of action. When disagreement occurred, staff suggested they could use the experiential knowledge they held to advocate effectively for residents. However, although there were instances where staff did this in practice, there were also instances in which staff felt unable or unwilling to challenge or "overrule" healthcare professionals and/or family carers.

Staff valued being able to consult their colleagues, particularly when decision-making was surrounded in uncertainty. Being able to escalate in-house amongst the staff team provided a means for staff to manage and minimise risk, particularly risks to themselves as decision-makers. Therefore, internal escalation could be conceptualised as a 'risk intervention' (Gale et al., 2016). This approach to managing risk required care home staff in senior positions to take on some of the responsibilities and professional risks associated with decision-making. In addition, in order for this strategy to be effective, staff needed to trust their colleagues' abilities to identify and interpret changes in residents' health.

Frequently, staff described the involvement of family carers in decision-making, particularly when a family carer held a LPOA. However, even when residents had capacity (and therefore family carers technically did not hold any legal

power over decision-making) staff placed importance on involving family carers in transfer decisions. Although staff described this as a 'courtesy', they were concerned that acting contrary to family carers' wishes could result in legal and/or disciplinary procedures, which could have consequences for them as an individual. This was highlighted as a source of power for families in decision-making and staff suggested that instances where staff and family carers disagreed about the appropriateness of a hospital transfer were difficult to manage.

When care home staff felt unable to assess or manage a situation in-house, they often chose to escalate to external healthcare professionals. Whilst staff described their role in transfer decisions as a process of deciding *whether* to escalate a situation and deciding *who* to escalate a situation to, staff suggested that the decision to *transfer* a resident (or not) was ultimately the responsibility of external healthcare professionals, such as GPs or ambulance staff. Although staff believed external healthcare professionals had skills and knowledge that would enable them to provide additional support to residents, the process of escalating to an external healthcare professional (and allowing them to decide whether or not a transfer was required) provided a way for staff to minimise risks to themselves as a decision-maker.

Some participants suggested that they would be happy to follow an external healthcare professional's advice about whether or not to transfer a resident, even if it was at odds with their own perception of what was 'best' for the resident. This appeared to be related to a desire to be 'covered' and to minimise risks to themselves as an individual. However, there were also instances where care home staff were willing and able to challenge the decisions of healthcare professionals. Staff felt more able to challenge healthcare professionals when they felt a greater degree of action was required. In contrast, staff felt less able to 'push' for the resident to remain in the home when a healthcare professional had deemed a transfer necessary. Again, this seemed to be related to difficulties in providing justification for *not* acting, against the advice of healthcare professional.

When deciding whether or not to escalate a situation to an external service, care home staff anticipated the likely reactions of healthcare professionals. Staff believed that the adverse interactions they experienced were influenced by broader perceptions of care homes as a negative place to live and work. It is important to note that none of the participants made explicit statements to suggest that these interactions would deter them from seeking help when they felt it was required. Therefore, although staff thought carefully about the likely reactions of external healthcare professionals, it is not possible to determine whether these anticipated responses could, in turn, prevent staff from contacting external services.

In addition to providing care home staff with advice and shouldering some of the risks associated with decision-making, staff across all care homes suggested that the presence of a supportive GP increased family carers' confidence in the care home staff's ability to care for the residents, particularly during the end-of-life. Staff reported calling on the support of a GP when there was disagreement amongst the staff team and family carers about the appropriateness of hospital care. In addition, staff highlighted the vital role that GPs played in discussing potential end-of-life situations with family members and in creating advance care plans. Staff suggested that advance care planning should predominantly be led by GPs, who were perceived to have overall responsibility for this process, but felt comfortable supporting these conversations.

CHAPTER NINE: Discussion and recommendations

Guided by the central research question, '*How do care home staff decide to initiate a resident hospital transfer within the context of care homes in England?*', the aim of this project was to develop an in-depth understanding of staff decision-making when deciding whether or not to transfer a resident to hospital. At the beginning of the project, whilst becoming familiar with literature surrounding hospital transfers from care homes, I identified several gaps in the existing knowledge base. The majority of existing research was quantitative in nature, seeking to identify the causes of hospital transfers from care homes by exploring the primary health conditions associated with resident transfers. In comparison, few studies had sought to explore the events that preceded a hospital transfer from a qualitative perspective. Although there had been a number of systematic reviews published in recent years that explored care home staff experiences and involvement in transfer decisions (Arendts et al., 2013, Laging et al., 2015, O'Neill et al., 2015), very few of the primary studies included within those reviews were conducted in England.

Given that existing research has emphasised the importance of the wider social context in understanding hospital transfers (Arendts et al., 2013, Dwyer et al., 2015), the applicability of existing knowledge to the decision-making of staff working in care homes in England was not clear. Therefore, I sought to investigate staff decision-making within the context of care homes in England by exploring the processes (chain of events) that precede a transfer and the factors that influence staff decision-making about potential hospital transfers.

In this chapter, I provide a summary of the project's findings, before bringing together and discussing key threads that run throughout the thesis. Then, by contextualising the findings of this study within broader bodies of literature, I discuss how the findings of this project compare and contrast with existing knowledge and highlight the new insights they contribute. In this chapter, I also consider the strengths and limitations of the study, before discussing the potential implications of the findings for research, policy and practice.

9.1. Summary of the study

The findings of my study suggest that within the context of care homes in England, with the exception of scenarios in which staff feel a hospital transfer is immediately necessary, hospital transfers tend to unfold as a series of escalations. When faced with a resident who may require a hospital transfer, staff have to determine whether they are able to manage the situation, or whether they should escalate to somebody else. If deciding to escalate to somebody else, they also have to determine *who* this should be.

Staff decision-making begins when a member of staff becomes aware of a change in a resident. This can happen in a number of ways: a resident or family carer may alert the staff member to the change; staff might identify a change based on their experiential knowledge of what is usual for the resident; or staff may identify a change through the use of standardised and/or routine monitoring tools (for example structured nursing observations) used within the home. When this happens, staff have to determine whether they are able to manage the situation, or whether they should escalate to somebody else. If deciding to escalate to somebody else, they also have to determine to *whom* this should be.

In order to determine to whom an escalation should be made, staff have to decide whether or not the situation at hand could potentially represent an emergency. An assessment of whether or not the situation represents an emergency could be based on generic information (i.e. applicable across the majority of residents). For example, staff generally consider life-threatening symptoms such as heavy bleeding or shortness of breath to require a hospital transfer, regardless of the individual circumstances surrounding the situation. However, staff perceptions of what constitutes an 'emergency' could also be influenced by resident-specific information, for example if a resident who usually ate well suddenly started to refuse their food.

After determining whether or not the situation at hand represents a potential emergency, staff have to decide whether they can manage the situation alone or whether to escalate to someone else in the staff team. In order to do this, the decision-making that care home staff undertake is complex, multifactorial and

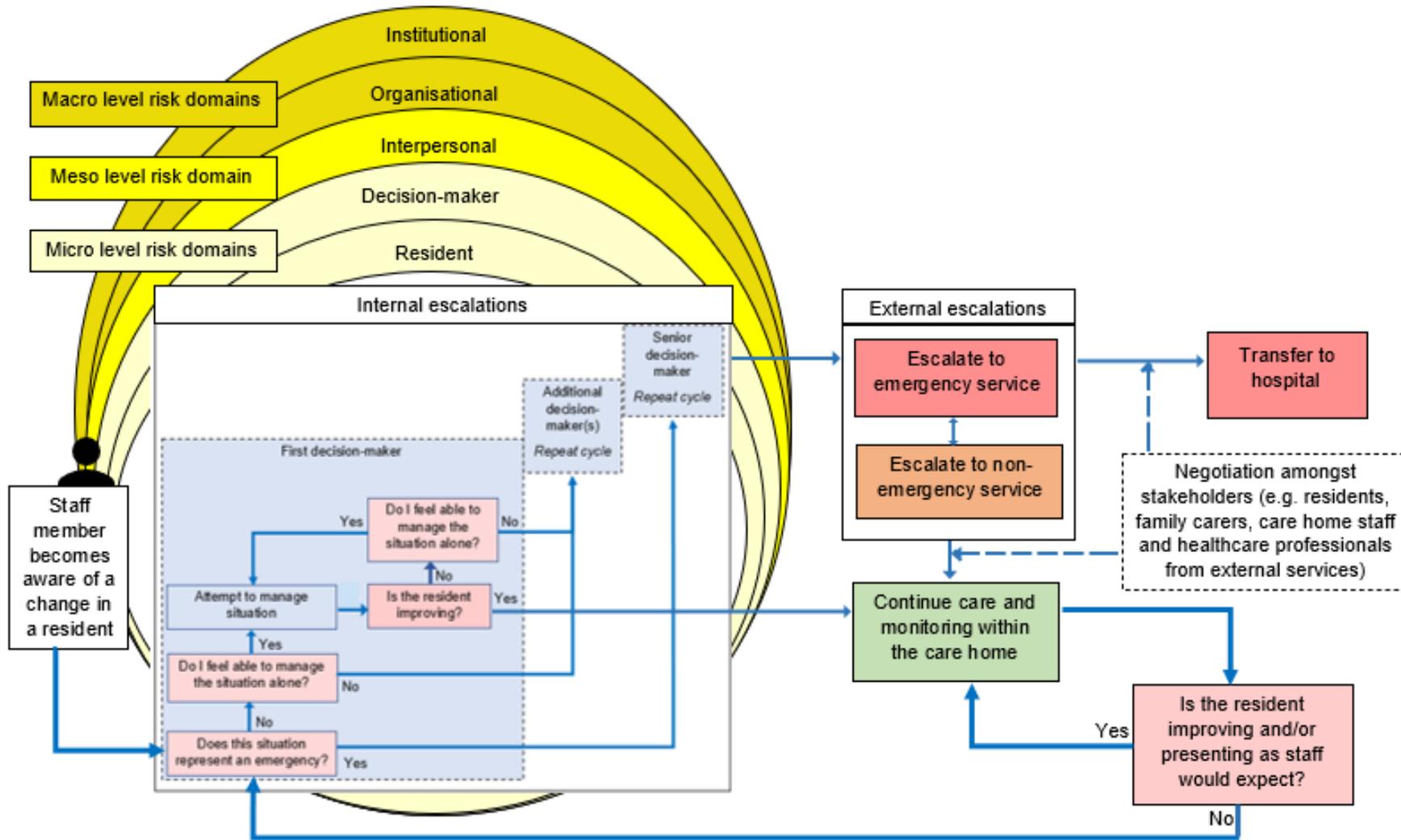
influenced by a variety of factors. Moreover, these influences can also be thought of as forms of risk, or 'risk domains', which staff perceive and feel responsible for prioritising and managing (see Table 5 below). Therefore, in the context of care homes in England, staff decision-making about potential hospital transfers can be conceptualised as a series of escalations in which staff make complex, multifactorial decisions about perceived benefits and risks. This includes risks that occur at a range of levels: the micro - related to individual residents and staff decision-makers); meso - related to interpersonal relations between staff and other stakeholders); and macro - related to organisations (care homes) and wider institutions (health and social care systems).

This process, of deciding whether or not to escalate a situation and to whom an escalation should be made, can repeat several times as additional members of staff are consulted or included in decision-making. Often, but not always, this is related to the different types of staff in the home's staffing structure. Eventually, a decision will be made to either resume normal care, often whilst continuing to monitor the resident, or to make an external escalation to a non-emergency or emergency service. In turn, a decision may be made to transfer a resident to hospital or to continue to care for the resident within the care home. A conceptual model of staff decision-making when faced with a resident who potentially requires a transfer to hospital is presented in Figure 11.

Table 5: A table to describe the different factors and perceived forms of risk that influence staff decision-making (*colleagues, residents, family carers and healthcare professionals)

Level of influence		Factors influencing staff decision-making	Perceived forms of risk (i.e. risk domains) that influence staff decision-making
Micro	Resident	<ul style="list-style-type: none"> • Preferences and wishes regarding care (including advance care plans) • Existing diagnoses (including whether the resident is considered to be at the end-of-life) • New symptoms and/or 'changes' in what is usual for the resident • Likely benefits and burdens to the resident's health and quality of life 	<ul style="list-style-type: none"> • Risk of poor outcomes (i.e. reduced health and/or quality of life) • Risk of experiencing poor care in hospital • Risk of experiencing a poor death (i.e. in an unfamiliar environment, surrounded by unfamiliar people)
	Decision-maker	<ul style="list-style-type: none"> • A desire to feel as if one has acted in the best interest of the resident • A desire to be personally and professionally able to justify one's actions • Level of comfort in discussing deteriorations with others (e.g. residents, family carers, healthcare professionals) 	<ul style="list-style-type: none"> • Personal risks – "feeling awful" as if one has made the wrong decision • Professional risks – potentially facing disciplinary hearings and/or being reprimanded
Meso	Interpersonal (social relationships)	<ul style="list-style-type: none"> • The opinions and preferences of others* • Anticipation of potential reactions of others* • Shared perceptions of the likely benefits and burdens associated with a transfer 	<ul style="list-style-type: none"> • Damaged relationships with others*
Macro	Organisational (care home)	<ul style="list-style-type: none"> • Written policies and procedures • Availability of senior staff to support decision-making • Formally imposed ways of working 	<ul style="list-style-type: none"> • The risk that the care home, as an organisation, will be seen to be at fault for deteriorations in residents' health • Damage to the care home's reputation
	Institutional (wider health and care system)	<ul style="list-style-type: none"> • Availability of support from external healthcare services (e.g. GPs or Out-of-Hours GPs) 	<ul style="list-style-type: none"> • The potential to "waste" healthcare resources, • The potential to damage broader public perceptions of social care

Figure 11: A conceptual model of care home staff of the decision-making when faced with a resident who potentially requires a hospital transfer



Despite differences in the specific escalation pathways in each care home, a pattern of escalation occurs across homes. Initially, escalations tend to occur internally within the care home (amongst the staff team) prior to externally (to emergency or non-emergency healthcare services). Therefore, my findings highlight the substantial amount of work that staff undertake 'in house' prior to calling external services for support. Furthermore, although there were occasions in which staff described decision-making as relatively straightforward (for example where the benefits clearly outweighed the potential burdens), more often than not staff describe a process of 'weighing up' risks - feeling that both options (to transfer or not to transfer) could have potentially negative consequences.

This project provides new insights into the ways in which this process of 'weighing up' occurs so that staff come to understand and prioritise the different potential benefits and risks associated with deciding whether or not to transfer a resident to hospital. Staff primarily draw upon their knowledge of what was (un)usual for each resident. This form of knowledge, often described by staff as 'knowing' each resident, has four characteristics: it is largely experiential (grounded in carers' experience); longitudinal (acquired gradually over time); socially mediated (influenced by the individuals staff interact with and the organisations in which they work) and dynamically evolving (staff adjust their perception of what is 'normal', and by extension what is unusual and representative of a threat to each resident's health, over time). Staff also make use of other forms of risk knowledge, which they combine, or 'bricolage' with their experiential knowledge (Horlick-Jones et al., 2007). This includes knowledge derived from advance care plans and structured clinical observations, which provide an objective and codified way of assessing potential risks to the resident but which is qualitatively different from their use of experiential knowledge.

The results of my study suggest that individual understandings of the likely benefits and risks associated with transferring a resident to hospital (or not) are socially mediated in several ways. At an interpersonal level, through discussion, staff reach a negotiated understanding of what is considered (un)usual for each resident, for example through informal one-to-one interaction or through

formalised, structured discussions. At an organisational level, written policies, normative working practices (i.e. shared understandings of what behaviours are expected and desirable) and shared conceptualisations about the likely benefits and burdens of hospital transfers at each home lead to specific ways of 'doing risk' at each care home, which influence the decision-making of individual members of staff.

My findings also highlight that transfer decisions occur within the context of multiple social relationships. This includes relationships with residents, family carers, other members of care home staff and external healthcare professionals, including but not limited to GPs and ambulance staff. Although the involvement of others provides a way for staff to minimise risks for themselves as individuals by sharing some of the responsibilities and risks associated with decision-making, it also introduces the potential for disagreement, which can be particularly challenging for care home staff. This includes disagreement about the nature of the problem (i.e. whether or not the 'problem' at hand was a cause for concern) and disagreements about the most appropriate course of action.

At times, staff feel pressure to follow the wishes of family carers who appear to hold a powerful position in decision-making, even when family wishes do not align with their own perception of what would be 'best' for the resident. In particular, staff are concerned that acting against family wishes could result in legal and/or disciplinary procedures which could have consequences which might be severe and long-term for them as an individual. However, there appear to be limits to the perceived power of family carers. Whilst staff suggest that family carers can push for a hospital transfer in instances where staff and healthcare professionals feel it is not necessary, staff also suggest that families are less able to prevent a hospital transfer when staff and/or healthcare professionals feel that one is required.

Similarly, whilst staff describe their role in transfer decisions as a process of deciding *whether* or not to escalate a situation and deciding *who* to escalate to, staff describe the decision to *transfer* a resident (or not) as ultimately the responsibility of external healthcare professionals such as a GP or a member of

ambulance staff. At times, staff suggest that in order to be personally and professionally 'covered', they feel obliged to follow a healthcare professional's advice, even if it is at odds with their views about the most appropriate course of action for the resident. However, there are also instances where staff challenge the advice of healthcare professionals. This usually occurs when staff feel a greater degree of action is required, often taking the form of calling an additional service in order to obtain a second opinion or access a treatment. However, whilst staff feel able to push for a hospital transfer, they feel less able to argue for residents to remain in the home when a healthcare professional has deemed a hospital transfer necessary.

9.2. Transfer decisions as complex decisions centred on risk

Taken together, the findings presented in this thesis suggest that to fully understand why hospital transfers occur, one must explore the factors that influence staff decision-making beyond the immediate clinical signs, symptoms or acute event that staff find themselves faced with. This thesis outlines a range of important factors which influence and limit staff's decision-making about potential hospital transfers in the context of care homes in England. These factors occur across a range of levels including: the micro - related to individual residents and staff (as decision-makers); meso - related to interpersonal relations between staff and other stakeholders); and macro - related to organisations (care homes) and wider institutions (health and social care systems).

This suggestion, that to understand why hospital transfers occur one should attend to the wider social context, rather than to the immediate clinical situation, is not new. A number of scholars have made similar arguments (Arendts et al., 2013, Dwyer et al., 2015, Laging et al., 2015). However, this thesis builds on these suggestions to argue that to fully understand the factors that drive hospital transfers from care homes, one must attend to the different risks that staff perceive during transfer decisions. This shift in thinking has important implications for understanding hospital transfers from care homes.

By thinking about transfer decisions explicitly in terms of the different forms of risks which are managed, one can start to understand why, at times, care home

staff can feel as if it is safer (i.e. less risky) to do more - to call an external healthcare professional, to seek additional support via 111 or to transfer a resident to hospital – rather than to care for the resident within the home. This re-shifting of focus can help to explain transfers that occur without the expectation of improved health and/or well-being for residents. In these circumstances, a transfer may be considered clinically *inappropriate* for the resident, yet still a logical response situated within the broader social context that shapes staff decision-making.

In recent years there has been growing interest in identifying and reducing hospital transfers that are considered ‘inappropriate’, although it is important to note that this term is contested and has received criticism, particularly on the grounds that at present there is a lack of agreement about what exactly constitutes an ‘inappropriate’ transfer to hospital (as discussed in sections 2.4 and 2.5). The results presented in this thesis demonstrate the complex and multifactorial nature of transfer decisions, raising further questions about whether the dichotomous framing of transfers, as either appropriate or inappropriate, can capture this complexity. Even if agreement is reached about what exactly constitutes an ‘inappropriate’ transfer, the findings of my study suggest that in order to reduce transfers, one must first understand both the broader social context surrounding decision-making and the different forms of risks staff perceive and weigh up during transfer decisions. In the absence of a clearer, shared understanding of what exactly constitutes an ‘inappropriate’ transfer or a more nuanced understanding of the broader social context which influences hospital transfers, there is a danger that residents will continue to be regarded as ‘out of place’ in both the care home and the hospital.

9.3. Transfer decisions as situated within a local moral world

To better understand staff decision-making about potential hospital transfers, particularly to understand instances where staff decide to act in ways that did not align with their own perception of what was ‘best’ for residents, one could turn to the work of Arthur Kleinman (2006) who explores individual moral experiences by examining the ways individuals and groups deal with danger and uncertainty. Kleinman differentiates between ‘ethics’ (a broad set of moral

principles that aspire to universal application) and the moral experience of individuals (which occur in a local context characterised by change and uncertainty). Kleinman suggests that individual perceptions of what is 'normal' and 'moral' behaviour develops in line with the particular groups and societies to which individuals belong. Therefore "taken alone, ethics, such as principles of virtue and justice, can be irrelevant to our local worlds" (Kleinman, 2006, p26). Kleinman proposes that what is considered 'moral' needs to be understood in context, at a local level, before the actions of individuals can be judged or scrutinised.

In order to understand the reasons why people make particular decisions, Kleinman (2006) suggests that it is important to attend to what matters most to that individual, by asking 'what is most at stake?'. Participants in my study referred to a number of things that they considered to be 'most at stake' when deciding whether or not to transfer a resident to hospital. At times, staff decided to act against their own perception of what was 'best' for the resident in order to preserve things that they valued. This included: their personal and professional reputation; their relationships with colleagues, residents, family carers and visiting healthcare professionals; their conscience (feeling they had done the 'right' or 'wrong' thing); the reputation of the care home they worked in and, more broadly, of the wider care sector; and their employment status (which for nurses included their professional registration), which provided them and their families with financial stability.

Kleinman suggests that when people become aware that their local environment does not align with their own sense of right and wrong, individuals may "respond with criticism, protest, and personal efforts to do the right thing, no matter how great the odds against them" yet "many will not rock the boat... This is how people come to collaborate publicly with unethical policies, in spite of their private reservations." (Kleinman, 2006, p3). The results of my study provide support for this argument. Individual members of staff described situations where they had reservations about decisions that were being made. Although at times staff felt able to speak out and challenge these decisions, often they did not due to concerns that doing so would threaten the things that 'mattered most' to them (for example their employment, their reputation etc.). It

is noteworthy that staff felt more able to speak out in situations where they felt the need to advocate for more action - for example pushing for a hospital transfer – which was perceived to be less risky than pushing for less action, for example arguing that the resident should remain within the care home.

Towards the end of his book, Kleinman suggests that as well as asking ‘what is most at stake?’, a helpful way to provide challenge to decisions that are influenced by multiple agendas would be to ask, ‘what *should* really matter?’. In the case of hospital transfers from care homes it would be uncontroversial to suggest that what *should really matter* is the health and well-being of the resident. However, the results of this research suggest that what is ‘best’ for the resident can become lost amongst a plethora of other things that are at stake during transfer decisions. Later sections of this chapter explore ways that concerns for the resident might be foregrounded during transfer decisions in the future.

9.4. Deteriorating residents as ‘out of place’

Throughout data collection care home staff described a preference for caring for residents in the care home. Staff raised concerns that a busy hospital environment was not the “right place” for care home residents, however at times staff also felt unable to meet a deteriorating resident’s needs in the care home. Furthermore, once in hospital, staff suggested that healthcare professionals may also believe care home residents are ‘out of place’, particularly if the transfer is related to a chronic health condition that hospital staff feel could be considered ‘manageable’ in the community. Therefore, at times, care home residents can be considered as “matter out of place” in both hospitals and care home environments.

This phrase, coined by Mary Douglas in her exploration of the ways that risks are socially constructed within particular historical and cultural contexts, suggests that both objects and people can be perceived as dangerous or ‘risky’ when they are “matter out of place” (Douglas and Wildavsky, 1982, Douglas, 1966). Particularly during times of social, political or economic uncertainty, groups of people can be constructed as presenting a risk to wider society. Often, those who are presented as ‘risky’ are individuals who may also be

considered 'vulnerable' in a society, for example migrants, young people, women and individuals from lower socioeconomic backgrounds, or people experiencing physical and mental illness (Douglas and Wildavsky, 1982). The findings of my thesis suggest that the notion of "matter out of place" may be relevant to discussions about hospital transfers from care homes. As a result of being 'out of place', care home residents are presented as both 'at risk' of experiencing a burdensome and potentially inappropriate hospital transfer and 'risky' to whichever setting they receive care.

The suggestion that care home residents can be perceived as both out of place in the care home and in the hospital raises an important question: when residents experience deteriorations in their health, where would be an appropriate place for them to receive treatment? Due to the complexity of transfer decisions, the individuality of care home residents and the unpredictability of their health trajectories, there is unlikely to be a definitive answer to this question. However, this question closely resembles the often asked 'When is a transfer to hospital appropriate? Without an agreed upon definition of what constitutes 'appropriate' hospital use by care home residents, it is unlikely that consensus about the 'right place' for residents to receive care will be reached. Continuing to focus on an over-simplistic distinction (between transfers that are either appropriate or inappropriate) will lead to residents continuing to be regarded as 'out of place' in both the care home and the hospital. This in turn hinders the provision of high-quality care and might even paradoxically increase the number of transfers residents experience.

9.5. Comparison with existing literature

9.5.1 Comparison with literature into hospital transfers from care homes

This study did not seek to determine the prevalence of hospital transfers in England, nor did it seek to estimate what proportion of those transfers could be considered 'inappropriate'. Instead, this study sought to provide a qualitative, in-depth exploration of the factors that shape staff decision-making regarding potential hospital transfers, within the context of care homes in England.

Existing research which has attempted to understand the reasons for which resident hospital transfers occur have pointed to clinical symptoms (for example

shortness of breath or a sudden and unexpected change in their health status), particular health conditions (for example pneumonitis), and the presence of multimorbidity or cognitive impairment (Ashcraft and Owen, 2014, Smith et al., 2015, Stephens et al., 2014). The results of this project do not discount these findings, yet they suggest that clinical features represent only some of the factors that influence staff decision-making. Indeed, these clinical features are likely to be noted as a 'change from usual' detected by care home staff.

This study is not the first to highlight the role of non-clinical factors in staff decision-making. Existing research has suggested that concerns about medico-legal issues shape transfer decisions (Cohen et al., 2017), however, my study extends this observation to issues of wider professional liability and a sense of a personal, moral duty of care, in which staff express concern about having 'done enough' for the resident. Importantly, the results of this study highlight the vulnerability felt by care staff when faced with a deteriorating resident, particularly when their assessment of the situation at hand, and by extension their perception of how best to respond, does not align with the views of family carers.

Furthermore, although previous studies have suggested that families have a powerful sway over decision-making (Arendts et al., 2013, Laging et al., 2015, Trahan et al., 2016), this study suggests that family carers' reactions, which could include 'pushing' for a transfer when staff thought it was not necessary, were often borne out of a similar sense of 'duty' or by a natural emotional response to a deteriorating loved-one. Moreover, the results of my study provide insight into the relationships between the perceived power of family carers and professional-legal concerns. Staff voiced fears that acting in ways that did not align with family carers' wishes might lead family carers to make complaints (either to the care home manager, or to professional and regulatory bodies) which could have significant, potentially severe and long term, implications for them as an individual.

The findings of this study support existing international research that has suggested decision-making about potential resident hospital transfers is complex. Whilst seeking to describe care home nurses' perceptions of hospital

transfers, O'Neill et al. (2015) highlighted the complexity of transfer decisions, drawing attention to: the range of knowledge, skills and resources staff require to assess and manage deteriorating residents in the care home; the powerful influence of family carers on staff decision-making and; the difficulty staff faced when decision-making involved multiple stakeholders and/or ambiguity about a resident's condition. As a result of their findings, the authors concluded that "the overarching message is that nurses need and want some structure or 'plan' to help them to manage transfers" (O'Neill et al., 2015, p427).

O'Neil et al. (2015) are not alone in calling for more structure in decision-making. There are frequent calls for standardised assessments and responses to deteriorating residents, for example through advance care planning or standardised decision-aids (Ahearn et al., 2010, Givens et al., 2012, Kirsebom et al., 2014, O'Neil et al., 2017). Whilst this suggestion may represent one potential solution, the findings of my study suggest that alone, standardisation of staff assessment of and responses to deteriorating residents will not be sufficient to address the multiple factors that influence decision-making. Interventions that acknowledge the complexity of staff decision-making – in which staff make complex, multifactorial decisions in which they 'weigh up' a number of risks – are required.

The findings of this study also contribute new knowledge regarding advance care planning in the context of care homes in England. Whilst the majority of existing research focusses on the process of engaging in advance care planning discussions (for example Sharp et al. (2018), Sharp et al. (2013)), this study provides insights into how care home staff use advance care planning documents during 'in-the-moment' decision-making. Findings suggest that staff perceive both the *process* and the *output* of advance care planning to be useful (as discussed in section 9.7.5), reflecting existing research and national policy documents that call for advance care planning as a means to improve end-of-life care (Ahearn et al., 2010, DoH, 2008, NHS, 2019, NICE, 2019b).

Based on my findings, it is clear that advance care plans require interpretation by care staff and other professionals at the time of deterioration. Therefore, my findings also provide support for studies that suggest that although advance

care planning is important, the creation of an advance care plan document is only one step in a broader decision-making process (McDermott et al., 2012, Palan-Lopez et al., 2017). The difficulties of making specific advance care planning recommendations for care home residents due to their less predictable illness trajectories has been highlighted (Barclay et al., 2014, Sharp et al., 2018) but care home staff feel that they need this specificity and have limited discretion to interpret plans that are written in more general terms.

9.5.2. Relationships with theoretical literature

Throughout this thesis I have drawn upon theories and concepts from various bodies of literature. Drawing on sociological concepts of risk I have sought to demonstrate how everyday risk-related practices are enacted in the context of transfer decisions in care homes in England. For example, sociological risk theorists have examined the different forms of knowledge that individuals use to conceptualise and assess risk. Horlick-Jones (2005) suggested that despite the importance attached to 'objective' and 'formal' forms of risk knowledge in modern and late-modern societies, individuals develop their own 'informal logics' of risk that are influenced by both individual perceptions of risk and the broader social context in which individuals operate. This can include objective, calculative information about risk as well as subjective knowledge based on individual experiences and concepts such as hope and magic (Alaszewski, 2015, Brown, 2015, Horlick-Jones et al., 2007).

A framework for categorising the different forms of knowledge individuals use to manage risk and uncertainty was outlined by Zinn (2008, 2016). This included 'rational', 'non-rational' and 'in-between' strategies (see Figure 4 in section 3.1.3). Importantly, all three approaches to managing risk and uncertainty can be considered to be 'reasonable', with authors suggesting that to determine the most appropriate approach, one must attend to the nature of the situation at hand (Alaszewski, 2015, Baillergeau and Duyvendak, 2016, Zinn, 2016). Similarly, models of clinical decision-making have outlined different 'modes of enquiry' that individuals use to make decisions, positioning these modes along a continuum ranging from an objective 'analytical' mode to a subjective 'intuitive' mode (see section 3.2.1 for more details). Again, both intuitive and

analytical reasoning are positioned as legitimate approaches to decision-making, dependent upon the nature of the task. (Cader et al., 2005, McCutcheon and Pincombe, 2001, Pearson, 2013, Standing, 2014).

It is possible to use the language put forward within sociological theories of risk and models of clinical decision-making to explore the types of knowledge that staff use during transfer decisions. For example, the use of structured clinical observations could be described as 'rational', 'objective' or 'analytical' knowledge. Conversely, there are times when care home staff appeared to be relying on 'non-rational' forms of risk knowledge. This included what some authors might call 'magical' reasoning, based on the broad anthropological understanding of 'magic' as rituals which aim to make particular futures or outcomes more certain (Alaszewski, 2015, Brown, 2020, Douglas, 1966). For example, despite raising concerns about the scientific accuracy of using urinalysis strips (referred to as "dipsticks") to determine whether a resident might have a urinary tract infection, staff continued to use them in practice. Whilst the use of dipsticks can be thought of as a 'non-rational' approach to managing risk and uncertainty, this approach can still be considered logical within the context in which staff were operating. Staff had few other 'objective' alternatives for diagnosing urinary tract infections, relying instead on their subjective understanding of what was usual for each resident (see chapter 7.4.1. for more information) and often undertaking this process was a prerequisite to obtaining a prescription to combat the potential infection.

Finally, staff placed importance on their use of experiential knowledge when decision-making about potential hospital transfers. This form of 'knowing' may be considered an 'in-between' form of knowledge (Zinn, 2008, Zinn, 2016) or a type of 'quasi-rationality' (Hamm, 1988) based on information that staff have gathered over time, albeit subjective and contestable. Although this way of knowing was experienced by staff as intuitive - occurring rapidly, almost unconsciously - as staff described their thought process it appeared that this form of knowledge was rooted within their experiences. This included their experiences of what was usual for individual residents, and what was considered usual, more generally, across residents. Therefore although Standing (2014) differentiated between the terms 'experiential knowledge'

(which refers to embodied and tacit knowledge) and 'intuition' (which refers to having a pre-conscious feeling without being fully able to explain or articulate that feeling), the results of my study support the work of Kahneman and Klein (2009) who suggested that what is experienced as 'intuition' is the unconscious recognition of cues that guide decision-making, derived from a person's own experiences.

Existing research has suggested that individuals combine or 'bricolage' different forms of risk knowledge. Results from my study support this claim but also identify occasions in which this is experienced as problematic. Although there were occasions where staff found it useful to draw upon several sources of information, the process of bricolaging became problematic when different forms of knowledge led staff to different conclusions (see section 7.4.2). When this happened, staff were faced with a dilemma regarding which form of risk knowledge to privilege. Often when this occurred staff felt the need to privilege forms of risk knowledge which could be considered more 'rational' and measurable over their own experiential knowledge, despite believing their experiential knowledge provided a legitimate means through which they could assess risk. Moving forwards, using the language associated with models of clinical decision-making and sociological theories of risk, which suggest that both objective and subjective approaches to decision-making can be considered legitimate and appropriate under particular conditions, may provide a means for care home staff to explicitly discuss and validate their decision-making based on intuitive judgements (Cader et al., 2005).

Finally, the results of my thesis strongly support the notion that in order to understand risk, one must attend to the social context in which risk is known and understood (Douglas and Wildavsky, 1982). Furthermore, these findings address Brown's (2016) call for greater attention to be directed towards the ways in which individual understandings of risks are located within broader social processes. The findings of my study describe ways that individual understandings of risks are socially mediated. This occurred at both an interpersonal level, for example through interaction with others, and at a broader organisational level, for example through written policies, normative working practices and shared conceptualisations of the likely benefits and

burdens of a hospital transfer at each home. Therefore, whilst all care homes had procedures in place to assess, manage and mitigate against risk, the specific ways of 'doing risk' varied significantly across care homes, borne out of interactions between individuals and their environment.

9.5.3. Conceptualising hospital transfers as a form of risk work

This thesis draws heavily on the concept of 'risk work', developed by Gale et al. (2016) to foreground the practices that individuals use to assess and manage risk, particularly in client-facing contexts. Risk work is comprised of three interconnected components - 'risk knowledge', 'risk interventions' and 'social relations' (Brown and Gale, 2018a, Gale et al., 2016) - see section 3.1.4 for more details. Conceptualising transfer decisions as a form of 'risk work', as I have done in this thesis, provides novel insights into the phenomenon under study, by foregrounding the different forms of risk that staff attempt to assess and manage.

Using the language of 'risk knowledge' enables an exploration of the different forms of knowledge that staff draw upon, and the ways in which particular forms of knowledge are privileged over others under certain conditions. Furthermore, the component 'social relations' encourages a focus on the wider social context surrounding individual experiences of risk, enabling the identification of forces that may promote or limit the provision of care. Focussing on the social relations surrounding transfer decisions, it is possible to identify circumstances in which staff feel unable to act on their own perception of what is 'best' for a resident – for example when their own perception conflicts with the view of families and/or healthcare professionals.

Viewing hospital transfers through the lens of risk work provides new insights into phenomena and trends that staff perceive to occur in practice. Drawing on the concept of 'risk interventions' encourages the identification of processes that staff use to manage and minimise risk. For example, re-framing the support of management staff and a regular GP as a 'risk intervention' through which care home staff minimise risk, provides support for the idea, widely held by care home staff, that decision-making can feel particularly 'risky' during periods of

time that these people are not available to be consulted, namely evenings and weekends.

On considering what makes a theory useful, Strubing suggests: “Apart from the logical soundness of the formation of a theory, its real test is in its usefulness.... the proof of every proposition lies in its practical consequences or, colloquially speaking: ‘The proof of the pudding is in the eating’.” (Strubing, 2007, p588). Therefore, although conceptualising hospital transfer decisions as a form of ‘risk work’ appears to be helpful for understanding the work of care home staff, further research is needed to explore the application of this concept to developing interventions aimed at ensuring residents receive appropriate care in an appropriate setting. Understanding the processes that staff use to manage risk, considering how effective each process is, and ascertaining the conditions that are required to maximise effectiveness will aid this process. This recommendation will be discussed in more detail in section 9.7.2.

9.6. Strengths and limitations

9.6.1. Methodological strengths and limitations

Care homes are complex environments, spanning both health and social care, representing both home (to residents) and the workplace (to staff), each with their own routines, practices and procedures. Due to this complexity, researchers can find the process of conducting research in such environments challenging (Froggatt et al., 2009, Luff et al., 2011). In order to increase the likelihood that the study design would be acceptable and feasible in a care home environment, my project benefitted from different forms of stakeholder engagement. This included early discussions with four care home managers, who provided advice about suitable research methods and information on common situations that could lead to residents in their care home to be transferred to hospital (see section 4.3.1. for more detail). These discussions provided me with an initial insight into hospital transfers from care homes, which was used in the development of an interview schedule and vignettes. In addition, whilst planning ethnographic observations, I discussed my proposed project at a ‘Relatives Meeting’ at a care home registered to provide nursing care for people living with advanced dementia.

The study was conducted across six care homes in the East and West Midlands of England. The relatively small number of research sites could have led to findings that are context specific and therefore not applicable to other care homes (Barbour, 2014). However, in order to increase the applicability of findings I have undertaken a number of steps. Firstly, I purposively sampled care homes in order to ensure a variety of homes were included in the study. This included homes that did and did not provide nursing services, and those that were and were not registered to provide specialist services for people living with dementia. In addition, participating care homes had a range of CQC ratings, were owned by a range of providers (both in terms of the size of the company and whether they operated on a for-profit or not-for-profit basis); and were located across two large geographical areas (see Table 2: 'A table to describe the characteristics of participating care homes.' in section 5.1.2).

All six of the participating care homes were registered with ENRICH, a national initiative that aims to increase the amount of research that is conducted in care homes. It could be suggested that these care homes, who have a particular interest in taking part in research, are qualitatively different to homes that are not registered to ENRICH. However, across the six care homes there were wide discrepancies with regards to the home's previous involvement in research. For example, whilst Sycamore Gardens had previously been involved in piloting a scheme to improve end-of-life care and Wren Grange had been involved in several research projects, other care homes, such as Starling Manor and Cedar Court had no previous experience of being involved in a research project.

Once each home had been recruited, I used a number of research methods to gather data. First, I conducted semi-structured interviews with care home staff. During interviews with care home staff, a purposive sampling approach was used to ensure I captured the experiences of a cross-section of staff in each home. Whilst the majority of existing research into staff decision-making about hospital transfers has focussed on the views of registered nurses, or to a lesser degree carers working in care homes with nursing services (often referred to in international literature as nursing aides), this project included a wide range of staff including managers, deputy managers, nurses, senior carers and carers,

both in care homes with and without nursing services. This is particularly important in the context of care homes in England, as approximately two thirds of all care homes in England do not provide nursing services (CQC, 2019).

Despite undertaking steps to increase the robustness of the data collected during interviews, Silverman (2011) suggests that interview data should be treated as perspectival; representing one plausible account of reality rather than a definitive 'truth'. This suggestion is consistent with tenets of critical realism, which suggest that an external 'reality', independent of human consciousness exists but knowledge of reality will always be imperfect and flawed. To overcome this limitation, I also carried out ethnographic fieldwork in which I directly observed the work of care home staff, analysed relevant documents and artefacts related to hospital transfers, and carried out informal interviews with staff, family carers, residents and visiting healthcare professionals. Conducting ethnographic fieldwork provided an opportunity to triangulate data and to compare what was reported in the interviews with what was observed in practice (Horlick-Jones, 2005, Silverman, 2011).

During ethnographic data collection, the extensive informed consent process that was required by the Social Care Research Ethics Committee introduced limitations to what I was able to observe. As discussed in Chapter 5 (see section 5.3.6), although the primary participants in this study were care home staff, due to the ethnographic nature of the project, a consent process was developed that included care home staff (as the focus of observation), visiting healthcare professionals and residents (in recognition that I may also observe residents as they received care from staff at times of potential vulnerability and/or temporary loss of capacity). As a result, whilst I was permitted to seek verbal consent from residents who had the capacity, I was required to obtain consent and declaration and consent forms from staff and appointed consultees for residents who lacked the capacity to consent, respectively.

The process of obtaining appropriate consent was difficult and time consuming, particularly in the two larger homes who each had over 30 residents and over 40 members of staff. As a result, there were limitations on what could be studied and at times I was not able to observe and record interactions and/or

events due to not yet having the appropriate permissions in place. In addition, due to the physical size and layout of each care home and the impossibility of being in two places at once, it was not possible to see everything that occurred within the home. Instead, I carefully chose the locations of my observations, which were predominantly carried out in communal areas of the home, based on the planned and spontaneous activities of care home staff.

Several authors suggest that to reduce the chances for researcher bias and to improve the trustworthiness of qualitative research findings, researcher reflexivity is a necessity (Kolb, 2012, Timmermans and Tavory, 2007).

Therefore, in addition to considering the impact of the methodological choices that I made throughout the study, I must also consider the impact that I, as a researcher, may have had on the project. In earlier sections of this thesis, I have sought to be open and honest about my own experiences and preconceptions regarding hospital transfers from care homes and to consider how these facets may have influenced the project's design, conduct and findings. In section 4.5. and 5.5 I described my prior experiences of working in care related roles (for example as a Support Worker, a Healthcare Assistant and as a Care Home Research Facilitator) and my personal experience of supporting a close relative, my Nan, as she experienced several 'transfers' – from her own home, to hospital, to a 'Discharge to Assess' unit and finally to permanently reside in a care home, where she spent the final year of her life.

I have reflected on the ways in which these experiences have shaped my preconceptions of what care is and ought to be, how they have influenced my understanding of some of the challenges associated with caring for older people with complex health and care needs, and how they may have influenced some of the decisions that I have taken during this project. As noted previously in section 5.5, throughout analysis and through the writing of this thesis, rather than to portray staff as 'saints or monsters' (Foner, 1994, p245), I have sought to present a balanced account of staff behaviours by considering the contextual factors that influence staff decision-making. By being transparent about my thought processes, my own biases and the actions I took to reduce these biases, I hope I have reassured the reader and increased the trustworthiness of the findings I have presented.

9.6.2. Reflection on the project findings in light of COVID-19

As discussed in the Introduction, the data presented within this thesis was collected between May 2018 and November 2019, at a time few people within England, including people working in the care sector, were aware of COVID-19. The outbreak of COVID-19 has had a devastating impact on care homes in England. In addition to high levels of excess mortality amongst care home residents (Comas-Herrera and Fernandez, 2020), care homes have faced difficulty in obtaining tests and adequate personal protective equipment to keep residents and staff safe (Gordon et al., 2020, Harwood, 2020). Many authors have suggested that the pandemic simply highlighted pre-existing issues surrounding social care. Many of these issues, for example, lack of integration between health and social care services, funding pressures and negative public perceptions of care homes, were covered in Chapter 1 of this thesis.

On one hand, the completion of data collection prior to the widespread outbreak of COVID-19 was fortunate, preventing the study from being halted or significantly changed. However, given the impact COVID-19 is having on the care sector, particularly on decisions about whether or not residents should be transferred to and from hospital settings, the current and future applicability of the findings presented in this thesis may be questioned. Staff are likely to consider whether a resident may have COVID-19 whilst in the care home or whether they may be exposed to COVID-19 in hospital. Therefore COVID-19 will likely feature in staff decision-making, as they weigh up the potential benefits and risks of transferring a resident to hospital.

Despite the potential for COVID-19 to influence staff decision-making, the central argument, that hospital transfers from care homes can be conceptualised as a series of escalations, in which staff make complex and multifactorial decisions about risk, is likely to remain applicable in light of COVID-19. Although COVID-19 will likely represent an additional factor that staff must consider, many of the themes raised within this thesis remain, and will perhaps have even been magnified. This includes: a focus on the likely benefits and risks associated with transferring a resident to hospital (or not); the need for strong healthcare support in care home settings (particularly from

GPs); and a need to encourage family carers to think ahead about potential future deteriorations, needs and wishes (particularly at the end-of-life) to reduce the likelihood of disagreement between staff and family carers about the appropriateness of a hospital transfer. As such, the findings presented in this thesis will have application for policy and practice, both during the COVID-19 pandemic and beyond.

9.7. Recommendations for research, policy and practice

The final section of this thesis considers the implications of the findings presented, for research, for policy, and for practice. Although suggestions about the specific ways in which these recommendations could be implemented are presented at the end of the section and separated into recommendations for different stakeholders (see Boxes 1 - 4), they are not separated out in the discussion below as they are applicable to more than one stakeholder (researchers, policy makers, care home managers, health service staff) and/or require different stakeholders to work together.

9.7.1. Acknowledging complexity and foregrounding risk

My findings suggest that, in the context of care homes in England, staff decision-making about potential hospital transfers can be conceptualised as a series of escalations in which staff make complex, multifactorial decisions about perceived benefits and risks. This includes risks to residents, to themselves, to their social relationships, to the care home as an organisation and to wider health and social care systems. Therefore, in order to understand hospital transfers from care homes, one must first acquire a detailed understanding of the broader social context, or to use the language of Kleinman (2006) 'the local moral world' in which decisions are made.

At present, much academic research and policy surrounding hospital transfers from care homes focusses on reducing those which are considered 'inappropriate' - the limitations surrounding the concept of 'inappropriate' healthcare use have been discussed throughout this thesis. Within this chapter, I have suggested that this over-simplistic distinction - between transfers that are appropriate and inappropriate - does not capture the complexity of staff decision-making regarding potential hospital transfers. Moving away from

discussions of (in)appropriate transfers and towards an acknowledgement of the complexity involved during decision-making is an essential step in understanding hospital transfers from care homes.

Building on the suggestion that in order to understand why people make particular decisions, one must first understand the local moral world and what is 'most at stake' to decision-makers, Kleinman suggests that openly acknowledging risks and uncertainties can be beneficial. Throughout data collection, staff frequently described occasions in which the outcome of a transfer decision did not align with their own perception of what was 'best' for residents. On many of these occasions staff felt unable to implement what they felt was the right thing, because to do so would put other things that mattered to them at stake. This could include, but was not limited to, their reputation, employment and financial stability.

Foregrounding risks could be advantageous. For example, focussing on the multiple forms of risk that staff prioritise and manage can enable us to see logic in otherwise incomprehensible behaviour. This is particularly true for transfers that occur without the expectation of improved health and/or well-being for residents. In addition, closely examining the risks that staff have to navigate provides a deeper understanding of hospital transfers from care homes, illuminating the forces that shape individual understandings of risk and identify ways to reduce perceived risks. By reducing risks to other non-clinical things that are 'at stake' during transfer decisions, it is more likely that staff will be able to prioritise risks to residents in the future.

In section 7.3 I asserted that care homes as organisations could shape individual staff members' understandings of risk, which in turn could influence their decision-making. For example, when documents in the immediate environment reminded staff that they could be personally held responsible if particular actions were not undertaken, concerns about personal and professional risks for the decision-maker featured more heavily in staff decision-making, encouraging staff to undertake risk averse practices, often described as "erring on the side of caution". However, if care homes, at an organisational level, are able to shape individual staff members perceptions of risk, and in turn

ultimately to shape the steps staff take to manage risk, then they too can shape staff decision-making in ways that encourage staff to focus on risks to residents. Making changes at an organisational and institutional level to reduce these risks may help to ensure that non-clinical concerns are not most 'at stake' in staff decision-making. Alleviating the sense of vulnerability associated with these concerns may allow staff to prioritise the risks to the resident in future.

In two of the six care homes that participated in the study, staff took part in regular structured sessions which encouraged them to reflect on events that had occurred within the home. This included, but was not limited to, resident hospital transfers. Moving forwards, introducing discussions about the risks associated with hospital transfers may provide an opportunity for staff to critically reflect on their thought processes and the factors that influence them. Confronting these shared moral experiences openly and honestly may provide a means for identifying strategies and interventions that could lessen some of the risks that staff perceive. Even in the absence of immediate resolutions, regular reflection sessions in which care home managers and staff explore the ways risks are socially constructed and understood, could provide a means for allaying staff fears, that what matters most to them is at risk. This in turn, could encourage working practices that prioritise risks to residents.

9.7.2. Identifying, evaluating and implementing interventions based on their ability to address risk

The conceptualising hospital transfer decisions as a form of 'risk work' appears to be helpful for understanding the work of care home staff. However, further research is needed to explore the application of this concept to developing interventions aimed at ensuring residents receive appropriate care in an appropriate setting. In order to do this, researchers and policy makers should seek to identify the rational, non-rational and in-between strategies that staff use to manage risk during potential transfer situations. They should also seek to determine to what extent each of these strategies are effective and what conditions are required to maximise effectiveness. In turn, these strategies could then be built into services and interventions. Therefore, future research should consider the ways in which new and existing interventions to reduce

hospital transfers can help staff to manage or mitigate against risks. These findings provide insight for policy makers that seek to reduce the number of 'inappropriate' hospital transfers from care homes.

Existing interventions to reduce hospital transfers and/or admissions from care homes have been categorised into three main strands. These are: *'interventions to structure or standardise clinical practice'*, for example promoting standardised decision-aids and assessment tools; *'geriatric specialist services'* that provide specialised healthcare for residents; and *'interventions that aimed to increase influenza vaccinations'* (Graverholt et al., 2014). Using the lens of 'risk work' to re-evaluate these interventions could help to explain why particular interventions are effective. For example, it could be sensible to suggest interventions which introduce healthcare professionals into care homes may be successful if staff feel that the addition of these healthcare professionals helps to alleviate risk. This could include alleviating risks to the resident by providing additional skills and knowledge, or alleviating risks to the decision-maker by shouldering some of the responsibility for decision-making.

Another common strategy for reducing hospital transfers from care homes, which some might argue has a more robust evidence base, is to ensure, where appropriate, care home residents have advance care plans in place. This strategy can help to reduce the likelihood that there will be disagreements amongst staff during 'in-the-moment' decision-making, reducing the risks that these social relationships will be damaged. Recommendations regarding advance care planning will be discussed in more detail in section 9.7.5.

As discussed throughout this thesis, there is currently a lack of agreement about what constitutes an (in)appropriate transfer across academic research (Lemoyne et al., 2019) and amongst healthcare professionals that support care home residents (Harrison et al., 2016). This lack of agreement has implications for interventions intended to reduce inappropriate transfers. Indeed, previous evaluations of projects designed to improve care transitions for older people have found that a lack of consensus, particularly between hospital and care home staff, about the nature of the 'problem' to be addressed posed a significant barrier to improvement (Sutton et al., 2016). Until a consensus is

reached, or more nuanced, context-specific understandings of hospital transfers are developed, it will be difficult to robustly evaluate interventions that aim to reduce 'inappropriate' transfers.

9.7.3. Valuing experiential knowledge

The findings of this project highlight the importance that staff place on 'knowing' each resident. Staff perceived this experiential-based form of knowing to be a legitimate source of knowledge they could use to identify potential deteriorations in residents' health and to make resident-specific assessments about the likely benefits and risks of initiating or avoiding a hospital transfer. However, relying on experiential knowledge during decision-making became problematic under certain conditions, for example when new residents moved into the home or new members of staff came to work there. Developing ways of rapidly building experiential knowledge, for example by taking a detailed medical and social history of a resident when they move into a facility, or by 'buddying' new members of staff with more experienced staff who have developed rich experiential knowledge, may be beneficial to ensure staff come to know what is usual for each resident, which in turn will enable them to identify and interpret changes in residents' health and wellbeing more accurately

Despite positioning the use of experiential knowledge as a legitimate way of assessing risk, staff often described feeling vulnerable when making decisions based on this form of knowledge. This appeared to be related to difficulties in articulating (and therefore justifying) decisions and actions based on experiential knowledge due to its subjective nature, particularly in the presence of other contradictory forms of risk knowledge. Although seldom expressed explicitly, it appeared that these concerns were rooted in a belief that this form of knowledge was believed to hold less value by people *outside* of the care home team, for example by healthcare professionals such as GPs and paramedics, who often privileged objective, codified sources of knowledge, for example knowledge derived from structured clinical assessments. Despite holding this broad view, staff acknowledge that the degree to which this form of knowledge was prioritised and privileged varied amongst individual healthcare

professionals but was influenced by the social context in which healthcare professionals worked.

As discussed in section 2.3, attempts to reduce the need for hospital care amongst care home residents have focussed on interventions to structure or standardise clinical practice, for example promoting standardised decision-aids and assessment tools. Staff suggested that external healthcare professionals placed value on structured nursing observations, believing this approach to assessing health was more objective and therefore more legitimate. However, in contrast, the results of this study suggest care home staff privilege experiential knowledge, choosing to use structured nursing observations to confirm or further investigate concerns grounded in experiential knowledge. The results of this study could point towards standardised tools that are able to accommodate (and therefore legitimise) the experiential knowledge of care home staff, for example the RESTORE 2 tool, developed by the Royal College of Physicians, which combines 'soft signs' of deterioration (for example changes in what is usual for the resident) alongside structured nursing observations.

9.7.4. Recognising the central role of GPs in providing healthcare in care homes

For decades, concerns have been raised about the healthcare support available to people living in care homes in England (BGS, 2011, Goodman et al., 2017a, NHS England, 2016, RCP et al., 2000). In particular, research has highlighted extensive inequality and variation in access to medical services across care homes in England (Glendinning et al., 2002, Goodman and Woolley, 2004, Gordon et al., 2014, O'dea et al., 2000, Ong et al., 2011). At present, responsibility for healthcare provision in care homes lies with primary care services, predominantly GPs. The results of this study suggest that care home staff value the support of a GP. Care home staff prefer to have contact with an individual or small team of GPs that visit the home regularly, suggesting that this enables them to develop a relationship and assists GPs in getting to 'know' each resident – particularly what is (un)usual and therefore representative of a threat to a resident's health or well-being.

Furthermore, results suggest that the role of GPs extends beyond attending to individual residents, with staff suggesting that GPs also play a crucial role in managing relationships with family carers, reassuring family carers and ensuring they have an accurate perception of the benefits and limitations of hospital care. Therefore the results of this study provide support for calls to formally commission GPs to work with care homes in order to legitimise the use of more extensive GP time and to acknowledge the importance of care home medicine, which would enable better healthcare support in care homes (Alcorn et al., 2020, Glendinning et al., 2002, Goodman et al., 2017a, Oliver et al., 2014).

9.7.5. Creating advance care plans that decision-makers feel comfortable following

Staff perceived both the process and the output of advance care planning to be useful. The process of creating an advance care plan provided an opportunity for staff to understand the wishes of residents and their family carers in the event of a potential deterioration in health. In doing so, advance care planning moved decision-making temporally, so that discussions and decisions took place prior to a deterioration. This minimised the potential for disagreement between staff and family carers about the most appropriate course of action in the face of a deterioration in a resident's health. In addition, the output, in the form of the written advance care plan document, was also valuable as it could be used to guide 'in-the-moment' decision-making.

Often staff were concerned that the decision *not* to transfer a resident to hospital would be perceived as a failure to fulfil a duty of care. Care home staff suggested that the presence of an advance care plan provided them with a defence against potential future suggestions that they had 'not done enough'. Drawing on the work of Susie Scott (2018) into the 'sociology of nothing' provides insight into the benefit of advance care planning. The author suggest that negatively defined phenomena, for example non-participation and non-identification, are symbolic social objects, created and managed through social interaction. Scott (2018) differentiates between 'nothing' that is accomplished either by active commission (i.e. by doing and/or being a non-something) and

'nothing' that is accomplished by passive omission (i.e. by not-doing and/or not-being something). Following an advance care plan which advises against a transfer enables staff to frame their decision as a deliberate and considered act of commission (i.e. actively deciding to 'do nothing'), rather than a passive act of omission (failing to act or respond). Staff suggested that this subtle but significant shift provided them with the assurance that they were 'covered' and therefore not personally or professionally at fault, or at risk, of deciding against a hospital transfer.

Despite their advantages, advance care plans are subject to interpretation at the time of a deterioration. My findings show that, from the perspective of care staff, plans should be clearly worded, specific, and unambiguous, reviewed regularly and understood by families in order for them to be effective. For GPs, who are perceived by staff to have overall responsibility for advance care planning for care home residents, the challenge is to prepare a plan that is specific enough to reduce the likelihood that staff and other healthcare professionals will mis-interpret or raise concerns about the applicability of the plan to the situation at hand, but general enough to reflect the illness trajectories of care home residents, which can often be unpredictable. Further research is needed to understand how to achieve this balance.

Furthermore, my study showed the *process* of advance care planning was valuable, suggesting that rather than introducing policies, interventions and incentives that simply seek to increase the number of residents with advance care plans, there is a need to create a climate in which there is time for adequate discussion. This should include regular updates as residents' clinical situations and wishes change. Although this will be time consuming, my findings suggest that it will support more effective advance care planning in the context of care homes.

Box 1: Recommendations for care home providers and managers

- Create opportunities for staff to openly discuss their perceptions of risk surrounding hospital transfers in order to identify opportunities to reduce particular fears or concerns. This could be via one-to-one discussions or structured group reflection.
- Regularly encourage residents and their family carers to think about and discuss the potential benefits and risks associated with hospital transfers (which should be documented in an advance care plan where possible).
- Develop ways to accelerate the development of experiential knowledge when new residents and new staff enter the home (for example through collecting a detailed social and medical history by involving family carers, or by 'buddying' less experienced staff with more experienced staff).

Box 2: Recommendations for healthcare services and staff

- Acknowledge the complexity of decisions surrounding hospital transfers from care homes and move away from over-simplistic language associated with (in)appropriate admissions.
- Educate staff about the different forms of knowledge that individuals use to make decisions (for example by using the language associated with models of clinical decision-making and sociological theories of risk, which legitimise the use of both objective and subjective approaches to decision-making).
- Use a clinical approach and decision tools which include and legitimise the experiential knowledge of care home staff (e.g. RESTORE 2).

Box 3: Recommendations for researchers

- When developing, implementing and evaluating new or existing interventions regarding hospital transfers and/or admissions from care homes, seek to: i) provide an explanation of how the intervention enables staff to manage risks and ii) provide information on the broader social context that is required in order for the intervention to be successful.
- Investigate ways that advance care plans can be generalisable enough to accommodate the sometimes less predictable illness trajectories of care home residents, but specific enough that staff and healthcare professionals feel comfortable to interpret and follow them.
- Move away from research based on over-simplistic notions of (in)appropriate hospital transfers and towards more nuanced understandings of hospital transfers as located within a broader local context.

Box 4: Recommendations for policy

- Commission healthcare services to work with care homes to ensure care home residents have timely access to healthcare professionals and to support the development of relationship between healthcare professionals and people working and living in care homes.
- When implementing policies surrounding advance care planning, rather than focussing on the number of residents with an advance care plan in place, focus on developing a climate in which there is adequate time to discuss and review plans.

9.8. Summary

Guided by the central research question, '*How do care home staff decide to initiate a resident hospital transfer within the context of care homes in England?*', the aim of this project was to develop an in-depth understanding of staff decision-making when deciding whether or not to transfer a resident to hospital. The findings presented in my thesis suggest that within the context of care homes in England, when deciding whether or not to transfer a resident to hospital, care home staff make complex, multifactorial decisions, which are centred on potential benefits and risks. This can include risks to: residents, staff (as decision-makers) and their social relationships, care homes (as organisations), and wider health and social care systems. In order to fully understand the factors that drive hospital transfers from care homes, it is necessary to attend to the different forms of risks that staff perceive during transfer decisions and to the wider social contexts in which transfer decisions occur. Acknowledging the complexity of staff decision-making and foregrounding staff perceptions of risk provides insights for further research, practice and policy.

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APPENDICIES

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APPENDIX A: Interview schedule

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Interview Questions

Prior to starting the interview -

Thank you. Remind - free to withdraw / take a break at any time. This is not a 'test' and there are no right or wrong answers - I am interested in your experience of occasions in which residents have been transferred out of the care home to a hospital. Remind - to remind confidential, unless a risk to residents.

Warm up question:

Can you tell me a little bit about your role in the care home?

What is your job title? What does your role involve? How long have you been working here? Prior to this role, did you work in a similar environment or somewhere different?

Experience of transfers:

1. Ok, so in this project I am particularly interested in occasions in which a resident may need to be transferred from the care home to a hospital – Can you think of any occasion in which this has happened whilst you were on shift?
Probes - Can you tell me a little bit about the chain of events (what happened)? What was your involvement in this process? Who else was involved in this process?
2. Thinking about the occasion which you just described (question 2) – how typical is this of resident transfers?
Probes – Is this the usual pattern / chain of events? Was this occasion particularly different? Is the process here (in the care home in which you work) similar or different to other places you have worked?
3. When you were making that decision [to call GP / 999] what things did you take into consideration?
Probe: What other things may you consider? How confident were you in your decision?
4. What are the most important influences on your decision?
Probes: Are your decisions influenced by: written policies and protocols? Other people? Wider organisational factors such as staffing levels or your own workload?
Probes: Do you consider the risks / benefits of transferring / not transferring a resident? What do you feel those risks / benefits are?
5. Are any other people involved in the transfer process?
Probe: Family? Care home staff? Other healthcare professionals /services?
Probe: Do you ever disagree? How do you manage that?

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More general views on transfers:

7. Are there any reasons for which you feel a transfer is always necessary?
8. Are there any reasons for which you feel a transfer could be avoided and the resident could be kept in the home?

Preventing / reducing transfers:

9. Can you think of a time where a resident was prevented from needing a transfer, for example times when you were able to manage the resident's condition in the care home?
10. Can you think of anything that would enable care homes to reduce the number of residents that are transferred to hospital?

Vignettes

Ok, thank you for answering my questions here in part 1. Next I would like to show you a number of scenarios. Please could you read through the scenarios and discuss your thoughts. I am happy to read them to you if you would prefer.

[Introduce 1-3 vignettes per interviewee – at least one that is related to the content of the previous answers and one that is not]

Final questions:

11. I feel you have answered all of the questions I wanted to ask – is there anything that you would like to add that we have not yet discussed?
12. Do you have any question for me? |

APPENDIX B: Vignettes used during interviews

Scenario 1

Mr Barlow is a 85 year old male who has been living at the care home for 2 months. Mr Barlow has advanced dementia and is usually disorientated to time and place. Mr Barlow spends a lot of time walking around the home. On your shift you witness Mr Barlow trip and fall. Mr Barlow does not hit his head and is able to get up and walk. Mr Barlow is not displaying any signs of pain, however you notice that his arm is swollen and warm to touch.

Probe – You call Mr Barlow’s family to inform them that although he appears well, you suspect he may have a fracture to his arm. His family state that they would prefer if he did not attend the hospital.

Scenario 2

Mrs Smith is a 77 year old female who has been living at the care home for 3 weeks. She has been diagnosed with moderate dementia, high blood pressure and asthma. She was previously living alone in her own home but her family grew concerned when they noticed that Mrs Smith was regularly forgetting to take her medication and her neighbours reported having to help Mrs Smith find her way home after she had been to the shops. Mrs Smith usually has a poor appetite but over the past 2 days she has also had a very small fluid intake. Mrs Smith appears to be drowsy, more confused and her mouth and lips appear dry. You become concerned that she is dehydrated.

Probe - Mrs Smith’s daughter visits later that day, reports that she is concerned about her mother and asks you to call the GP.

Probe 2 – The GP is unable to visit the home today and asks you to call again tomorrow

Scenario 3

Mrs Shah is an 84 year old female who has been living at the care home for 9 months. Mrs Shah had a major stroke and as a result has difficulty with mobilising independently. Mrs Shah also has problems with swallowing, but these have become worse over time and during the past couple of weeks you have witnessed two occasions in which Mrs Shah appeared to be choking on her food. You are on shift with Mrs Shah and notice that she does not have any of her breakfast and she appears tired. You decide to record Mrs Shah’s physical observations (blood pressure, temperature) and notice that she has a high temperature of 38.5°C but other observations are within normal range.

Scenario 4

Mrs West is a 91 year old female who has been living at the care home for 6 months. Mrs West has a diagnosis of Parkinson’s disease. She previously lived at home, but found difficulty in performing daily living tasks independently (such as washing, dressing and cooking). Whilst on your shift you assist Mrs West to make her way to the dining room for her breakfast. You notice that Mrs West is having difficulty breathing and is sweating.

Probe: Before moving into the care home Mrs West was aware that her condition would progressively get worse so made the decision to have a DNA CPR* order in place. Would this alter the way in which you may respond?

*DNA CPR (Do Not Attempt Cardiopulmonary Resuscitation) order is an advanced decision that a person should not receive cardio-pulmonary resuscitation if their heart or breathing stops, which may be made due to an individual’s wishes and/or when CPR is felt to be clinically inappropriate.

Scenario 5

Mr Bayliss is an 81 year old male. Mr Bayliss moved into the care home 12 months ago after he had a major stroke that resulted in him requiring full-time assistance with daily living. Mr Bayliss is unable to use a toilet or commode due to difficulties with his mobility. As a result he has a long-term indwelling catheter. Whilst emptying Mr Bayliss’ urine bag you notice that his urine is a dark colour and has a strong odour.

Probe: [If reporting to senior member of staff] The staff member you report this to states that Mr Bayliss is probably dehydrated

APPENDIX C: Participant Information Sheet (for staff taking part in interviews)

V1 14/03/2018



Participant Information Sheet

Project Title: Understanding Transfers from Care Homes to Hospitals in England

Investigators: Fawn Harrad, Dr Chris Williams, Professor Natalie Armstrong

You are invited to take part in a research study. Before you decide if you would like to take part, it is important that you understand why the study is being carried out and what your participation would involve. Please take the time to read the following information carefully. Please ask if there is anything that is not clear or if you would like more information.

1. What is the purpose of this study?

This project is being carried out by Fawn Harrad as part of her PhD at the University of Leicester. The purpose of this study is to develop a better understanding of occasions in which a care home resident might be transferred from the care home to a hospital. In particular, this project aims to better understand the process of transferring a care home resident to the hospital (i.e. the chain of events), the people involved in the process and the factors that influence the decision to transfer.

2. Why have I been invited to take part?

You have been invited to take part in the study because you are currently working in a care home. Care home staff play a crucial role in managing the health of care home residents. Therefore the researcher (Fawn) would like to speak with care home staff, including managers, nurses and care staff.

3. Do I have to take part?

No, your participation is completely voluntary. Although the care home manager has given permission for the researcher to approach you, you are not required to take part in the study. If you decide that you do not want to take part in the study this will not lead to any repercussions. If you decide that you would like to take part, you are able to change your mind and stop the interview at any time (please see question 8 for more information).

4. What will my participation involve?

You will meet with the researcher (Fawn) to take part in a one-to-one interview. The interview will last approximately 30 minutes to 1 hour, depending on how much you would like to say. The researcher will ask you questions about your experience of resident transfers. The researcher will also present you with a number of written scenarios and ask you to discuss what care home staff could do in each situation. The interview will take place in a private room at the care home and will be audio-recorded and later transcribed by the researcher.

V1 14/03/2018



5. Will the information I provide be kept confidential?

Yes, any identifiable data you provide will be kept confidential. No identifiable data will be shared outside of the research team and we will not be shared with anyone from your work environment. Any quotes will be fully anonymised before publication so that no-one can identify you, a resident, colleague or your place of work. If you disclose information that leads the researcher (Fawn) to be concerned about the welfare of residents, she has a responsibility to share this information, confidentially, with an appropriate person or body.

6. What are the possible benefits of taking part?

This study may not benefit you directly but your participation will help the researcher to develop a better understanding of resident transfers. You will not be paid for your participation.

7. What are the possible disadvantages / risks?

The risks of taking part are minor. For example, you may find specific questions sensitive or distressing. In this situation, you will not have to answer any questions you are uncomfortable with. You may take a break from the interview at any time and return to it at a later date and time convenient for you.

8. What if I decide to take part but later change my mind?

You are able to withdraw from the study at any time without giving a reason. If you take part and later decide you would like to withdraw your data, you can contact a member of the research team using the details at the bottom of this form.

9. Who is funding and organising this study?

This study is funded by the University of Leicester and is being organised by Fawn Harrad and her supervisors in the Department of Health Sciences.

10. Who has approved this study?

This study gained ethical approval from the University of Leicester's Research Ethics Committee on Friday 13th April 2018.

Contact information:

If you would like more information about the study please do not hesitate to contact me (Fawn Harrad). Alternatively if you have concerns about the way in which the study is being carried out you can contact the supervisory team Dr Chris Williams and Professor Natalie Armstrong at the University of Leicester.

Fawn Harrad
fh127@le.ac.uk
07903627118

Dr Chris Williams
cdw4@le.ac.uk
0116 252 5430

Prof Natalie Armstrong
natalie.armstrong@le.ac.uk
0116 252 3197

APPENDIX D: Consent Form (for staff taking part in interviews)



V1 13/03/2018

Consent Form – Interview with Care Home Staff

Project Title: Understanding Transfers from Care Homes to Hospitals in England

Investigators: Fawn Harrad, Dr Chris Williams, Professor Natalie Armstrong

Before completing this form you should have been given time to read the Participant Information Sheet, to ask questions and decide whether you would like to take part. If you have decided that you would like to take part in the study, please read the information below. Please initial each box to signal that you have read and understood the form. Please also provide your name, signature and today's date at the bottom of the form.

- I confirm I have read the Participant Information sheet (Version 1, 14/03/2018) had the opportunity to ask further questions and have had them answered

- I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified, except in circumstances where the researcher is concerned about risks to my welfare, or the welfare of others

- I agree that data gathered in this study may be stored anonymously and securely, and may be used for future publications related to this study

- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason by using the contact details provide on the Information Sheet (Version 1, 14/03/2018)

- I agree to take part in this study

Participant's name: _____

Participant's signature: _____

Date: _____

Investigator's name: _____

Investigator's signature: _____

Date: _____

APPENDIX E: Ethical approval from University of Leicester's Research Ethics Committee



University Ethics Sub-Committee for Medicine and Biological Sciences

13/04/2018

Ethics Reference: 15304-fh127-Is:healthsciences

TO:

Name of Researcher Applicant: Fawn Harrad

Department: Health Sciences

Research Project Title: Understanding Transfers from Care Homes to Hospitals in England

Dear Fawn Harrad,

RE: Ethics review of Research Study application

The University Ethics Sub-Committee for Medicine and Biological Sciences has reviewed and discussed the above application.

1. Ethical opinion

The Sub-Committee grants ethical approval to the above research project on the basis described in the application form and supporting documentation, subject to the conditions specified below.

2. Summary of ethics review discussion

The Committee noted the following issues:

Thanks you for this application which we are pleased to approve.

3. General conditions of the ethical approval

The ethics approval is subject to the following general conditions being met prior to the start of the project:

As the Principal Investigator, you are expected to deliver the research project in accordance with the University's policies and procedures, which includes the University's Research Code of Conduct and the University's Research Ethics Policy.

If relevant, management permission or approval (gate keeper role) must be obtained from host organisation prior to the start of the study at the site concerned.

4. Reporting requirements after ethical approval

You are expected to notify the Sub-Committee about:

- Significant amendments to the project
- Serious breaches of the protocol
- Annual progress reports
- Notifying the end of the study

5. Use of application information

Details from your ethics application will be stored on the University Ethics Online System. With your permission, the Sub-Committee may wish to use parts of the application in an anonymised format for training or sharing best practice. Please let me know if you do not want the application details to be used in this manner.

Best wishes for the success of this research project.

Yours sincerely,

Dr. Chris Talbot
Chair

APPENDIX F: Provisional approval from Social Care Research Ethics Committee

Social Care REC

Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 0207 972 2568
Fax:

10 October 2018

Miss Fawn Harrad
PhD Researcher
University of Leicester
Room 4.11, George Davies Centre
University of Leicester, University Road
Leicester
LE1 7RH

Dear Miss Harrad

Study Title: From the care home to the hospital: Developing an understanding of resident transfers from care homes in England
REC reference: 18/IEC08/0033
IRAS project ID: 244710

The Research Ethics Committee reviewed the above application at the meeting held on 05 October 2018. Thank you for attending to discuss the application. The Committee noted that this was a very good application, especially the knowledge of the Mental Capacity Act requirements.

Provisional opinion

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair in consultation with Dr Michael Dunn.

Further information or clarification required

1. The Committee would like to inform Miss Harrad that applications to HRA RECs need to include the whole project, including any research with staff. During the discussions you confirmed that interviews with staff had already taken place and the observations were intended to validate the information from the interviews. The whole project should have been submitted to the Committee. The Committee therefore request information on the first part of the project, the interviews with staff and whether these had now finished.

2. The Committee requested clarification on how Miss Harrad would use her time (6 weeks) in the care homes. Would she join in activities? This could lead to a blurring of roles between researcher and member of staff. How would she ensure that participants understood her role? Would she be in the care home every day of the 6 weeks? Would she see enough transfers during the 6 weeks and what would be the process if there were insufficient transfer during this time?
3. The Committee had not been completely satisfied with the arrangements in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act. The Committee had not been clear from the application that Miss Harrad understood that participants showing signs of distress due to the research must be withdrawn immediately and permanently from the research. Provide confirmation that this requirement would be followed.
4. Develop a formal consent process, including the production of a consent form for visiting health care professionals so that they could consent to being observed. Revise the current PIS for them.
5. Forward a protocol for dealing with safeguarding issues.
6. In consultation with the care homes, develop a process so that members of the care home staff photocopy sections of resident's case notes involving the transfer to hospital only and give these to Miss Harrad so that she does not have access to whole of the case notes.
7. Provide clarification on the relationship between the requirements of the Mental Capacity Act and any Advanced Directives participants may have as well as how the End of Life Pathway would fit in with the transfer to hospital.
8. Develop a process for appointing nominated consultees and a participant information sheet (PIS) for them. The current Consultee Declaration form would be suitable for them.
9. The Committee requested the following changes to the participant documentation:
 - a. Add information to the PISs about having the researcher in the home conducting observations, even if the person did not agree to participate.
 - b. Develop a consent form for residents with capacity which includes consent for access to the transfer section of the case notes and consent for the observations.
 - c. Following consultation with the care home add information about how the £100 would be spent to all the PISs.
 - d. On the consultee PIS reference was made in the section 'What are the possible benefits/risks of taking part' to 'your involvement' which is inaccurate as consultee's are not involved.
 - e. The Committee recommend that the supervisors were not named on the PISs, instead 'supervised by members of staff at the University' or even 'senior staff'.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact the REC Manager, Mrs Barbara Cuddon, rescommittee.social-care@nhs.net

APPENDIX G: Favourable opinion for the minor amendment from Social Care Research Ethics Committee



Social Care REC
Ground Floor
Skipton House
80 London Road
London
SE1 8LH

Telephone: 0207 972 2568
Fax:

12 November 2018

Miss Fawn Harrad
PhD Researcher
University of Leicester
Room 4.11, George Davies Centre
University of Leicester, University Road
Leicester
LE1 7RH

Dear Miss Harrad

Study title: From the care home to the hospital: Developing an understanding of resident transfers from care homes in England
REC reference: 18/IEC08/0033
IRAS project ID: 244710

Thank you for your letter of 05 November 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair in consultation with Dr Michael Dunn.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

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

The Chair and Dr Dunn had been impressed with how well you had responded to the Committee. You had obviously thought hard about their comments.

The Chair and Dr Dunn are happy with your suggestions in the section 'Request for Further Advice' – i.e. getting retrospective consent from the visiting doctors, and retrospective consent from residents for looking at records. They think this is a pragmatic response which protects the participants. Please forward the revised documents as a minor amendment for information.

Mental Capacity Act 2005

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

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at <http://www.r4forum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ('participant identification centre'), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication terms).

APPENDIX H: Protocol for reporting concerns

Protocol: Reporting Concerns

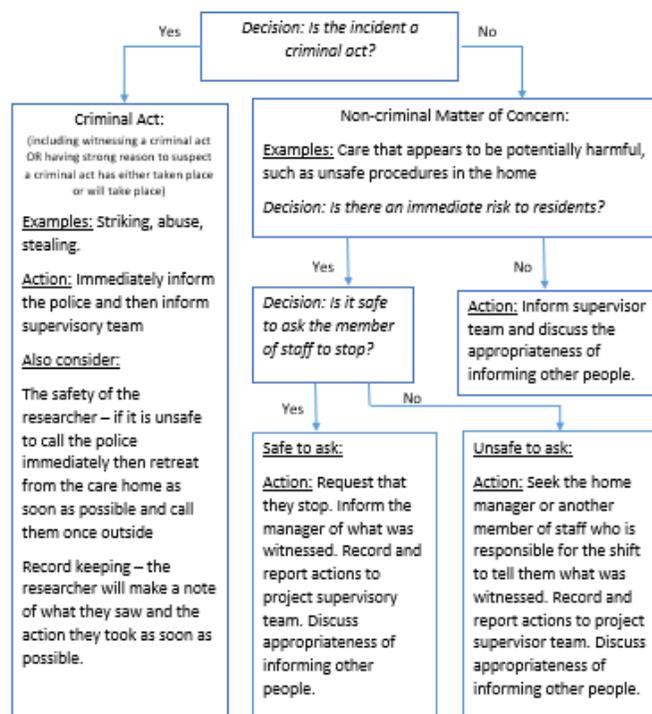
Study title: From the care home to the hospital: Developing an understanding of resident transfers from care homes in England

REC reference: 18/IEC08/0033

IRAS project ID: 244710

This protocol describes the possible steps the researcher (Fawn Harrad) could take if she were to come across something that she felt needed reporting whilst in a care home as part during the research project listed above.

The protocol can also be summarised using the flow chart below:



Informing other appropriate people / organisations:

It may also be appropriate to contact the people / organisations listed below, for example where concerns have been reported to the manager but the researcher continues to witness unsafe procedures. However, the people / organisations will only be contacted after discussion with the researcher's supervisory team.

- Local council boards for Adult Social Care
- Local council Safeguarding Leads (available within normal office hours)
- Local Emergency Social Work Teams (available outside of normal office hours)
- The Care Quality Commission (Tel: 03000 616161 / Email: enquiries@cqc.org)

The exact names and contact details of a-c will be identified once the care home manager has agreed that the care home will take part in the research study. This is because the study will recruit care homes across the East Midlands and West Midlands and it is not yet known which local council participating homes will fall under.

At all times, the researcher will seek to ensure that their actions relating to reporting of concerns are responsible and proportionate. The researcher understands that whilst they have responsibility to report anything that is of concern to them, they do not have any powers of arrest and are therefore to report to emergency services in the event of witnessing or suspecting a criminal act.

APPENDIX I: Participant Information Sheet for Staff and Visiting Healthcare Professionals (ethnographic phase)

Participant Information Sheet for Staff and Visiting Healthcare Professionals

[Name of care home] is currently taking part in a research study titled, "Understanding hospital transfers from care homes in England".

1. Who is carrying out this study?

This project is being carried out by Fawn Harrad as part of her PhD at the University of Leicester and this is being supervised by senior staff from the Department of Health Sciences at the University of Leicester



2. What is the purpose of this study?

The purpose of this study is to develop a better understanding of occasions when care home residents are transferred to a hospital. In particular, this project aims to understand the chain of events when transferring a resident, the people involved in the process and the factors that influence the decision to transfer.

You are being invited to take part in the study because you are currently either working at [name of care home] or are visiting a resident there.

3. What will the study involve?

The researcher will be spending long periods at [name of Care Home] (between 4 and 10 hours per visit) over the course of approximately 6 weeks, during which the following activities will be undertaken:

- Observations of the way in which residents' health conditions are managed
- Observations of occasions in which a resident may need a transfer to the hospital
- Observing interactions between staff, residents and visiting healthcare professionals, such as GPs
- Informal interviews about your experience of being involved in a resident transfer
- Reading [Name of Care Home's] official policies relevant to resident transfers
- Looking at the way in which transfers are written about in residents' care notes. Fawn will only have access to copies (either printed copies or photo-copies of written notes) of the sections of the care notes that are relevant to a hospital transfer, potential or actual. These sections will not contain personal identifiable data. Fawn will not have access to complete sets of care notes.

Do I have to take part?

No, participation is completely voluntary. Although the care home manager has given permission for the researcher to be present in the home you are not required to take part in

the study. Specifically, you do not have to speak with the researcher and if you prefer not to be observed, please let the researcher or the care home manager know. This will not lead to any repercussions. Even if you decide not to participate, the researcher will be present in the home observing other people.

4. Will personal information be kept confidential?

Yes, all identifiable data (e.g. your name, job title) will be kept confidential. No identifiable data will be shared outside of the research team listed at the end of this information sheet, or with other people in the care home. Any quotes will be fully anonymised before publication so that no-one can identify you, a resident, colleague or [name of Care Home]. However, if you disclose information that leads the researcher to be concerned about the welfare of residents, she has a responsibility to share this information, confidentially, with an appropriate person or body. Please also see the information provided at the end of this sheet regarding the University of Leicester's role as sponsor of this study.

5. What are the possible benefits / risks of taking part?

This study may not benefit you directly but your participation will help the researcher to develop a better understanding of resident transfers. The risks of taking part are minor. For example, you may find specific questions sensitive or distressing or you may feel that you would prefer not to be observed at times. If you feel this way, please inform the researcher or care home manager, you do not have to be observed and you do not have to answer any questions you are uncomfortable with.

6. What if I decide to take part but later change my mind?

You are free to withdraw from the study at any time without giving a reason and without repercussion. If you take part and later decide you would like to withdraw please contact a member of the research team using the details at the bottom of this form. Any data you have provided will be retained for use in the study unless you explicitly request for it to be removed and destroyed.

7. Who is funding and organising this study?

This study is sponsored by the University of Leicester and is being organised by Fawn Harrad and her supervisors in the Department of Health Sciences who is also funding the study.

8. Who has approved this study?

This study gained ethical approval from the Social Care Research Ethics Committee.

Contact information:

If you would like more information about the study please do not hesitate to contact:
Fawn Harrad (fh127@le.ac.uk / 0790362711)



Understanding hospital transfers from care homes in England

Statement from the University of Leicester:

The University of Leicester is the sponsor for this study based in UK. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leicester will keep identifiable information about you [for 5 years after the study has finished].

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information <https://www2.le.ac.uk/offices/ias/dp> or by contacting Information Assurance Services 0116 229 7945 or by emailing ias@le.ac.uk.

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#).

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer is ~~Parmit~~ ^{Parmit} Gill and you can contact them at pg170@le.ac.uk.

More detail can be found here: <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/what-you-need-do/transparency/>

APPENDIX J: Consent Form for Staff and Visiting Healthcare Professionals
(ethnographic phase)



Understanding hospital transfers from care homes in England

I

Participant Consent Form
Care Home Staff

Study title: Understanding hospital transfers from care homes in England
Investigators: Fawn Harrad, Dr Chris Williams and Professor Natalie Armstrong

Please read the statements below and initials each box to signal if you agree.

- | | Initials |
|---|--------------------------|
| 1. I confirm that I have read the information sheet dated 06/09/2018 (version 1.0), had the opportunity to discuss any questions and these have been answered. | <input type="checkbox"/> |
| 2. I understand that my participation in the research is voluntary and that I am free to withdraw at any time by talking to the researcher or by using the contact details provided on the aforementioned information sheet. | <input type="checkbox"/> |
| 3. I agree to being observed. This will include observations of the way in which resident's health conditions are managed, particularly at times where residents may require a transfer to hospital. I understand that observations can occur within any part of the homes. | <input type="checkbox"/> |
| 4. I agree to being approached for informal conversations and I understand that what I say will be confidential unless the researcher has concerns about the safety of residents. | <input type="checkbox"/> |
| 5. I understand that the information I provide will be anonymized and my personal information will be removed before the results are analysed and written up for the researcher's doctoral thesis, which could include the use of direct quotes. | <input type="checkbox"/> |
| 6. I agree that any study-related data will be stored on University of Leicester secure computers, solely for the purpose of this research. | <input type="checkbox"/> |
| 7. I understand that my study-related data may be looked at by responsible individuals from the study team, Sponsor, and regulatory authorities where it is relevant to my taking part in the research. I give permission for these individuals to access this information. | <input type="checkbox"/> |

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

(Optional) If you would like to receive a summary of the study results by email, please write your email address in the space provided: _____

APPENDIX K: Participant Information Sheet for Residents with capacity (ethnographic phase)

Understanding hospital transfers from care homes in England

UNIVERSITY OF LEICESTER

Study Information Sheet for Residents

[Name of care home] is taking part in a research project.

Who is carrying out this study?

This study is being carried out by Fawn Harrad as part of her PhD at the University of Leicester.



What is the purpose of this study?

Fawn is interested in 'hospital transfers'. These are occasions in which residents are transferred from the care home to a hospital.

You have been invited to take part in the study because you are living at [name of care home]



What will the study involve?

Fawn will be:

- Spending time at [name of Care Home]
- Watching staff to see how they help residents when they are unwell
- Talking to people about hospital transfers
- Reading sections of resident's care notes (only when they are relevant to the project)
- Making notes about all of the above



Do I have to take part?

No. You do not have to speak with Fawn. If you prefer that Fawn did not observe you, please let Fawn or any member of staff know. This will not affect your care in any way. If you do decide to take part you can change your mind at any time. Even if you decide not to participate, Fawn will be present in the home observing other people.



Page 1 of 2 IRAS number: 244710 V2.0 22.10.2018

Understanding hospital transfers from care homes in England

UNIVERSITY OF LEICESTER

What are the possible benefits / risks of taking part?

This study may not benefit you but your involvement will help Fawn to understand hospital transfers.

You may not want to be observed by Fawn. If this happens, please tell Fawn or a member of staff. Fawn will stop observing you immediately.



What will happen to my personal information?

Fawn will not collect any personal information about you (e.g. your name, date of birth, medical conditions). However, if Fawn is concerned about you or other residents, she has a responsibility to share this information with an appropriate person or body.

If you would like to find out more about how data from the study will be used and stored, please ask and we will provide you with this information.



Who has organised, funded and approved this study?

This study is sponsored by the University of Leicester.

The study and is being organised by Fawn and her supervisors in the Department of Health Sciences. They are also funding the study.

The study has been also been approved by the Social Care Research Ethics Committee.



Who can I contact for more information?

You can contact Fawn Harrad:
Tel: 07903627118 / Email: fh127@le.ac.uk



Page 2 of 2 IRAS number: 244710 V2.0 22.10.2018

APPENDIX L: Participant Information Sheet for Personal and Nominated Consultee's (ethnographic phase)

Understanding hospital transfers from care homes in England



Information for Personal Consultee

Project Title: Understanding hospital transfers from care homes in England

Investigators: Fawn Harrad, supervised by senior staff from the Department of Health Sciences at the University of Leicester.

Introduction

[Name of Care Home] is taking part in the above referenced research study. We believe your relative/friend is unable to decide for himself/herself whether or not to participate in this study.

To help decide if he/she should be included the study, we'd like to ask your opinion about whether or not they would want to be involved. We ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research because these should take priority.

We will keep you fully informed during the study so you can let us know if you have any concerns or you think that your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part it will not affect the standard of care they receive in any way. If, at a later date, you think that your friend/relative should be withdrawn from the study, please let the researcher know. The researcher would like to retain any data already collected up until the point of their withdrawal, but should you request otherwise, any data will be removed and destroyed.

If you are unsure about taking the role of consultee you can contact the research team using the contact details at the bottom of the information sheet. You may also speak with friends and family members or seek independent advice. We will understand if you do not want to take on this responsibility.

The following information is similar to the information that would have been provided to your relative/friend.

Information for Consultee

Project Title: Understanding hospital transfers from care homes in England

[Name of care home] taking part in a research project.

Who is carrying out this study?

This study is being carried out by Fawn Harrad as part of her PhD at the University of Leicester. She is being supervised by two members of staff.



What is the purpose of this study?

The purpose of this study is to develop a better understanding of occasions in which residents are transferred from the care home to a hospital. These occasions are referred to as 'hospital transfers'.

Your relative has been invited to take part in the study because they are living at [name of care home]



What will the study involve?

Fawn will be spending prolonged periods of time at [name of Care Home] (approx. 4 – 10hours per visit for a period of approximately 6weeks).

Fawn will be observing staff to see how the support residents during periods of ill-health and to learn about how staff respond when residents need to be transferred to the hospital. Fawn will also be informally talking to staff and residents about their experience of a hospital transfer.

Occasionally Fawn may look at sections of residents care records. If your relative becomes unwell and a transfer to hospital is considered, Fawn will ask care home staff to provide her with a copy of the relevant section of your relatives care notes. This could be done via printing or photocopying. Fawn will only look at sections of the notes if they are related to hospital transfers and will not have access to other sections of care notes that contain identifiable data about your relatives (such as date of birth, medical conditions etc.)

Any notes that Fawn makes during the study period will be stored in locked filing cabinets (for paper notes) and password protected computers (digital copies) at the University of Leicester for 5years in order to give Fawn time write up the findings from the study.



Does my relative have to take part?

No. If you prefer that Fawn did not observe incidents involving your relative, please let Fawn or any member of staff know. This will not affect their care in any way. If you decide that your relative would like to take part but later change your mind, please let Fawn or a member of staff know. Even if your relative does not take part in the study, Fawn will still be present in the home observing other residents.



What are the possible benefits / risks of taking part?

This study may not benefit your friend/ relative directly but their involvement will help Fawn to understand occasions when residents have to go to hospital. Your relative may not want to be observed by Fawn. If this happens, and your relative shows any signs of distress as a result of being involved in the study, Fawn will stop observing them immediately and will ensure a staff member is aware of their distress. Fawn will not re-approach your relative again.



What will happen to my relative's personal information?

Fawn will not collect any personal information about your relative (e.g. name, date of birth, medical conditions). Any data Fawn collects will not be shared outside of the research team. However, if Fawn is concerned about the welfare of your relative or other residents, she has a responsibility to share this information with an appropriate person or body.



Who has organised, funded and approved this study?

This study is sponsored by the University of Leicester and is being organised by Fawn Harrad and her supervisors in the Department of Health Sciences who are also funding the study. The study gained ethical approval from the Social Care Research Ethics Committee.



Who can I contact for more information?

You can contact Fawn Harrad directly
Tel: 07903627118
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APPENDIX N: Participant Information Sheet for Nominated Consultee's (ethnography)

Information for Nominated Consultee

Project Title: Understanding hospital transfers from care homes in England
Investigators: Fawn Harrad, supervised by senior staff from the Department of Health Sciences at the University of Leicester

Introduction

____ [Name of Care Home] is taking part in the above referenced research study. We would like to include ____ [Name of Person] (referred to throughout this document as 'the resident') in this study but we believe that this person lacks the capacity to provide consent for themselves.

We have sought to appoint a Personal Consultee but we have been unable to do so. As a result we are inviting you to act as a Nominated Consultee.

To help decide if he/she should be included the study, we'd like to ask your opinion about whether or not they would want to be involved. We ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research because these should take priority.

If you believe that this person would not wish to take part it will not affect the standard of care they receive in any way. If, at a later date, you think this person should be withdrawn from the study, please let the researcher (Fawn) know. The researcher would like to retain any data already collected up until the point of their withdrawal, but should you request otherwise, any data will be removed and destroyed.

If you are unsure about taking the role of consultee you can contact the research team using the contact details at the bottom of the information sheet. We will understand if you do not want to take on this responsibility.

The following information is similar to the information that would have been provided to the resident or a Personal Consultee.

Participant Information Sheet for Staff and Visiting Healthcare Professionals

[Name of care home] is currently taking part in a research study titled, "Understanding hospital transfers from care homes in England".

1. Who is carrying out this study?

This project is being carried out by Fawn Harrad as part of her PhD at the University of Leicester. Fawn is being supervised by senior staff within the Department of Health Sciences.



2. What is the purpose of this study?

The purpose of this study is to develop a better understanding of occasions when care home residents are transferred to a hospital. In particular, this project aims to understand the chain of events when transferring a resident, the people involved in the process and the factors that influence the decision to transfer.

You are being asked to act as a Nominated Consultee for [the resident] because the research team believe this person does not have the capacity to provide consent for themselves.

3. What will the study involve?

Fawn will be spending long periods at [name of Care Home] (between 4 and 10 hours per visit) over the course of approximately 6 weeks, during which the following activities will be undertaken:

- Observations of the way in which residents' health conditions are managed
- Observations of occasions in which a resident may need a transfer to the hospital
- Observing interactions between staff, residents and visiting healthcare professionals, such as GPs
- Reading [Name of Care Home's] official policies relevant to resident transfers
- Looking at the way in which transfers are written about in residents' care notes. During the fieldwork, if a transfer or potential transfer occurs, Fawn will ask care home staff to provide a copy the relevant section of the residents' care notes in order to look at the way in which transfers, and the events that precede a transfer, are documented by staff. No identifiable data will be available in the section of notes that Fawn examines and the Fawn will only look at sections of the notes if they are related to the phenomena of interest (hospital transfers).

4. Do residents have to take part?

No, participation is completely voluntary. Although the care home manager has given permission for Fawn to be present in the home there is no requirement for [the resident] to take part in the study. The decision not to involve [the resident] in the study will not lead to any repercussions. However, even if you advise the research team that [the resident] would not have taken part if they had the capacity to do so, Fawn will still be present in the home observing other people.

5. Will personal information be kept confidential?

Yes, all identifiable data about [the resident] (e.g. their name, date of birth, medical conditions etc.) will be kept confidential. No identifiable data will be shared outside of the research team listed at the end of this information sheet, or with other people in the care home. Any quotes will be fully anonymised before publication so that no-one can identify residents, staff or [name of Care Home]. However, if Fawn witness anything that leads them to be concerned about the welfare of residents, she has a responsibility to share this information, confidentially, with an appropriate person or body. Please also see the information provided at the end of this sheet regarding the University of Leicester's role as sponsor of this study.

6. What are the possible benefits / risks of taking part?

This study may not benefit [the resident] directly but their involvement will help Fawn to understand occasions when residents have to go to hospital. [The resident] may not want to be observed. If [the resident] shows any signs of distress as a result of being involved in the study, Fawn will stop observing them immediately and will ensure a member of staff is aware of their distress. [The resident] will be withdrawn permanently and immediately from the study.

7. What if I advise that the resident would have taken part but later I change my opinion?

You can contact Fawn at any time if your opinion about [the residents] willingness to take part changes or if you have any concerns about [the residents] involvement in the study. Any data that has been collected regarding [the resident] will be retained for use in the study unless you explicitly request for it to be removed and destroyed.

8. Who is funding and organising this study?

This study is sponsored by the University of Leicester and is being organised by Fawn Harrad and her supervisors in the Department of Health Sciences who is also funding the study.

9. Who has approved this study?

This study gained ethical approval from the [insert REC details here] Social Care Research Ethics Committee.

Contact information

If you would like more information about the study please do not hesitate to contact:

Fawn Harrad fh127@le.ac.uk / 07903627118)

Statement from the University of Leicester:

The University of Leicester is the sponsor for this study based in UK. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leicester will keep identifiable information about you (for 5 years after the study has finished).

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information <https://www2.le.ac.uk/offices/ias/dp> or by contacting Information Assurance Services 0116 229 7945 or by emailing ias@le.ac.uk.

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#).

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer is [Parmjit Gill](#) and you can contact them at pg170@le.ac.uk.

More detail can be found here: <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/what-you-need-to-do/transparency/>

APPENIDX O: Consent form to access residents care notes

<p style="font-size: small; margin: 0;">Understanding hospital transfers from care homes in England IRAS number: 244710</p> <div style="text-align: right; margin-bottom: 10px;">  </div> <p style="text-align: center; margin: 0;"><u>Consent Form to Access Care Notes</u></p> <p>Study title: Understanding hospital transfers from care homes in England Investigators: Fawn Harrad, Dr Chris Williams and Professor Natalie Armstrong</p> <p>Dear [name],</p> <p>[Name of care home] is taking part in a research study. This study is being carried out by me, Fawn Harrad, as part of my PhD at the University of Leicester. I am interested in 'hospital transfers'. These are occasions in which residents are transferred from the care home to a hospital.</p> <p>Recently [you / your relative] experienced a hospital transfer. [You / they] were taken from the care home to the hospital. This will have been recorded in [your / their] care notes in the care home.</p> <p>I am writing to ask for your permission to access these care notes. This would enable me to understand the way in which hospital transfers are documented by care home staff. I will not have access to full sets of notes that include personal information, such as date of birth or medical diagnoses. Instead, I will only have access to the relevant sections of the notes.</p> <p>I have enclosed a copy of the Participant Information Sheet with this letter. If you have any questions about the study, your information and how this information will be used, please do not hesitate to contact me (Fawn). You can do this by speaking with me whilst I am in the home or by using the contact details below.</p> <p>If you agree, and you are happy for me to access the relevant section of your care notes, please complete the consent form provided on the next page.</p> <div style="text-align: right; margin-top: 20px;">  </div> <p style="font-size: x-small; margin: 0;">Fawn Harrad Fh127@le.ac.uk 07903627118</p> <p style="font-size: x-small; margin: 0;">Page 1 of 2 <u>Consent Form Actual Transfer</u> v1.0 01/02/2019</p>	<p style="font-size: small; margin: 0;">Understanding hospital transfers from care homes in England IRAS number: 244710</p> <div style="text-align: right; margin-bottom: 10px;">  </div> <p>Please read the statements below and <u>initial</u> each box.</p> <p>1. I agree to allow the researcher (Fawn Harrad) access to the relevant sections of my / my relatives care notes. <input style="float: right;" type="checkbox"/></p> <p>2. I understand that the researcher (Fawn Harrad) will <u>not</u> have access to or make a copy of any personal identifiable data such as my name, date of birth or diagnoses. <input style="float: right;" type="checkbox"/></p> <p>Name of resident: _____ Signature: _____ Date: _____</p> <p>If applicable: Name of consultee: _____ Relationship to resident: _____</p> <p>Name of person taking consent: _____ Signature: _____ Date: _____</p> <p style="font-size: x-small; margin: 0;"><u>Fawn Harrad</u> _____ _____</p> <p style="font-size: x-small; margin: 20px 0 0 0;">Once completed: Original copy to be kept by researcher in study master file, One copy to the participant/relative One copy in the care home notes</p> <p style="font-size: x-small; margin: 0;">Page 2 of 2 <u>Consent Form Actual Transfer</u> v1.0 01/02/2019</p>
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