What are the experiences and perceptions of unplanned readmissions to hospital within 30 days of discharge from the perspective of older people and their families within an English NHS context?

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Dedication

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Abstract

Background: Older people continue to have a higher risk of unplanned readmission. The current landscape on unplanned readmissions is dominated by quantitative research exploring associations, patient characteristics and unplanned readmissions and little attention has been given to the experiences of older people and their families. There is a gap in understanding the patient perspective and viewing unplanned readmissions in a more holistic manner and a clinical need to further understand the patient and family experience of unplanned readmissions.

Methodology and method: An interpretivist paradigm and constructivist approach were adopted. A collective case study informed by Stake (1995, 2006) was conducted. A *case* was defined as an adult aged 65 years or over and who has had an unplanned readmission to the study site hospital Trust within 30 days of discharge. Each case was viewed from the perspective of the patient, in addition to that of a family member if available, alongside documents, observations, and reflections. This is a c*ase of* experiences and perceptions of unplanned readmissions to hospital within 30 days of discharge situated within this context. 14 cases were included in this study. Data were collected via interviews; observations and a reflective diary was used. Case descriptions were written, and multiple case study analysis was conducted following the ethos of Stake (2006) combined with the tools of framework analysis as described by Ritchie and Spence (1994).

Findings: Unplanned readmissions were experienced as a disrupter by patients and families, with disruptions to their existential condition, with emotional and practical impacts. Within this case study unplanned readmissions were a phenomenon characterised by misaligned expectation and need in both communication and expectations. Unplanned readmissions were also a catalyst for change and viewed as lifesaving and key to unlocking care and/or support. Finally, they were perceived as symptoms of perceived organisational pressures.

Unique contributions: 1. The findings from this study present a deeper and richer understanding of experiences and perceptions of unplanned readmissions to hospital among older people and their families. This study has presented the magnitude of the disruption and illustrated how the impacts of these unplanned readmissions can ripple out across time and wider society.

2. Nuance around the experiences and perceptions of unplanned readmissions have captured the fact that as a catalyst for change they can be viewed as key to unlocking care and support. This suggests older people and their families are reaching a type of crisis point before things change for them.

3. This study's findings involving the experiences and perceptions older people have of their unplanned readmission offer contextually bound first-hand accounts of the lived experience of being older and accessing healthcare, which contributes to diversifying the narrative around older age and supports combatting ageism.

Conclusion: The experiences and perceptions of unplanned readmissions are based on experiences that transcend the specific moment of unplanned readmission incorporating instances before, during and after the unplanned readmission. The unplanned readmission has ripple effects with waves that touch on wide personal and professional networks which have deep and varied impacts on peoples' lives. This study confirms the misalignment

between how unplanned readmissions are conceptualised by organisations, health care professionals, patients, and families. It is imperative nurses appreciate and understand the experiences and perceptions older people and their families have of unplanned readmission so they can provide responsive, holistic care and support patients and families appropriately.

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1.0 Chapter 1 – Introduction and background

Chapter introduction

Unplanned readmissions of older people to acute hospitals within 30 days of discharge is an extensive problem, both globally and in England. Internationally, the World Health Organization has identified addressing readmissions as a strategic priority (World Health Organization 2005). In England, the number of these unplanned readmissions has increased by 26% between 2013/14 and 2019/20 (Nuffield Trust 2022). The rate of emergency readmissions in 2013/14 was 12.4% (758,955 readmissions) and 14.4% in 2019/20 (941,217 readmissions) (Nuffield Trust 2022). Older adults, classified as people aged 65 or above (NHS England 2021), continue to have a higher risk of unplanned readmission (Gilbert et al. 2021). Unplanned readmissions have a detrimental effect on patients, their families, and the wider health system due to reasons including patients feeling unsafe or stressed (Healthwatch 2015), impacts on patient flow (Kings Fund, 2010) and financial cost (The National Audit Office, 2018). Thus, unplanned readmissions affect the health and wealth of the nation and can impact broader healthcare delivery.

This thesis therefore aims to explore the experiences of unplanned readmissions from the perspectives of older people and their families to identify what is currently often 'invisible' to healthcare professionals (Braun and Clarke 2019). The creation and development of nursing knowledge is in keeping with a professional discipline (Smith, 2019), thus, this thesis is informed by and aims to inform professional nursing practice.

This chapter will begin by outlining global and local concerns surrounding unplanned readmissions and how older people are disproportionately affected by them. This will refer to the economic impact of unplanned readmissions and issues of quality and safety. Then, current data on unplanned readmissions is discussed, with particular reference to patient perspectives (sections 1.3 and 1.6). The evidence bases for policies and best practice currently being used to address unplanned readmissions are also explored (section 1.4.1 and 1.4.2) and the importance of patient experience data will be considered (section 1.6). Capturing, understanding, and using patient and family experience is deemed pivotal to service improvement within the context of NHS England (NIHR 2019). Thus, it is pertinent to use patient and family experiences of unplanned readmissions to assist with the identification and development of strategies to reduce unplanned readmissions among older people.

Understanding unplanned readmissions to hospital from the perspectives of older people and their families is timely, relevant, and important for nurses and healthcare professionals, and patients and families. This understanding will benefit patients and their families by helping to identify issues that are a priority for them so this can be included in care delivery and future healthcare policy decision making. The meaning and significance that patients and their families ascribe to unplanned readmissions will help nurses to care and support people in these situations, improving patient experience and quality of care as a result. This study will contribute to what is currently known about unplanned readmissions by creating themes that illustrate what is meaningful to patients and their families about their contextual experiences. Policy and decision makers will be able to include these perspectives and address these needs alongside wider health system requirements. When looking to reduce unplanned readmissions the value patients and families place on them will be able to be factored into this future planning.

1.1 Unplanned readmissions to hospital

1.1.1 Multiple definitions of unplanned readmissions exist

Whilst unplanned readmissions are of international interest, there is not a universal definition of the term (Landrum & Weinrich 2006; Singotani et al., 2019). Different countries and healthcare systems define unplanned readmissions in varying ways. A definition may also be comprised of multiple elements which can make the definition itself unclear or vague. A case in point can be seen when the Centers for Medicare and Medicaid (CMM) in the United States of America (USA) define unplanned readmissions as both "*Unplanned readmissions that happen within 30 days of discharge from the index (i.e., initial) admission*" (CMS 2020) and *"or patients who are readmitted to the same hospital, or another applicable acute care hospital for any reason*" (CMS 2020). The lack of definition specificity may have considerable consequences such as inconsistent statistical methodologies when calculating rates (NHS Digital 2019b), issues with reliability of data and inconsistencies in what data are collected (National Audit Office 2018), and challenges when wanting to compare unplanned readmissions between regions or countries. Consequently, clarifying terms and using a clearly understood definition of unplanned readmissions is important when studying this phenomenon.

Landrum and Weinrich (2006) identified the issue of unclear definitions and attempted to better define unplanned readmissions, suggesting some specific definitions for terms related to hospital admissions, readmissions, and discharge. Their definition of an unplanned readmission is:

"*Readmission that follows an index hospitalisation that cannot be foreseen at the time of discharge from the index hospitalisation that may occur on a nonemergency or emergency basis*" (Landrum & Weinrich 2006 p.89).

The authors also propose criteria when measuring readmissions in quantitative studies. Their criteria for measurement have five components:

- Identify the index hospitalisation and define terms as recommended
- Establish clinical diagnosis for readmission
- Establish the purpose of the readmission
- Set discharge-to-readmission timeframe
- Identify sources of information

The criteria offered by Landrum & Weinrich (Landrum & Weinrich, 2006) are valuable as a way of assessing whether all relevant elements are included in a definition. The need to define terms and set discharge-to-readmission timeframes are helpful when assessing for definition quality. However, this set of criteria will only capture the quantitative aspect of an unplanned readmission and considers unplanned readmission as an event (Coatsworth-Puspoky et al. 2021) as opposed to a wider phenomenon. A recent concept analysis proposes a definition of unplanned readmissions specifically for older people (Coatsworth-Puspoky et al. 2021), suggesting the following:

"*An unplanned readmission is an experience, process, and event. Unplanned readmission is an older person's need for acute care treatment for an urgent or emergent health crisis that has occurred after a previous hospitalization(s)*" (p.12)

This approach to the definition of unplanned readmission incorporating experiences and processes invites us to view unplanned readmissions as more than just something to count and pushes us to consider the complexity surrounding it. Focusing this definition on older people also suggests that they may have a particular experience of unplanned readmissions that is not captured in other more generic definitions. This approach is reflected in this thesis in that it focuses on the experiences of unplanned readmissions from the perspectives of older people.

1.1.2 Different definitions as problematic

The lack of a single accepted definition of an unplanned readmission to hospital negatively affects researchers' ability to study the phenomenon and impacts on how this issue is prioritised. The historical lack of a standardised definition leads to difficulties comparing studies between settings and countries (Landrum & Weinrich 2006) limiting the formulation of a global perspective on this issue. There is a lack of quality and quantity of data on unplanned readmissions, with uncertainty over definitions and terms being used interchangeably leading to confusion (Landrum and Weinrich, 2006). Within the NHS, not having an agreed definition has led to a lack of data being collected (Healthwatch 2018) with NHS Digital (2019a) stating that methodological concerns are cited as the reason for this. A lack of meaningful data has been viewed as problematic by groups representing patients (Healthwatch 2018) who believe this has contributed to a lack of focus on patients affected by unplanned readmissions, including older adults. Thus, having different definitions is problematic, and results in a continued lack of understanding of unplanned readmissions especially in how older people experience them.

As there has not been one agreed universal definition of unplanned readmission, thought needs to be taken when studying this phenomenon and researchers must consider whether to adopt the definition used by governments or health and care institutions in their study setting or even to adapt definitions for their study purposes. For instance, Considine et al (2020) defined unplanned readmissions in their study as those occurring within 72 hours of the index discharge as their interest lay in exploring unplanned readmissions occurring very soon after discharge. In the case of this thesis the NHS England definition was used, the rationale for this is outlined below.

1.1.3Unplanned readmissions – NHS definition and rationale for its use in this study

As the site where I practice clinically and the setting for my research are both within the English NHS, I decided to use the NHS England definition of unplanned readmissions whereby an unplanned readmission is defined as when an individual is discharged from hospital but is then readmitted to hospital within 30 days (NHS England 2015). An element of this definition to underline is that a readmission implies a subsequent admission to hospital and not only a visit to the Emergency Department (ED). This definition also excludes planned follow-up visits and unplanned readmissions due to mental illness, cancer or for obstetric reasons.

This definition meets the suitability criteria described in Landrum & Weinrich’s (2006) work, as it defines the term, underlines the unplanned nature of the readmission, includes clarity over what it is not, and sets a discharge-to-readmission timeframe. Furthermore, the NHS definition is devised for use within the NHS, which is the context for this study setting, as such there is a shared understanding of this topic. As with many other definitions used, this definition concentrates on an unplanned readmission as a discrete event in time, does not specify any population within it and does not incorporate any wider issues. At the time of developing this study this definition was deemed the best available to use. Since then, a concept of unplanned readmissions for older people has been developed (Coatsworth-Puspoky et al. 2021) which will be considered when discussing the findings of this study.

1.2 Other Definitions

1.2.1 Older people

Older adults are generally classified as people aged 65 or above (NHS England 2021). Whilst chronological age is questioned as an accurate parameter of health status (NHS England 2021), with older people themselves not necessarily 'feeling' their chronological age (Choi et al., 2014), the 65 and above age group was used in this thesis. This is the age group typically used in research on older adults and in much of the quantitative research on unplanned readmissions amongst older people. Focusing on the older adult experience is also valuable as older people are often excluded from research (WHO 2021b) and this study contributes to understanding the experience of being an older person accessing healthcare, supporting the call to change the narrative around age and ageing to combat ageism (WHO 2021b).

1.2.2 Family

Throughout this thesis the term 'family' is used. The definition of family has evolved through time and each family is different (Mirabelli 2018). The term family used in this thesis acknowledges the existence of 'chosen family' (Levin et al. 2020) where friends are deemed family and reflects the definition of family as defined by the Vanier institute (Mirabelli 2018) which states that "*It's a family if there is a set of relationships over time with individuals looking after the needs of another*" (Mirabelli, 2018, p.4). This definition captures the range of supportive relationships that exist and avoids the need to use a range of terms (significant other, loved one, friend and family, caregiver) with varying connotations which could become confusing.

1.3 Problematising unplanned readmissions to hospital

1.3.1 Unplanned readmissions – a global concern

Interest in unplanned readmissions is of concern to healthcare organisations across the world (Conroy et al., 2020; Friebel et al., 2018; Kristensen et al., 2015), especially as reducing readmissions is viewed as a way of reducing healthcare costs (Kristensen et al. 2015; Friebel et al. 2018) and improving healthcare quality and safety (Kristensen et al. 2015; Considine et al. 2019). Concerns over these readmission rates are cited from the perspective of healthcare organisations and researchers (Verma et al., 2019; Zhao & Yoo; 2017) and patients and families (Berry et al., 2018; Healthwatch, 2018). Furthermore, there is now a call to understand this phenomenon in a more patient centred manner (Taylor and Davidson 2021).

The concern around unplanned readmissions has taken on an extra dimension with the impact of the COVID-19 pandemic. Adjusted odds ratios of unplanned readmission rates from the USA point to the odds of unplanned readmissions decreasing after the age of 65 (Berry et al. 2018); however, this is not echoed in other work (Zabawa et al., 2018; Lavery et al., 2020; Islam and Davies, 2021). Data from the USA in 2020 specifically exploring hospital activity amongst patients who had COVID-19 found the rate of unplanned readmissions to be 9% but older people aged 65 or above had higher odds of unplanned readmission (Lavery et al. 2020). Data from England found that 28% of patients discharged after a stay in hospital for COVID-19 were readmitted or died within 60 days and rates were twice as high for those aged over 65 and over (Islam and Davies, 2021). Knowing the scale of the global COVID-19 pandemic, the long-term impact on mortality and morbidity (Clarke et al. 2021), and associated hospitalisations amongst older people, this suggests that understanding the phenomenon of unplanned readmissions continues to be of high importance and has contemporary relevance.

1.3.2 Unplanned readmissions and older people

Selected data from different countries indicates the scale of readmission rates and associated healthcare costs: rising unplanned readmission rates among older adults are observed internationally (Li et al 2015). Older adults continue to be at higher risk of unplanned readmissions from hospital (Gilbert et al. 2021) and internationally rates among this age group remain high regardless of reason for initial admission (Zabawa et al. 2018). In the USA, among Medicare patients one fifth (19.6%) were readmitted within 30 days of hospital discharge (Jencks et al. 2009) and in Hong Kong researchers found rates of unplanned readmission were rising (Wong et al. 2011). A recent Danish cohort study amongst older adults reported one fifth of the older adults in the study experienced an unplanned readmission within 30 days (Klinge et al. 2020). Researchers in Sweden observed the risk of unplanned readmission among older adults was common especially if they had requirements for polypharmacy (Glans et al, 2021). Whilst these data identify relevant statistics and show interest in the issue of unplanned readmissions amongst older people, they do not provide detail that helps us to understand the phenomenon. Furthermore, this is acknowledged by the study authors themselves who call for further research to understand patient care and care planning (Glans et al, 2021; Zabawa et al., 2018).

The reasons underlying higher readmissions among older people are complex (Conroy & Dowsing 2012), with no simple solutions in the face of the plethora of potential risk factors (Harvey et al. 2021). The variety of risk factors noted include age (Walsh 2014) deprivation, lower educational achievement, living in urban areas, living close to the Emergency Department (ED), having a chronic disease, lifestyle factors, pollution (Purdy & Huntley 2013), hospital practice, discharge destination, post-discharge support (Wong *et al.* 2010) and number of previous admissions (Visade et al. 2021). These cohort studies are limited by issues with incomplete or inaccurate data (Song and Chung 2010). The vast range of different associations studied in discrete geographical areas or among very specific populations makes it hard to extrapolate wider themes for older adults in general. Furthermore, the factors chosen may not even be useful to calculate predictions, as a study found that neither an algorithm nor clinicians could accurately predict whether older patients would require readmission within 30 days in a medical centre in San Francisco California, USA (Allaudeen et al. 2011). In addition, a systematic review of risk prediction models (Kansagara et al. 2011) concluded that most models perform poorly. Thus, these studies help to paint a picture of the wide range of potential factors that *can* be associated with unplanned readmissions without telling us about causation or experience.

The studies described above focus on numbers, rather than experiences, and the extent of potential risk factors is varied and vast. The studies explore associations between quantitative variables where there is limited consistency between variables studied; all of which limits our understanding of the phenomenon of unplanned readmissions among older people (White et al., 2015); this suggests that further qualitative exploration is required. Of note is the need to specifically understand how unplanned readmissions are conceptualised and valued by older people who may see them as a rational choice in the circumstances (Taylor and Davidson 2021). Furthermore, when studying unplanned readmissions, it has been suggested that patients are more likely to notice system issues (such as timing of discharge, timing of follow up with a doctor, or assistance with activities of daily living) as opposed to healthcare professionals who focus on patient factors that may be specific to each individual in their care, for instance, if a patient did not adhere to plans (Smeraglio et al. 2019). Consequently, a qualitative exploration of patients' perspectives on their unplanned readmissions could aid understanding of these system factors, that is, how patients and families feel about these issues and what they mean to them to enable them to be addressed.

1.3.2 Unplanned readmissions – local concerns

The international picture of readmission rates is reflected within NHS England. As an Arm's Length Body NHS England provides national leadership and direction to the NHS (NHS England 2022e) and works in partnership with other NHS and other health and care organisations to plan and deliver care across England. The data published for England in early 2016 showed unplanned readmissions within 30 days of discharge accounted for 12% of hospital admissions in 2011/12 (HSCIC 2015). Furthermore, available statistical data indicated that there had been a rise in readmission rates for older people from 2001/02 to 2010/11: 103,000 older people were readmitted as an emergency in 2001/02 and the figure rose to 201,000 in 2010/11 (Age UK 2013). There was also data showing 15% of older people were readmitted after discharge (Oliver 2015), with that rising to 16% for over 75s (Age UK 2013). These data sparked widespread concern among healthcare professionals including physicians (Oliver 2015) and nurses concerned over a doubling of unplanned readmission rates over the decade 2001 - 2010 (NT 2013). De Castella (2018), attributed continued rises in unplanned readmissions in part to problems with older patient care.

Since my study was conceptualised there have been changes to national data collection which illustrates ongoing challenges with the definition of unplanned readmissions. The data being collected on unplanned readmissions within 30 days by NHS Digital (previously the Health and Social Care Information Centre HSCIC) has changed and there was a five-year gap in reporting on unplanned readmissions whilst NHS Digital worked on refining the methodology used to collect this data (NHS Digital 2019b). The age bands being used when collecting data and producing statistics have changed, the 65 and above cut off is no longer being used, with ages 16 - 74 included in one age band, and 75 and above in the other. Furthermore, unplanned readmissions for both physical and mental health are now combined. These changes to the definition used means it is not possible to elicit a clear picture detailing unplanned readmissions amongst older people in England since the start of the study.

Whilst the latest statistics for England are viewed as experimental (work on the indicator methodology is still ongoing), they indicate a general increase in unplanned readmissions (NHS Digital 2019a). Recently, NHS Digital (2019) statistics indicated that the 75+ age group accounted for 18.4% of unplanned readmissions within 30 days, whereas the 16 - 74 age group account for 12.4%. Both age group percentages have increased since 2014/2015 (NHS Digital 2019). The latest published data from 2020 shows an increase in unplanned readmissions to hospital from 12.5% in 2013/14 to 14.4% in 2019/20 (NHS Digital 2021). Although there is a lack of clarity over precisely which populations are most affected, these data indicate the issue of unplanned readmissions in England is not going away.

1.4 The NHS in England

The NHS policy climate is shaped by key documents which affect how care delivery is framed: The 2010 White paper “Equity and Excellence: Liberating the NHS” (Great Britain. Department of Health. 2010) and the “Five year forward view” (NHS 2014). The 2010 White paper reinforced the focus on personalising care and the term ‘no decision about me without me’ was cited (Department of Health., 2010) along with a commitment to encourage strong joint arrangements between NHS services, social care, and health improvement. The aim was to save money, ensure patient safety, and to commit to far-reaching cultural reforms within the NHS to promote patients being at the centre of their own care (Department of Health., 2010). The five year forward view gave a new direction to the NHS (NHS, 2014), including promoting emerging models of integrated care, reducing demand for and numbers of hospital beds, and committing to engaging with patients and caregivers. The plan also noted that a positive outcome of these emerging models of care included reduced emergency admissions (NHS 2014). Investigating unplanned readmissions to hospital from the perspectives of patients and their families reflects the policy direction of the NHS but also will provide a sense of how this direction may be impacting on patient experience and the care provided to patients and families.

Later, in 2019, the NHS Long Term Plan (LTP) (NHS, 2019) reiterated the plans laid down in the “Five year forward view”. Of interest, the LTP focused on multimorbidity and healthy ageing with a commitment to models of same day emergency care and Integrated Care Systems (ICS) that integrate primary, specialist, physical, and mental health care and, health and social care (NHSE, 2019). This suggests a continued interest by the government in the health of older people and in integrated care, which it is proposed, will help reduce unplanned readmissions (Harvey et al. 2021). By exploring unplanned readmissions using a qualitative approach it is possible to identify issues that are currently often invisible to healthcare professionals and that, once addressed, may enable the reduction of unplanned readmissions. In this way, aspects of missed care, or discharge processes that are ineffective, may be identified. Thus, understanding the experiences older people have of their unplanned readmissions aligns with the policy direction of the LTP and is an appropriate area for investigation.

1.4.1 Current clinical practice to reduce unplanned readmissions: the focus on hospital discharge

In the NHS in England the default pathway for hospital discharge is called “Discharge to assess” (D2A) (NHSE 2015) and the aim is to reduce the amount of time people need to stay in hospital once they no longer require acute care and, importantly for this study, to reduce readmissions, by ensuring any needs assessments can be conducted in the individual’s home or another social care setting (NHSE 2015; DHSC 2021). This stems from NICE guideline on transitions of care for adults (NHSE 2015; DHSC 2021) which posits that a major outcome of getting discharge right should be a reduction in unplanned readmissions.

There is not one model included in the D2A pathway, rather a set of principles underpinning D2A[1], these encourage discharge planning to start from the moment a patient arrives at hospital and patient centred care. This is mirrored in local best practice (hospital leaflet – appendix seven). The quick guide underlines the importance of involving patients and their families/care givers in discharge planning; providing clear and easy to understand

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[1] Definition of D2A “Where people who are clinically optimised and do not require an acute hospital bed but may still require care services are provided with short term, funded support to be discharged to their own home (where appropriate) or another community setting. Assessment for longer-term care and support needs is then undertaken in the most appropriate setting and at the right time for the person” (Quick Guide p.2)

information; and ensuring patients understand what the plans are and who they can contact after discharge (NHSE 2015). These principles are mirrored in other work describing effective discharge from hospital for older adults (DHSC 2021) that highlight the need for effective communication and multidisciplinary teamwork to optimise these stages (Pellett, 2016). In addition, this discharge process should involve the patient, their family or caregiver as appropriate, and should be supported by written documentation (Department of Health & Social Care 2021).

There continue to be challenges with hospital discharge, with considerable variation in practice (Gonçalves-Bradley et al., 2016; Mabire et al., 2015); practice does not always fit the needs of patients and their caregivers (Bauer et al. 2009; Pellett, 2016). These challenges exist despite an awareness and acknowledgement of the benefits of comprehensive discharge planning for older people that includes considering patient experience (Pellett 2016). The two main components of discharge planning that have been studied have an assessment element (multidisciplinary working, patient, and family involvement) and an implementation element (sometimes involving post-discharge follow-up) (Gonçalves-Bradley et al., 2016; Mabire et al., 2015). Specific challenges have been cited around communication, interprofessional working, coordination of services (Pellett 2016) and the existence of structural and process barriers to providing discharge planning (Mabire et al. 2019). Weiss et al (2019) found that assessing discharge readiness did not improve unplanned readmission rates. A meta-analysis of nursing discharge planning interventions found that these did not reduce readmissions, nor did they increase quality of life for patients (Mabire et al. 2018). The authors of this study underlined the intricacy of discharge planning, viewing it as a complex intervention that can be challenging to evaluate (Mabire et al. 2018). Furthermore, issues such as time constraints (Nosbush et al.

2010), low staffing (Ball et al. 2014) and pressures on nurses to ration care can leave the discharge preparation work undone (Ausshofer et al. 2014). This includes elements such as talking with patients, communicating with families and care planning (Ball et al. 2014).

An element of the discharge process that has also been well studied is around medication management. Despite there being recommendations on best practice for medication management there is considerable variation in how well hospitalised patients are involved in their own medication management (Bucknall et al. 2019). Older people are dissatisfied with the discharge process, often receiving inadequate information and explanations regarding their medication (Knight et al. 2013), with real potential for them to experience harm (Parekh et al. 2018; Age UK 2019).

Despite clear policy recommendations for involving patients and caregivers, and local commitments to ensure safe and effective discharge, this does not always appear to be taking place. In addition, the expected outcome, i.e., reduced unplanned readmissions, does not seem to be occurring. Furthermore, elements of the discharge process that involve a focus on the patient experience, such as talking with patients and involving family, are hampered by structural issues. These include ageist attitudes of healthcare staff and older people (Heyman et al. 2020). Ageism can be manifested through stereotypes, discrimination and prejudice that are interpersonal or even be self-directed (WHO 2021b). These interpersonal experiences can impact on communication and care received, and this is associated with poorer physical and mental health and a reduced quality of life (WHO 2021b). Other structural issues that can impact the discharge process include the health literacy of patients (Tang et al. 2019),poverty, and income inequality (Tang et al. 2019; Hart et al. 2020). For instance, lower health literacy can impede effective communication and shared decision making between patients and healthcare professionals (Tang et al. 2019). Thus, these factors can all have a detrimental impact on communication between healthcare professionals, patients, and families and have corresponding health outcomes.

Exploring the experience of unplanned readmissions among older people using a qualitative approach will identify issues that have hitherto been often less visible to healthcare professionals and policy makers. This exploration will be an opportunity to consider what is meaningful to patients and their families and examine the conditions that they deem optimum for discharge. Thus, this relevant and timely study will enable nurses to consider the wider elements of hospitalisation that may impact on unplanned readmissions, as opposed to focusing heavily on other aspects of the discharge process.

1.4.2 Best practice – Other interventions to reduce unplanned readmissions

There are many suggested interventions to reduce unplanned readmissions, with optimum hospital discharge being only one. However, a series of systematic reviews conclude there is limited evidence of effectiveness for any of these (Purdy et al. 2012). Suggested interventions include measuring patient preparedness to go home, having structured discharge planning, intensive focused case management, self-management education (Purdy and Huntley 2013) or personalised healthcare plans (Kings Fund 2010), having adequate nurse staffing to provide discharge teaching (Weiss et al., 2011); continuity of care (Facchinetti 2020), post discharge phone calls, transition coaches and links to ambulatory care (Hansen et al. 2011). Despite suggestions that these interventions should be best practice, evidence supporting these interventions continues to be inconsistent. A 2011 meta-analysis of interventions to reduce unplanned readmissions within 30 days (Hansen et al. 2011) found no association between interventions and a reduction in readmission risk. Evidence to support interventions to reduce unplanned readmissions remains weak, with inconclusive evidence found as to whether continuity of care interventions prevented hospital readmission for older people (Facchinetti 2020).

Thus, to date there are no clear evidence-based intervention to reduce unplanned readmissions which suggests more can be done to appreciate this phenomenon. Understanding the experience of unplanned readmissions from the patient and family perspective can contribute to the creation of relevant evidence-based interventions (Knox and Greysen 2019). To address this need for understanding, this study uses a qualitative approach which enables the identification of factors that are meaningful and relevant to patients and their families which are currently largely invisible to healthcare professionals.

1.4.3 Financial cost of unplanned readmissions

Unplanned admissions can impact on patients and their families through increased costs to healthcare systems with multiple studies pointing to the significant financial costs of unplanned readmissions (e.g. Jencks et al., 2009; Conroy & Dowsing 2012; Mitsutake et al., 2020). These costs include healthcare institutions being given financial penalties if their patients are readmitted (Clement et al. 2014), which also takes place in the NHS (DH 2010). As an indicator of the magnitude of this problem, the USA has an estimated annual cost to Medicare of unplanned readmissions of $17.4 billion (Jencks et al. 2009). In Canada, organisational costs linked to unplanned readmissions are over two billion dollars (Coatsworth-Puspoky et al. 2021). An Australian study initially conducted in 2016 estimated that the annual cost of unplanned readmissions to be A$1.5 billion (Considine et al. 2019). The cost of emergency admissions to the NHS is £13.7 billion per year (National Audit Office 2018), with unplanned readmissions making up just under a quarter of emergency admissions (Nuffield Trust 2010). Looking at current numbers this equates to 783,871 unplanned readmissions within 30 days of discharge, in England, for 2020/21 (Nuffield Trust 2023). A note of caution is advised when interpreting these numbers for two reasons: the change in hospitalisation pattern associated with the global COVID-19 pandemic, and, the changes in age ranges included within the indicator and these statistics still being classed as experimental by NHS England (Nuffield Trust 2023). At a more micro level, an audit of an Ear, Nose and Throat (ENT) department in the English NHS found that the cost of unplanned readmissions to this service during a three-month period was £25,237.50 (Rashid & Khalil 2014).

Whilst these numbers are consequential, they do not reveal the human cost or the wider implications these financial costs can have on patients and their families at an individual or family level. This underlines the importance of investigating the issue from the perspectives of patients and their families.

1.4.4 Quality and safety

The impact of unplanned readmissions on patients and their families crucially involves quality and safety issues. Transitions of care refer to all the transfers patients make during an episode of illness between different healthcare professionals and/or care settings (Enderlin et al. 2013). Also included in transitions of care are the actions and decisions made to coordinate this care, involving staff from different disciplines and settings (Singh et al. 2021). These transitions that are 'problematic junctions in a patient's care management' include hospital discharge and unplanned readmission (Enderlin et al. 2013). Unfortunately, transitions of care sometimes cause harm to the patient (Baxter et al. 2020).

The World Health Organisation (WHO) defines patient harm as:

> *"Impairment of structure or function of the body and/or any deleterious effect arising there from, including disease, injury, suffering, disability and death, and may be physical, social or psychological"* (WHO, 2009, p.16)

Harm, as defined above, can be experienced by patients during healthcare encounters. Some patient harm is viewed as preventable or unanticipated; (Panagioti et al. 2019) however, all harm experienced by patients is important with some viewing a minimal harm approach as key. Not enough is understood about how patients experience harm and what their perspectives are on how healthcare can be improved (Fernholm et al. 2020). Furthermore, older adults are at particular risk of preventable harm during hospitalisation (Han et al. 2021) for instance due to the impact of ageist interactions or processes (WHO 2021b; Dahlke and Hunter 2022). Thus, understanding unplanned readmissions among older people and contributing to preventing the unnecessary hospitalisation of older people is crucial to reducing harm among older adults.

Unplanned readmissions have been categorised as a patient safety issue (Lisby et al. 2019) and viewed as a measure of harm in and of themselves (Hestevik et al. 2019). Unplanned readmissions can also cause organisational challenges such as disruption to other forms of care, such as longer waiting lists (Kings Fund, 2010). Whilst this could be viewed as solely an organisational concern it does impact patients as it can disrupt availability of appointments and causes delays in care. In addition, unplanned readmissions are associated with harms such as reduced wellbeing, and increased risks of infection or confusion (Glans et al., 2021). Furthermore, an unplanned readmission means more time being hospitalised and so increasing the potential to experience hospitalisation related trauma (Verma et al. 2019). This trauma is manifested through sleep deprivation, immobility, stress, and anxiety all linked to the unpredictable and depersonalised hospital environment (Verma et al. 2019).

Third sector, (charity or voluntary organisation), reports are valuable in amplifying the patient experience of hospital discharge and readmission and highlight the human cost of care transitions. Work by Healthwatch (2015) illustrates the emotional harm such as distress and worry older people have experienced when leaving hospital, whilst other agencies note the depression, frustration (Age UK 2019) anxiety (Royal Voluntary Service 2015) and trauma (Ombudsman 2016) experienced by older people when going home form hospital. These reports combine experiences of older people with those of other patient groups (Healthwatch 2015) (Ombudsman 2016), only include the most severe examples (Ombudsman 2016) and were put together with specific advocacy and policy aims. As such, though vital, they do not capture the richness and depth of data required for nurses and other healthcare professionals to make care decisions.

There is a need for a deep understanding of patient experience to tackle the rise in unplanned readmissions (Steventon et al. 2018) and to enable nurses to tailor care to individual patients (Panagioti et al., 2019;Andreasen et al., 2015). Furthermore, nurses have a safety critical role to play when providing patient care. The role of nurses within patient safety is linked to adequate staffing levels (Ball et al., 2014) but also their skills and expertise. The essential roles nurses play in ensuring patient safety encompass a variety of actions including monitoring patients, detecting errors and near misses, and understanding care processes (WHO, 2020), such as unplanned readmissions is vital. Understanding patient experience may, therefore, help to reduce harm experienced by patients during a care episode, as issues that impact patients and are meaningful to them can be identified and addressed. Individual, family, and system wide factors that, to date, are largely invisible to healthcare professionals, can be recognised and explored.

1.5 Readmissions as an indicator

Unplanned readmissions to hospital are used as an indicator of the quality of care received during hospitalisation (NHS England 2015; Baxter et al., 2020), whereby high numbers of unplanned readmissions are viewed as a sign that care received in hospital did not provide effective recovery from the initial illness or injury (NHS England 2015). However, the usefulness of unplanned readmissions as a proxy for care quality is questioned for a variety of reasons (Benbassat & Taragin 2000). Their use as a proxy for care quality has weaknesses that have been highlighted since the 1990s (Ashton & Wray 1996), including concerns around how the unplanned readmission indicator is calculated (Fischer et al. 2014). Some of these weaknesses relate to the reliance on assumptions when calculating readmission rates; for instance, healthcare disparities due to ethnicity are not captured (Rumball-Smith et al 2013). In addition, unplanned readmissions could also represent natural disease progression (Byrne et al. 2017) despite best practice in care being followed (Shah et al. 2013), unrelated new diagnoses (Landrum & Weinrich 2006), and social characteristics (Byrne et al. 2017). These issues also raise the question as to whether unplanned readmissions are preventable or not (Byrne et al. 2017). The limitations of unplanned readmissions as a proxy for care quality led to some researchers suggesting it should be viewed alongside other metrics (Press et al. 2013) or that the time-to-readmission should be reduced from 30 days to seven days (Chin et al. 2016). These issues found within the literature are echoed in reports from third sector organisations such as Healthwatch (2015), Age UK (2012) and Royal Voluntary Service (2015), all of which highlight varied external factors, such as community care provision, that can impact on readmission. They also question whether unplanned readmissions truly reflect the care quality provided in hospitals.

Despite concerns about the suitability of unplanned readmissions as an indicator of quality care, unplanned readmissions continue to be a relevant issue to explore. Discussions around the use of unplanned readmissions as an indicator for care quality identify the need to focus on patient centred experience across the care spectrum (Byrne et al. 2017). In addition, there are many issues beyond the hospital that can play a role in readmissions (Singotani et al. 2019). Thus, viewing unplanned readmissions as whole concept, that is, considering them as an "*experience, process and event*" (Coatsworth-Puspoky et al., 2021, p.1) that have an impact on patient experience, as opposed to merely indicators of care quality or health system effectiveness, is valuable and needed. Investigating unplanned readmissions by exploring experiences will add to our understanding of this phenomenon, enabling the whole concept i.e., the experience process and event, to be examined from the perspective of patients and their families.

1.6 The Patient experience

1.6.1 A definition

Patient experience can be defined in its simplest of terms as "*what the process of receiving care feels like for your patient*s" (NHS III 2013 p.12), thus, what was the quality of care and quality of caring like as perceived by that individual (NHS III 2013). Patient experience encompasses more than patient satisfaction or patient outcome data (The Health

Foundation 2013) and incorporates relational and functional aspects (National Quality Board, 2015). Whilst satisfaction with and outcomes of a healthcare encounter can be useful indicators and continue to be relevant when assessing services, they do not give a holistic view of what healthcare processes and encounters are like for patients (NIHR 2019).

Patient experience in its widest form is viewed as valuable data by the NHS in England (NIHR 2019). Patient experience involves that of patients *and* families (NIHR 2019). Organisations outside of the NHS such as Healthwatch (Healthwatch 2015) also underline this and advocate for the inclusion of families in health care design, delivery and evaluation. There are a variety of ways to capture, understand and use patient experience data (The Health Foundation 2013); however, to capture a rich, holistic account it is necessary to consider a variety of potential methods used. This will be further explored in later chapters.

NHS organisations (Gleeson et al. 2016; NIHR 2019) and third sector strategic players in health service improvement and management collect and use patient experience data to plan and improve services (The Health Foundation 2013; NIHR 2019). In addition, organisations such as The Point of Care Foundation (POCF) advocate for experience-based co-design projects which are co-led by patients, to ensure what is being researched is patient centred (POCF, 2021; Rising et al., 2015).

The involvement of readmitted patients in research is deemed critical to developing interventions that work (Knox and Greysen 2019). In their work with all age readmitted patients, Howard-Anderson et al (2016) highlight how involving patients enabled them to identify key areas of focus for future interventions. Rising et al (2015) underlined the importance of patient involvement to improve hospital visits and reduce unplanned readmissions. Patient experience should be viewed holistically and not reduced to certain categories that effectively strip experience of context (NIHR 2019). In addition, a single story can act as a 'light bulb moment' helping practitioners to reflect on the care they provide and prompting them to act on improving the care provided (POCF 2020). Thus, carefully exploring patient experience is needed to ensure a holistic picture is captured to help improve care.

1.6.2 The importance of patient experience in healthcare

Patient experience has been acknowledged as a factor in unplanned readmissions. A recent cohort study noted the association between positive experiences of care and a reduced likelihood of unplanned readmission (Carter et al. 2018). However, this study focused on a narrow view of patient experience which does not reflect contemporary developments. Patient experience in its widest form has been central to NHS policies since 2008 when Lord Darzi highlighted the importance of incorporating positive patient experience alongside safety and effectiveness when defining quality healthcare (Department of Health 2008). A National Quality Board was set up in 2009 to drive quality improvement including a focus on patient experience (National Health Service 2021). In 2011, the NHS agreed on a working definition of patient experience and published a one-page document called the 'Patient experience framework' (Department of Health 2011) which was based on the Picker Institute 'Principles of Patient Centred Care' (Picker Institute Europe 2021). Patient experience has also been incorporated into conceptualisations of quality care for older people, with McCormack and McCance (2016) recognising the need for person centred cultures that respond to patient and family need, and Nolan et al. (2004) understanding the vital role of relationships between patients, staff and families in promoting enriched care environments.

A pivotal shift also occurred in 2013 with the publication of the report into the Mid Staffordshire NHS Foundation Trust public inquiry, also referred to as the ‘Francis Report’ (Francis 2013). This inquiry had huge repercussions across the NHS including a real push to value patient and family experience, to listen to patients and include them throughout their care journey. It also engendered many further reports, reviews, and recommendations. A year on Thorlby et al (2014) noted that the Department of Health (DH) and NHS provider organisations had accepted that fundamental change was required. This further cemented acceptance amongst the NHS that focusing on care quality and improvement was needed (Thorlby et al. 2014) and that listening to patients and their families was a crucial part of this.

Further aspects of patient and family involvement have gained traction since this time. Multiple reports called for patients to be at the centre of all care initiatives as a way of ensuring safe and effective care. The reports call for patients and families to be helped to understand their care and treatment (Clwyd & Hart, 2013)~~,~~ to be heard and always empowered (Department of Health 2013) and, highlight the important role caregivers play and how their health can be affected by those in their care (NHS England 2014). However, as underlined by the Nuffield Trust, hospitals found it hard to meet these demands to improve patient experience (Thorlby et al. 2014) due to issues around safe staffing, leadership (Lynas 2015) and culture (Francis, 2015; Department of Health, 2015),; this underlines the continued work to be done.

The relationship between care quality and positive patient experience has been fundamental to NHS activity since 2008 and the 2013 Francis Report further reinforced the need to listen to and address patient and family experience. In addition, specific considerations for nurses related to patient experience include both a need to understand that patient perception of their care can be associated with the nursing care they have received (Aiken et al. 2018); and that as nurses, especially when working at the point of care, we are leaders of the patient experience (Aspinall et al., 2021). Of note, Aiken et al (2018) reinforce the link between poor staffing, poor work environments and an ability of nurses to provide quality care. Thus, we as nurses have an important part to play in patient experience but we require appropriate care contexts to deliver this. Consequently, understanding and acting upon patient experience information contributes to providing quality healthcare. This thesis recognises the importance of this and investigates unplanned readmissions via patient experience to learn from patients and their families. By listening to their currently less heard perspectives and addressing what is meaningful to patients and their families it is hoped that improved care processes can be developed, thereby reducing unplanned readmissions to hospital among older people.

Thus, to reduce unplanned readmissions, it is imperative to increase our knowledge of the phenomenon. There continues to be a lack of understanding around whether unplanned readmissions are due to people being discharged too soon (National Audit Office 2018) or a myriad of other factors including expected illness trajectory or other issues with care provision. The current landscape on unplanned readmissions is dominated by quantitative research exploring associations between certain medical conditions and/or patient characteristics and unplanned readmissions. In addition, there is a focus on the discharge process when attempting to understand why patients return to hospital, yet little attention has been given to the experiences of patients and their families. This research focus reflects a potential misalignment that exists between how unplanned readmissions are conceptualised by policy makers and clinicians as opposed to patients (Taylor and Davidson

2021), which encourages us to ask ‘who is an unplanned readmission a problem for?’. Unplanned readmissions may be problematised because the timeframes and policies that surround them are based on bureaucratic organisational needs (technocratic rationality) (Hyde et al. 2005) as opposed to patient and family needs (value rationality) (Hyde et al. 2005). That is, there is a potential misalignment between how readmission is conceptualised by organisations, health care professionals and patients and families (Taylor & Davidson, 2021), whereby patient centred factors do not appear to be valued. The ‘Hospital Readmission Reduction Program’ in the United States of America (USA) is an illustration of this. Unplanned readmissions were viewed as problematic for hospital systems managers as every unplanned readmission incurred a financial penalty (Taylor and Davidson 2021). Consequently, unplanned readmissions were automatically viewed and treated as negative, and patient and family experiences were not considered. Blame was assigned, tension within the system increased and trust between patients, clinicians and hospitals increased (Taylor and Davidson 2021). This situation was not conducive to providing patient centred care or conducting successful quality improvement. In England, there was insufficient evidence around finance schemes approaches as being helpful to reduce unplanned admissions (Purdy et al. 2012). This issue is evolving, and recent studies have called for further research to understand patient care and care planning in relation to unplanned readmissions (Glans, 2021; Zabawa et al., 2018) suggesting there is a gap in understanding patient perspectives.

1.7 Thesis structure

The structure of the thesis is as followed:

Chapter 2:

- Outlines a review of the literature that was conducted at the start of the PhD journey along with a more recent update. The gaps in the literature are identified, highlighting the rationale for the direction of this thesis.

Chapter 3:

- The methodology and approaches taken within this PhD are discussed. The personal beliefs of the researcher along with the ontology and epistemology followed are outlined.
- Collective case study, informed by Stake (Stake, 2006; Stake, 2000), is described, along with methodological limitations.

Chapter 4:

- This chapter describes the methods used for data collection and analysis and includes a section on limitations.

Chapter 5:

- A description of the cases, including a selection of case summaries is included in Chapter 5. Contextual information is presented here about the case study.

Chapter 6:

- This chapter outlines the thesis findings, in the form of Assertions about the Quintain and provides quotes from the patients and families involved in the study.

Chapter 7:

- Discussion of the thesis findings, focusing on implications for nursing practice, education, research, and policy.
- Recommendations for nursing practice, education, research, and policy are outlined.

Chapter 8:

- Summarises the thesis and offers concluding remarks.

1.8 Chapter Conclusion

In summary, unplanned readmission to hospital within 30 days of discharge disproportionately affect older people in England. These readmissions have a detrimental effect on patients, their families and the health system via experienced harm, financial costs incurred, and wider impacts on system level organisation. To date, what is known about this topic is dominated by studies using quantitative data; these findings are yet to make a large-scale impact as unplanned readmissions continue to rise. To address unplanned readmissions, it is imperative we investigate the phenomenon from the perspectives of patients and their families. A qualitative approach enables what is currently often invisible to nurses, researchers, and policy makers to be explored. By understanding the experiences of patients and families, we can begin to address the issues raised and contribute to reducing unplanned readmissions and improving patient experience. Exploring unplanned readmissions in this manner acknowledges that they are more than just a discrete event and are an experience, process, *and* event (Coatsworth-Puspoky et al. 2021). This approach reflects the value placed on patient and family feedback within the NHS today. For nurses, understanding what factors are meaningful to patients and their families will help us to plan and develop appropriate care and to advocate more effectively for patient and family needs. For policy makers, insights generated by this research can be considered when developing pathways and processes around patient care and hospital discharge and can contribute to decision making around the use of unplanned readmissions as an indicator for care quality. The following chapter will describe the review of the literature conducted at the start of this PhD journey.

2.0 Chapter 2 - Review of the literature

2.1 Chapter Introduction

The following chapter focuses on what is known about the experience of unplanned readmissions among older people and identifies how this PhD study will contribute to expanding this knowledge. Reviews of the literature outline the state of the science, providing a helpful overview of a topic area (Aveyard 2019) and identify insights into gaps in the literature that may exist. A review of the literature exploring unplanned readmissions among older people was conducted and published (Blakey et al. 2017). This chapter will expand on this and discuss how this shaped the direction of this PhD study and informed the research question.

2.2 Review aim

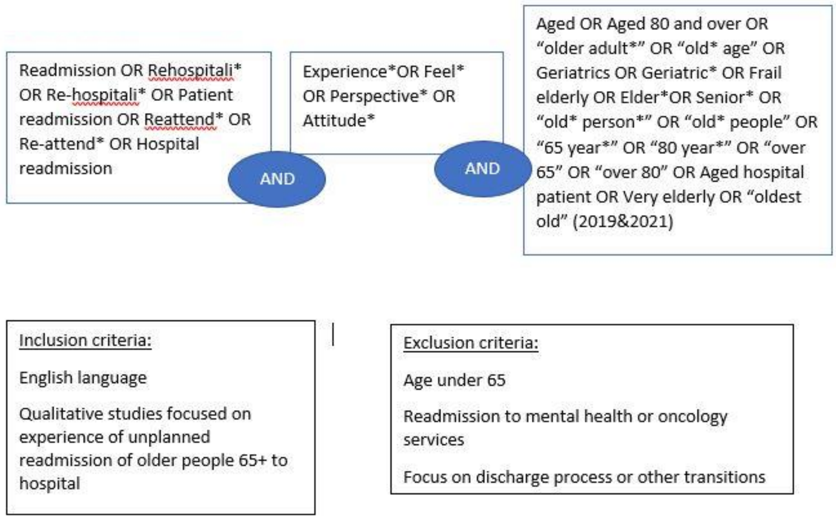
The aim of the review was to examine qualitative research papers that explored the experience of patients (aged 65 and over) who had been readmitted to acute care settings after discharge, within any discharge-to-readmission timeframe. The qualitative systematic review (Grant and Booth 2009)was inspired by interpretive approaches (Dixon-Woods et al. 2006), and answers the question ‘what is the experience of patients (aged 65 and over) who have been readmitted to acute care settings after discharge?'. A comprehensive search of the published literature was conducted, the search strategy will be outlined in more detail below, then included articles were appraised and thematic synthesis followed. Qualitative systematic reviews (Grant and Booth 2009) carried out in this way lead to an interpretive translation of a phenomenon and a broadening of understanding. This allows for the recognition of the importance of an issue and identifies where further understanding is required.

The first review was conducted during the initial phases of the PhD project (October 2016) and contributed to the identification of gaps in the literature, shaping the direction of the PhD study. The search was then re-run in September 2019 and July 2021 to identify any additional relevant published articles and incorporate them accordingly.

2.2.1 Search strategy

The search strategy was discussed and confirmed with a specialist librarian and conducted in CINAHL, Embase and Medline in October 2016. Initial configurations of the search strategy specified a discharge-to-readmission timeframe of 30 days. This resulted in 1000s of hits that were not appropriate, e.g., high numbers of quantitative studies. By removing the discharge to readmission time frame from the searches, it was feasible to manually exclude quantitative studies with a focus on causation. Furthermore, as there is no universally agreed definition of an unplanned readmission the studies that do exist have different time frames. If the 30-day timeframe had been kept this would have yielded only four studies. On balance and after discussion with the specialist librarian removing a specific 30 day discharge to readmission was removed as this was felt to be the best course to take . The issues highlighted by this process reflect the challenges of exploring an issue that does not have one universally accepted definition (see Chapter 1).

The search terms used were: Readmission, Rehospitali*, Re-hospitali*, Patient readmission, Reattend*, Re-attend*, Hospital readmission AND Experience*, Feel*, Perspective*, Attitude* AND Aged, Aged 80 and over, “older adult*”, “old* age”, Geriatrics, Geriatric*, Frail elderly, Elder*, Senior*, “old* person*”, “old* people”, “65 year*”, “80 year*”, “over 65”, “over 80”, Aged hospital patient, Very elderly. This is summarised in Figure 1.



Readmission OR Rehospitali* OR Re-hospitali* OR Patient readmission OR Reattend* OR Re-attend* OR Hospital readmission

AND

Experience*OR Feel* OR Perspective* OR Attitude*

AND

Aged OR Aged 80 and over OR “older adult*” OR “old* age” OR Geriatrics OR Geriatric* OR Frail elderly OR Elder*OR Senior* OR “old* person*” OR “old* people” OR “65 year*” OR “80 year*” OR “over 65” OR “over 80” OR Aged hospital patient OR Very elderly OR “oldest old” (2019&2021)

Inclusion criteria:

English language

Qualitative studies focused on experience of unplanned readmission of older people 65+ to hospital

Exclusion criteria:

Age under 65

Readmission to mental health or oncology services

Focus on discharge process or other transitions

Figure 1: Search terms and criteria

The original search, which was included in the published article (Blakey et al. 2017), took place in November 2016, subsequent searches took place in September 2019 and July 2021.

On discussion with a specialist librarian the search term "oldest old" was added for the later searches as this term had arrived into common usage. Search terms and relevant thesaurus terms were used in the following databases: CINAHL, Embase and Medline. Title and abstract were searched in all databases. Inclusion criteria required that articles should be written in English language, published between 1996 and 2021 and were qualitative studies focusing on the experience of readmission of people aged 65 and over. Articles were excluded if they assessed an intervention or new care model, included patients under the age of 65, focused on readmissions to mental health or oncology services, or solely explored the discharge process from hospital to home rather than the readmission process itself. Search strategy also included in Appendix 9.

All literature in CINAHL, Embase and Medline were screened using the search strategy and inclusion/exclusion criteria above. A total of 2504 articles were identified (n=1780 after duplicates removed). A total of n=1685 were excluded after screening, resulting in n=95 full text assessed and a final total of n=8 meeting the eligibility criteria included in the qualitative synthesis. See Figure 2: Prisma diagram. Citation searches were carried out in web of science, but no further articles were identified.

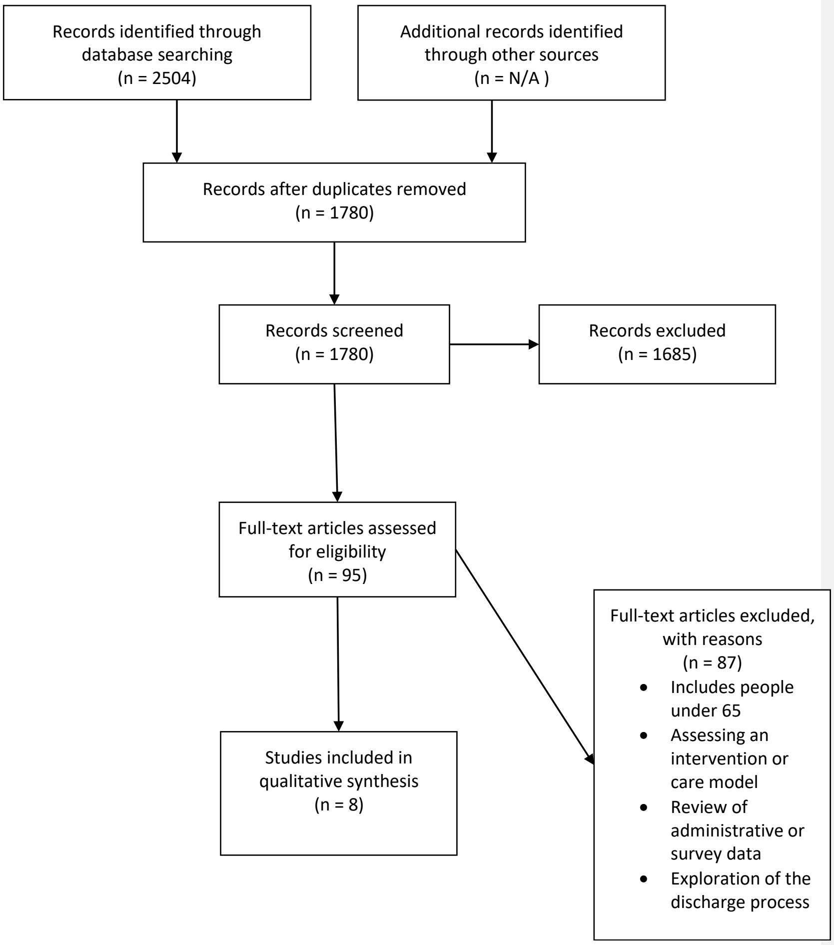


Figure 2 – PRISMA

2.2.2 Quality appraisal

Appraising qualitative data can be undertaken in a variety of ways and there are no agreed criteria for determining good quality qualitative research. Aveyard *et al.* (2016) refer to a range of published guidelines which recommend assessing for credibility, resonance, significant contribution, ethics, and coherence. The selected articles were assessed for these using the Joanna Briggs checklist (JBI, 2016) and were examined to establish if there was congruity between methodology and research question, data collection, data analysis, data interpretation and conclusions.

All the selected articles had obtained relevant ethical approvals, yet some limitations were noted. Only one of the articles clearly located the researchers culturally and theoretically and addressed the influence of the researcher on the research (Dilworth *et al.*, 2012). This lack of theoretical and cultural positioning could have an impact on assumptions made by the researchers thus affecting results. Congruence was noted between findings and conclusions in all selected articles. One article (Stephens et al., 2013) used field notes as opposed to audio-recorded data, but direct quotes from patient participants were included in the article. Yu *et al's.*, (2007) article is a 'research in brief' as opposed to a full article and therefore contains less details. The two articles identified in later searches were also quality appraised using the Joanna Briggs Checklist (JBI, 2016). Of note is the inclusion of only male participants in one study (Pedersen et al. 2018) and a lack of a clear explanation of how the study method and analysis were conducted in another (Rijpkema et al. 2021). Despite these limitations, the articles were not deemed fundamentally flawed, so all the articles were chosen to include in the final synthesis.

Table 1 Summary of all the included articles

Commented [CB1]: Add critical appraisal

Papers	Aims	Methodology & Method	Sample	Setting (study / interviews) + **Critical appraisal summary**	Findings
Dilworth S, Higgins I and Parker V (2012) Feeling let down: An exploratory study of the experiences of older people who were readmitted to hospital following a recent discharge *Contemporary Nurse* **42** (2): 280-288	To explore the experience of older people who had been readmitted to hospital following discharge and to investigate the circumstances that led to their readmission.	Qualitative descriptive design. Face-to-face, semi-structured, in-depth interviews. Data analysis: inductive approach, thematic analysis	3 older adults, readmitted to hospital within 28 days of discharge All from a large tertiary referral hospital in Australia All English speakers.	Australia / Hospital + congruence between study elements + culturally & theoretically locates researchers + addresses researcher influence	Being left out, being cared for and feeling let down.
Slatyer S, Toye C, Popescu A, Young J, Matthews A, Hill A and Williamson DJ (2013) Early re-presentation to hospital after discharge from an acute medical unit: perspectives of older patients, their family caregivers and health professionals *Journal of Clinical Nursing* 22: 445-455	To describe the factors contributing to early ED re-presentation from the perspectives of (1) patients aged 65 years and older (2) family caregivers who provided care to patients between discharge and re-presentation, and (3) hospital and community-based health professionals involved in their care.	Qualitative descriptive design. Narrative approach. Individual, semi-structured interviews conducted face-to-face or by telephone. Constant comparison method to descriptive level for data analysis.	12 older adults (six female and six male), who returned to study hospital's ED within 28 days of discharge. 15 caregivers 35 health workers.	Australia / Hospital + Congruence between study elements - Lack of clarity & detail over philosophical perspective, methodology & researcher influence	-The health trajectory; communication challenges; discharge readiness; the decision to return. -Representation to hospital was seen as part of a declining health trajectory. -Patients and caregivers left hospital with limited understanding of health problems therefore they were ill-prepared for future health crises.
Stephens C, Sackett N, Pierce R, Schopfer D, Schmajuk G, Moy N, Bachhuber M, Wallhagen MI and Lee SJ (2013) Transitional care challenges of rehospitalized veterans: listening to patients and	To better understand patient and provider perspectives of the transitional care needs and challenges faced by re-hospitalised veterans.	Grounded theory. Semi-structured face-to-face interviews. Thematic analysis.	25 older, male veterans readmitted within 90 days to medical/surgical units in a Veterans Affairs medical centre in the USA. 14 health care providers were also included in this study. Interviews conducted in hospital.	USA / Hospital + Congruence between study elements - Lack of clarity & detail over philosophical perspective,	-Three patient- identified themes: knowledge gaps and deferred power, difficulties navigating the system, and complex psychiatric and social needs. -Five healthcare provider - identified themes: substance use and mental illness, lack of social or financial support and

providers *Population Health Management* **16** (5): 326-331				methodology & researcher influence - Participant voice not adequately represented (filed notes used not verbatim)	homelessness, premature discharge, poor communication, and non-adherence with follow-up.
Uscatescu V, Turner A and Ezer H (2014) Return visits to the Emergency Department: What can we learn from older adults' experiences? *Journal of Gerontological Nursing* **40** (7): 32-40	The study question was: What are the experiences of older adults after discharge from the ED that led to early return visits?	Qualitative descriptive design. Semi-structured face-to-face interviews. "Member checks" conducted. Thematic analysis.	15 English- or French-speaking participants readmitted to a Canadian ED within 14 days (seven women and eight men).	Canada / Hospital + Congruence between study elements - Lack of clarity & detail over philosophical perspective, methodology & researcher influence	-Three major themes 'Managing the symptoms', Care during the Initial ED Visit' and 'Who I Am'. Findings suggest that the main reason for older adults' return to the ED is the severity of the symptoms they experienced.
Vat M, Common C, Laizner AM, Borduas C and Maheu C (2015) Reasons for returning to the emergency department following discharge from an internal medicine unit: perspectives of patients and the liaison nurse clinician *Journal of Clinical Nursing* **24**: 3605-3614	To understand patients' reasons for returning to ED following hospitalisation on an internal medicine unit and to compare these reasons against the risk assessment tools completed by the health care professional prior to discharge.	Qualitative, descriptive study. Individual, semi-structured, interviews Inductive thematic content analysis according to Burnard's (1991) method of analysing interview transcripts. "Member checks" conducted.	Eight patients readmitted to the ED of a major teaching hospital in Canada within 14 days of discharge. (Six women, two men).	Canada / Hospital + Congruence between study elements - Lack of clarity & detail over philosophical perspective, methodology & researcher influence	-Patients attributed their return to hospital to being discharged too soon, feeling weak at discharge, having limited help to manage their chronic illness, and not having enough discharge instructions. -Tools used by clinicians to predict risk of readmission did not provide them with accurate predictions. -Either clinician's did not identify enough potential reasons for readmission, i.e. only one identified was 'general weakness' when patients identified more issues. -Or, clinicians' predictions did not reflect the patient experience, i.e., predicting a patient would return due to 'social issues' whereas the patient felt well at home.
Yu Yu, D. S. F., Lee, D. T. F., & Jean, W. (2007). The revolving door syndrome: The Chinese COPD patients' perspectives. *Journal of Clinical Nursing*, *16*(9), 1758–1760. https://doi.org/10.1111/j.1365-2702.2007.02089.x	To investigate the phenomenon of recurrent hospital readmission from the perspective of older Chinese COPD patients.	Exploratory qualitative design. In-depth, unstructured, face-to-face interviews. Thematic content analysis.	Five participants, all male, with multiple readmissions to a regional hospital in Hong Kong during 2004.	Hong Kong / Not stated + Congruence between study elements - Lack of clarity & detail over philosophical perspective, methodology & researcher influence - Participant voice not adequately represented (lack of quotes)	-Perceived powerless to manage the disease after discharge, Lack of confidence in community-based care, -Tense relationship between caregiver and recipient, -Satisfaction with social atmosphere in hospital.

Pedersen M. K., Mark, E., & Uhrenfeldt, L. (2018). Hospital readmission: Older married male patients' experiences of life conditions and critical incidents affecting the course of care, a qualitative study. *Scandinavian Journal of Caring Sciences*, *32*(4), 1379–1389. https://doi.org/10.1111/scs.12583	To explore life conditions and critical incidents pertained to hospital readmission from the perspective of older males	Qualitative explorative design using Critical Incident Technique. Narrative approach.	Four eligible patients who agreed to participate, all male. Readmission within 3 months of initial hospitalisation.	Denmark / Hospital & Home + Congruence between study elements - Lack of clarity & detail over philosophical perspective, methodology & researcher influence - Only male participants	-The analysis revealed four themes of life conditions: 'Ambiguity of ageing', 'Living with the burden of illness', 'Realisation of dependency' and 'Growing sense of vulnerability and mortality'. -Critical incidents comprised four areas: 'Balancing demands and resources in everyday life', 'Back home again – a period of recovery', 'Care interaction' and 'Navigating within and between healthcare system(s)'
Rijpkema, C. J., Verweij, L., Jepma, P., Latour, C. H. M., Peters, R. J. G., Scholte Op Reimer, W. J. M., & Buurman, B. M. (2021). The course of readmission in frail older cardiac patients. *Journal of Advanced Nursing*, *77*(6), 2807–2818. https://doi.org/10.1111/jan.14828	To explore patients' and (in)formal caregivers' perspectives on their role(s) and contributing factors in the course of unplanned hospital readmission of older cardiac patients in the Cardiac Care Bridge (CCB) program.	Qualitative multiple case study alongside the CCB randomized trial, based on grounded theory principles. Thematic analysis	Five cases of patients who had an unplanned readmission. Readmission within 6 months. Semi-structured interviews were held with patients (n = 4), informal caregivers (n = 5), physical therapists (n = 4), and community nurses (n = 5).	The Netherlands / Home & Workplace + Congruence between some study elements - Lack of clarity & detail over philosophical perspective, methodology & researcher influence - Lack of clarity & detail around study & analysis methods	-The involvement of (in)formal caregivers in adequate observation of patients' health status is vital to prevent rehospitalization (theme 1). -Patients and (in)formal caregivers' perception of care needs did not always match, which resulted in hampering care support (theme 2). -CCB caregivers experienced difficulties in providing care in some cases, resulting in limited care provision in addition to the existing care services (theme 3)

2.2.3 Thematic synthesis

The articles were analysed to capture a rich thematic description of the data. This was done following the methods outlined in Thomas and Harden (2008) and involved line-by-line coding of the data, construction of descriptive themes followed by analytical themes. The objective was to understand the experiences of unplanned readmission from the perspective of patients. Therefore, this review was conducted with an interpretive focus. Each article was read multiple times and reviewed to determine (i) how patients explained their readmission and (ii) what themes existed around the readmission experience. Data were extracted into tables and grouped by initial code words. These tables were then regularly reviewed, and themes were generated and refined using mind-maps. These themes were reviewed and agreed upon via group discussion with the supervisory team.

Table 2 Summary of themes generated through the thematic synthesis

	Experience during initial hospital stay distinguished by exclusion			**Patients experience uncertainty following discharge**		
	Feeling powerless	**Feeling disregarded**	**Perception of readiness for discharge**	**Perception that community based services are not available or adequate**	**Perception that hospital is the only safe place**	**Difficulty in adapting to a “new normal”**
Dilworth *et al.* (2012)	√	√	√	√	√	√
Slatyer *et al.* (2013)		√	√	√	√	
Stephens *et al.* (2013)	√			√		
Uscatescu *et al.* (2014)		√	√	√	√	√
Vat *et al.* (2015)			√	√		
Yu *et al.* (2007)		√	√	√	√	
Pedersen *et al.* (2018)		√	√	√	√	√
Rijpkema *et al.* (2021)				√	√	

2.4 Findings from the literature

2.4.1 Summary of findings

The experiences of unplanned readmissions are the consequence of a complex range of interacting factors. Older people experienced exclusion during their initial hospital stay and uncertainty after their discharge. Participants felt that they were not involved in decision-making, information was not shared or discussed, and they felt excluded from the discharge process. These examples point to a ‘cycle of exclusion’ that begins during the initial hospital visit and continues into the discharge process.

Immediately on discharge, some individuals experienced a feeling of uncertainty. Some felt they could not rely on community support, others had difficulty accessing it. For others the feeling of uncertainty appears linked to the contrast between how they felt in hospital versus home; or their ability to manage living with the effects of a diagnosis or treatment; a “new normal”. Therefore, the following sub-themes were developed: Perception that community-based services are not available or adequate; Perception that hospital is the only safe place and Difficulty in adapting to a “new normal”.

2.5 Themes

2.5.1 Experience during initial hospital stay distinguished by exclusion

Feeling powerless

Participants noted feeling uninformed about their own care and health and described feeling “*powerless, unheard and disrespected*” (Dilworth et al., 2012, p. 283). Stephens et al. (2013) reported patients deferred power to the healthcare professionals looking after them resulting in a lack of perceived control or ownership over their care. Similar examples are seen in Dilworth et al.’s (2012) study with some participants not questioning medication changes that later affected their health and contributed to their readmissions. Furthermore, one patient commented they could not discuss their care with the medical team due to self-perceived lack of education and understanding of medical language used in discussion. Powerlessness was also experienced through not having control over changes to plans and treatments or not receiving adequate information from which to make informed decisions. Patients noted they did not have information about what was happening to them, they had unanswered questions, and treatment changes were not explained or discussed (Dilworth et al., 2012). One participant stated feeling they were in a “no man’s land” where a lack of information was coupled with multiple changes to plans and treatments (Dilworth et al., 2012).

Feeling disregarded

Patients reported feeling that their knowledge of themselves, their values and preferences were ignored (Dilworth et al., 2012; Pedersen et al., 2018). Participants reported feeling disregarded multiple times during the initial hospital stay and discharge decision-making period (Yu et al., 2007; Dilworth et al., 2012). They described communication with staff where their needs and wishes were not acknowledged (Slatyer et al., 2013; Stephens et al., 2013; Uscatescu et al., 2014) and incidents when they were not given test results or information about their own health (Pedersen et al. 2018). Some noted they had limited recall of communication with healthcare staff and that the busy, stressful environment affected their understanding of their complex healthcare situations (Slatyer et al., 2013). Not being given enough information (Pedersen et al. 2018), a lack of information sharing and, patients receiving mixed messages were also noted (Dilworth et al., 2012). In some instances, different members of the healthcare team (doctors and nurses) provided diverse pieces of information, and sometimes included conflicting advice about treatment, discharge, or care plans (Dilworth et al., 2012). Participants noted they did not fully understand their conditions (Slatyer et al., 2013), could not recall all their medication or care plan details (Stephens et al., 2013), or left the hospital with no explanation as to the cause of their symptoms (Uscatescu et al., 2014). Being disregarded led to some people feeling frustrated and let down (Dilworth et al., 2012) or harmed (Dilworth et al., 2012; Uscatescu et al., 2014). For example, one participant experienced renal failure when a doctor disregarded their warnings about Non-Steroidal Anti-Inflammatories and prescribed them regardless (Dilworth et al., 2012).

Perception of readiness for discharge

Patients did not feel ready for discharge even when they felt positive about going home. Vat et al. (2015, p. 3609) report participants felt they were rushed out, "*discharged too soon*", "*definitely too early*" or "*not prepared to go home*". These participants felt the decision to be discharged should be based on "*their level of autonomy and physical capacity*" and not on their length of stay (Vat et al., 2015, p. 3609). Others felt they were discharged without feeling better and that the discharge was unexpected (Pedersen et al. 2018). One participant described knowing he was not ready for discharge (Yu et al., 2007). This participant immediately consulted a private doctor on discharge and was readmitted to hospital (Yu et al., 2007). In some instances, participants affirmed that their feelings of not being fully recovered or well enough to go home were ignored (Dilworth et al., 2012) others felt left in limbo (Pedersen et al. 2018). Two participants mentioned they had been looking forward to going home despite not having felt ready or healthy enough to go (Yu et al., 2007). Not feeling ready to go home could be associated with readmissions or the fear of readmission. Vat et al. (2015) noted their participants came back to the hospital as they did not feel ready to go home in the first place. Elsewhere, a participant re-presented to hospital as they had been sent home without knowing why they were in pain (Uscatescu et al., 2014). Others came back to hospital after experiencing anxiety and worry about having gone home with their condition unresolved (Slatyer et al., 2013). Furthermore, patients felt their readmission may have been prevented if their clinical condition had been considered as opposed to their length of stay in hospital (Yu et al., 2007).

2.5.2 Patients experience uncertainty following discharge

Perception that community-based services are not available or adequate

Participants perceived healthcare professionals in the community could not be trusted or relied upon (Uscatescu et al., 2014; Vat et al., 2015) due to both a lack of availability and perceived competence or clinical skill. Unavailability of resources in the community setting was noted when patients could not access community services (Stephens et al., 2013; Vat et al., 2015), some could not obtain a General Practitioner (GP) or physiotherapy appointment for over two-weeks post-discharge (Dilworth et al., 2012) and others felt there was both a lack of capacity and no coordination between services in the community resulting in poor care (Pedersen et al. 2018). Several participants stated it took too long to be seen (Uscatescu et al.2014), spoke of doctors and community-based nurses who did not show up (Vat et al., 2015), or found their expectations for home-based services were not understood (Rijpkema et al. 2021). Others were told they would have a home assessment at an unknown point in the future (Dilworth et al., 2012). Some noted they were not even aware of what community-based resources were available (Vat et al., 2015). Difficulties were also experienced when trying to make appointments or get medication (Stephens et al., 2013). Certain groups of patients, such as homeless or socio-economically disadvantaged individuals, also had difficulty accessing services due to an inability to pay for transport (Stephens et al., 2013). The absence of community-based resources is also illustrated by Uscatescu et al. (2014) who noted that only one participant in the study was able to access a follow-up appointment; the others were readmitted before they could attend one. Similarly, Slatyer et al. (2013) described how a patient’s condition had deteriorated whilst they had been waiting for a GP appointment and that they then had to return to the hospital.

In addition, community healthcare professionals were not trusted or relied upon due to the perception they could not manage patients' clinical conditions (Vat et al., 2015; Yu et al., 2007). Some stated that their GPs did not understand their condition (Vat et al., 2015) or were not competent to deal with it (Uscatescu et al., 2014) whilst others thought their condition could not be "*cured*" in the community (Yu et al., 2007).

Perception that hospital is the only safe place

The view that hospital is a safe place in contrast to the uncertainty of home is illustrated with some participants describing doubt about their ability to manage at home. All the participants (n = 3) in Dilworth et al.'s study (2012) described this, feeling their return to hospital was unavoidable and that they needed to return as they required help or felt unwell. Similar situations are described elsewhere (Slatyer et al., 2013) with individuals feeling uncertainty because they did not understand the complexity of their care or had a limited understanding of their health which contributed to feeling they could not manage (Slatyer et al., 2013). This was echoed in a later study where patients described feeling out of control and unable to manage due to living with chronic conditions (Pedersen et al. 2018). In some instances, participants felt hospital was a positive setting and their only lifesaver, with some noting their only resource in the face of death was to return to hospital describing this as an "*obligation with no alternative*" (Uscatescu et al., 2014, p. 37) or a relief and the best option (Pedersen et al. 2018). Similarly, when reflecting on their condition participants described readmissions as expected due to health status or frailty

(Rijpkema et al. 2021). Yu et al. (2007) noted patients felt powerless to manage Chronic Obstructive Pulmonary Disease (COPD) after discharge and they lacked confidence in their ability to manage symptoms. Some participants reported a feeling of impending death which meant they did not feel they had any other option but to return to hospital (Yu et al., 2007).

Hospital as a safe social space was experienced by some patients who had formed positive and supportive bonds with healthcare professionals and other patients (Yu et al., 2007). This contrasted with their uncertainty over what services were available in the community and a feeling of being a burden to their families. Participants in this study stated they experienced a positive social atmosphere in hospital and did not feel lonely there (Yu et al., 2007).

Difficulty in adapting to a “new normal”

Uncertainty was experienced by patients in terms of expectations of themselves and their ability to adapt to their altered situation because of their diagnosis or treatment, which can be referred to as a “new normal”. For some, this was linked to perceptions of vulnerability linked to experiencing frequent rehospitalisation and ill health (Pedersen et al. 2018). There is evidence that patients were experiencing new uncertainty that they needed to learn to live with, but they did not feel they had received adequate support from healthcare professionals to do so. Patients described not feeling back to normal after discharge or feeling isolated and some experienced acute or unresolved symptoms (Uscatescu et al., 2014). Some patients attributed this to not receiving discharge information or instructions which meant they could not tell if their health was getting better or worse when they went home, they did not know what to expect (Vat et al., 2015). For others this was because they had limited recall of conversations with healthcare professionals (Slatyer et al., 2013), thus they did not have clarity over what to expect on discharge. A lack of confidence about how to control symptoms was also cited by some as a reason for readmission (Uscatescu et al., 2014; Yu et al., 2007). Several patients even noted they felt anxious and scared (Slatyer et al., 2013).

Other participants contrasted the independence they experienced before their initial admission with how they felt on discharge; they noted this led to feelings of uncertainty and in some cases readmission (Dilworth et al., 2012). This was echoed in other articles, where some patients described they did not want to accept this situation or lose their independence (Slatyer et al., 2013). For others the “new normal” was yet another issue they needed to adapt to alongside complex life-changing events, such as being a veteran, experiencing homelessness and living with psychiatric conditions (Slatyer et al., 2013).

2.6 Discussion

2.6.1 Themes in context

This review highlights the experiences of older adults who are readmitted to hospital. Overall, the themes in this review indicate that returning to hospital can be the consequence of a prior experience in which individuals feel excluded from decision-making, are not ready for discharge and perceive a lack of support at home which paradoxically can lead to the perception that the hospital is the safest place to be. This review illustrates the psychological and emotional experiences that can run alongside physical health harms, which are associated with readmissions, as described by the Kings Fund (2014).

Effective discharge planning is recognised as a factor in readmissions and patient satisfaction (Gonçalves-Bradley, et al. 2016); however, the strength of this evidence is weak (Gonçalves-Bradley et al., 2016; Preyde, Macaulay, & Dingwall, 2009). Despite there being best practice guidance on discharge planning (Lees 2013; NICE 2015a) it is unclear what impact this is having on unplanned readmissions. The focus on discharge planning in England has developed during the Covid-19 pandemic with further guidance and support being shared by the Local Government Association (LGA, 2022), NHS (NHS 2022) and DHSC (2022). For instance, the nurse in charge action card highlights the necessity of communicating a discharge plan with the patient and family (DHSC 2021). The LGA (2022) model includes an aim to manage crises in the community to avoid admission. The model emphasises the importance of structure, inclusion of patient and family, clear communication, and transparent processes. Despite these organisations working closely together there are inconsistencies between their recommendations, for example, action cards do not specify a requirement to create a discharge plan *with* the patient and family as advised by the NHS, DHSC and LGA. In spite of these inconsistencies, the focus on discharge processes remains, whilst unplanned readmissions persist (Adamuz et al. 2021).

There is evidence in the wider nursing literature that many patients feel ill-prepared to go home from hospital (Annema *et al*, 2009; Kangovi et al., 2012; (Verhaegh et al. 2019)). Participants in Annema et al.'s study (2009) did not consider they received adequate help from healthcare professionals with this transition. Those included in Verhaegh et al's 2019 study of people with chronic conditions did not feel ready to leave resulting in them feeling unsafe and having subsequent readmissions. Not feeling prepared to go home was also found to be associated with readmissions among older adults (Annema et al., 2009; Coffey

& McCarthy, 2013). The inevitability of a return has been highlighted elsewhere (Jeffs, Dhalla, Cardoso, & Bell, 2014). It therefore seems logical to argue that feeling ill-prepared to go home might increase the likelihood of a readmission, but that despite this knowledge, readmissions attributed to feeling ill-prepared for discharge continue.

This review also suggests that patients do not feel included throughout the hospital stay; they describe a "cycle of exclusion" that indicates that their care is not being undertaken in a holistic manner and the psychological and emotional experiences that can run alongside physical health harms. As nurses, it is our role to help create therapeutic relationships with patients, creating environments where equality of worth is central and where patients feel able to be active and equal participants (Kuokkanen & Leino-Kilpi, 2000). For example, some respondents noted they felt powerless to manage their condition (Yu et al., 2007) or that they did not have the knowledge or authority to question the decisions made by healthcare professionals (Dilworth et al., 2012). This indicates that opportunities for creating authentic and therapeutic relationships may have been missed. A respondent noted they wanted to be spoken to about their condition using lay language (Dilworth et al., 2012) highlighting that power can be exerted through the language we use as professionals (Kuokkanen & Leino-Kilpi, 2000). This is reflected in other work that describes patients feeling like objects, with discussions controlled by healthcare professionals, use of medical language and communication being "about" instead of "with" them (Efraimsson *et al.*, 2003). Power can be viewed as the ability of people to exercise choice (Laverack, 2016), thus having no choice is synonymous with powerlessness. This is pertinent considering the respondents' views that they felt powerless or disregarded in decision-making throughout their stay and readmission.

To be ill has meaning to the person with the illness (Lindburg, Horberg, Persson, & Ekebergh, 2013) and addressing this meaning with patients should form part of routine nursing care. This review demonstrates this psychological and emotional care is often not addressed by healthcare professionals. This is not surprising as these aspects of care have been found to be some of the most reported activities of care left undone with 46% of nurses sampled citing, they did not have time for "comfort/talking with patients" and 34% not able to develop or update nursing care plans or care (Ball et al., 2016). Furthermore, other research has found that older adults can rationalise the need for extra support or time in hospital but their existential needs or feelings around grief and loss are not always addressed (Lindburg et al., 2013). Psychological adjustment is also required by patients when they are discharged from hospital but again this element of patient care is often overlooked by healthcare providers (Lees, 2013). Helping people to address existential matters and manage and understand changing expectations, of themselves as individuals and of healthcare services, are vital and form part of delivering holistic person-centred care.

The themes identified in this review are important as they have not been identified in individual qualitative studies. They illustrate that patients often feel excluded and uncertain during readmission, indicating that holistic care is not always being provided. This emphasises the value and importance of human connection in nursing practice. Sharp *et al.* (2016) identified that this can improve patients' experience of care and that incorporating personal, emotional and spiritual elements within nursing can have a positive impact on patient empowerment and recovery. Understanding how and why patients feel excluded and uncertain at readmission is therefore of paramount importance. To achieve this space should be given to patients and their families to discuss these issues.

2.6.2 Critique

The research outlined in this review draws on research from across the globe, however, there continues to be a gap in research on the experiences of patients in the UK. The studies included in the review also have a lack of noticeable diverse voices thus there is a distinct lack of voices of women, people from different black or minority ethnic groups, LGBTQ, and different socio-economic backgrounds inclusion. Of note is the focus on the male experience with some studies only including male participants (Yu et al. 2007; Pedersen et al 2018). One strength of this review lies in the consistent thematic findings despite heterogeneity between studies. The size, composition, geographic and clinical location all vary as do the readmission timeframes which range from 14 days to one year. The healthcare systems represented also vary. This review adds strength to the argument around the need to deliver holistic person-centred care and to value the nursing time and skill dedicated to this. It should not be seen as acceptable to rush or omit this aspect of care.

Though the articles selected for this review have an overarching aim to explore patient experience of unplanned readmission, their focus is often narrower and does not incorporate the wider definition of patient experience. When looking at the stated aims of each study one notices there is more of a focus on exploring causal factors than experience. For instance, Vat et al (2015) note their aims are to identify the patients’ stated reasons for returning to the ED and then explore how they compare to healthcare professionals. This is mirrored in work by Slatyer et al (2013) and Uscatescu et al (2014) who focus on factors influencing older adults’ decision to return to the ED. The more recent articles in the review continue this trend by focusing on critical incidents linked to readmissions (Pedersen et al

2018) and causes and possible explanations for readmissions (Rijpkema et al. 2021). Only Yu *et al*. (2007) and Stephens *et al*. (2013) aim to investigate and understand experiences older people have of the phenomenon of unplanned readmission to hospital. Thus, to date there is no research aiming to understand the experience of unplanned readmissions based in the UK that uses a holistic definition of patient experience (NHS III 2013) and that views unplanned readmissions in its fullest sense as an "*experience, process and event*" (Coatsworth-Puspoky et al., 2021,p.1).

Furthermore, only half of the selected articles wholly focused on the patient experience, the others incorporated views from caregivers and health professionals (Slatyer et al., 2013; Stephens et al., 2013; Vat et al., 2015; Rijpkema et al 2021). In addition, Rijpkema et al., (2021) note they used information contained in patient medical notes to prompt participants if they could not remember incidents. Thus, even within this selection of studies aiming to explore patient experience from the patient perspective issues of power remain (Bradbury-Jones et al., 2008), whereby the patient voice is viewed alongside professional voices instead of there being value in the patient story in and of itself.

This review highlights the importance of the patients' voices that are otherwise "silenced" (Serrant-Green, 2011) in wider research on readmissions to hospital that relies on administrative or survey data. Listening to patient voices is vital for healthcare professionals and enables the provision of person-centred care (Schwind *et al.*, 2016). Furthermore, viewing patients holistically and considering the way they describe their healthcare trajectories within and outside of hospital settings is important when we are providing care (Schwind *et al.*, 2016). The PhD study addresses this by focusing on the voices of patients and families to explore their experiences of an unplanned readmission to hospital.

2.6.3 Limitations of this review

All literature reviews have limitations (Aveyard et al. 2021), these can be linked to the findings and the methods used. Some of the limitations linked to the selected articles and the findings of the review have been identified and described above. In addition, the articles selected for this review each have their own limitations thus these findings should be viewed accordingly. Of note is that only articles written in English were included; and most of the interviews included in this review took place in a hospital setting, and not necessarily a setting of the participants choosing. This could cause participants to not feel comfortable or able to be as open, which may have an impact on the findings of each included study, and thus, this review.

The term 'systematic' is not reserved for use by the Cochrane Collaboration (Aveyard et al. 2021) however it is used in this instance as rigour was supported by following a systematic process, seeking the advice of a specialist librarian, discussing the method and findings with the supervisory team, using a standardised reporting mechanism (PRISMA). Nevertheless, rigour could be enhanced in the following ways: incorporating grey literature, unpublished papers and other evidence could add to the insights and perspectives included in the review. Having a team to work on all aspects of the review would improve rigour and fulfil the quality requirements of a full qualitative evidence synthesis (Noyes et al. 2018). As described earlier in the chapter this literature review was conducted in a systematic manner and a thematic synthesis was conducted whereby results were combined and reinterpreted (Aveyard et al. 2021). This was conducted to support a PhD study to both explain the importance of the subject area and identify where further research is required, consequently this review has contributed to the PhD study focus and design.

2.7 Chapter Conclusion

This review was carried out to explore published research on the experiences of unplanned readmission to hospital among older adults. Individual themes in this review are echoed in other research. However, when taken collectively the themes synthesised illustrate a negative experience and a cycle of exclusion for many. In addition, this review identified that individuals' existential, emotional, and psychological well-being was not being adequately addressed by healthcare professionals. This chapter also highlighted the limited published accounts that exist on returning to hospital in the words of older people themselves. Thus, there is still more work to be done on understanding unplanned readmissions among older people. This PhD study contributes to this by centring the experiences of older people themselves and viewing patient experience holistically as per the NHS definition and the concept of unplanned readmission as set out by Coatsworth-Puspoky et al., (2021), in that unplanned readmissions are more than one discrete moment. Furthermore, this study fills a gap in published research by providing a perspective from an English NHS context. The following chapter on methodology will cover the approach taken, and ontology and epistemology underpinning this research. In addition, this chapter will describe other approaches considered and discuss methodological limitations.

3.0 Chapter 3 - Methodology

3.1 Chapter introduction

The aim of this chapter is to outline the perspectives that form the basis of the methodology adopted and to provide justification for methodological decisions. The research aim will be described alongside the basis of some of the researcher's personal and professional beliefs to support the qualitative approach taken. The nature of qualitative research and potential approaches will be discussed. Then, the ontology and epistemology adopted in this study will be outlined before justifying the constructivist paradigm assumed and the use of a collective case study informed by Stake (2006). Finally, the limitations of the chosen methodology will be explored.

3.2 Research aim

The aim of this research was to understand the experiences and perceptions of older people and their families when faced with an unplanned readmission to hospital within 30 days of discharge. Furthermore, there was a desire to explore the perspectives of older people and their families themselves as their viewpoints had been hitherto underrepresented in the published literature. It was also important to ground this experience in an NHS context.

It is important for research to address social need and inspire change (Denzin and Lincoln 2018) and this was also a consideration of this research. The underlying aim was not to create direct change *whilst* conducting the research in the way that participatory action research does (Denzin and Lincoln 2018) rather to conduct useful research, relevant to nurses, that could directly inform future care, education, and policy, with ultimately the intention of improving care received by patients and families and supporting nursing staff to provide this care. The aim of this research was also informed by my personal and professional beliefs which are discussed later.

3.3 Qualitative approaches

The aim of this research is to highlight experiences, interpret and understand them, and to inform improvements to patient care. Personal and professional beliefs that prioritise multiple perspectives, the patient and family perspective, and inclusive approaches that reduce hierarchy are deemed important. All these elements are consistent with qualitative approach to research. Qualitative research is *"a set of interpretive, material practises that make the word visible*" (Denzin & Lincoln, 2018, p.10) that "*investigate the meaning of human experience*" (Halcomb, 2018, p.6) and to make changes in the world, thus, we can see how approaching the question posed in this study could most appropriately be explored using a qualitative approach.

A key tenet of qualitative research is that knowledge is created by people (Merriam & Tisdell 2009). Furthermore, this process involves researchers being instruments of data collection and analysis (Merriam & Tisdell 2009) so all value systems of researcher & knowers should be made transparent (Lincoln & Guba 2013 p.41). Ontological and epistemological assumptions are coloured by the values and beliefs held by the individuals' conducting research. These values and beliefs are shaped by politics, gender, sexuality, history, geography, race, ethnicity, class, abilities and so on (Darwin Holmes 2020). Researchers are encouraged to be reflective and consider how their own self affects the research process, decision making and outcomes as this back-and-forth process forms part of knowledge generation in qualitative research (Berger 2015); hence these will be described later.

3.4 Situating the self in the research process

Research does not occur in a vacuum. Human experiences are affected by wider social structures (Lofland & Lofland 1995) and opinions, experiences, perceptions, and consciousness are all affected by the everyday context one lives in; they do not passively appear in one's mind (Callinicos 1983). Thus, these social structures affect the researcher and the researched. Researchers are not separate from the social processes they are studying (Darwin Holmes 2020), so each phase of the research process is shaped by researcher position, from deciding an area to research, how to frame the research question, how to design and conduct the research itself and then how to present and share findings (Borbassi et al., 2005). Consequently, all elements of the research process are affected by wider social structures so situating myself within this process is fundamental and affects my understanding of why and what I am researching. This section outlines some of the personal and professional elements of my background which have influenced the direction and outcomes of the thesis.

3.4.1 Being a Registered Nurse

Nursing requires knowledge that captures the personal experience of health, illness, and life (Hoeck and Delmar 2018) and this knowledge should inform nurses on how to care for people facing those events. As a nurse, both my clinical and research practice is informed by my professional identity, thus explaining my focus on care and human relationships, my interest in social and climate justice, and the clinical context I practice in. How these aspects of my professional identity shape this PhD study are outlined below.

I am deeply interested in questions of patient care and how patients and their families experience their nursing care. What appears important to me as a nurse is a desire to improve the care experienced by patients and their families. I was drawn to the Ethics of Care as described by Held (2006) where care is viewed as both a value and a practice. Care "*must concern itself with the effectiveness of its efforts to meet needs, but also with the motives which care is provided*" (Held 2006 p.36). Care is labour, "*care...is work as well as an emotion or motive or intention*" (Held 2006 p.51) and to provide care nurses must recognise need in the other and be able to act on it (Martinsen, 2011; Hoeck & Delmar, 2018). The knowledge nurses hold as a profession is a form of power that can be held over patients and families (van Herk et al. 2011). In addition, nurses often work in settings with hierarchical and patriarchal cultures (Aspinall et al., 2021) where they can unwittingly perpetuate unequal power relations. Thus, the act of caring requires that nurses acknowledge their power (Delmar 2012) and create space to understand patients without resorting to sentiment or paternalism (Delmar 2012). Care is intrinsically relational (Swanson, 1991; Martinsen, 2011; Delmar, 2012), it is not simply delivering interventions but is a practice "*deeply rooted in human relationships*" (Hoeck & Delmar, 2018, p.5). Understanding how patients experience their care is important to me as a nurse. This understanding is key to developing nursing knowledge and fitting for our discipline (Smith 2019). Thus, my professional identity as a nurse has affected the decisions I have made throughout this research process, including the decision to focus on patient and family experience of care and the need for multiple perspectives.

Nursing is political, that is, the underpinning aim of nursing is to ensure maximum health and wellbeing for all (Butts & Rich 2015). Within the context of the NHS, a national, public system which provides healthcare free at the point of use, I feel privileged to be able to provide healthcare to all those who need it. However, there continues to be a multitude of inequalities within this system and continued issues of unequal access and treatment persist (NHS, 2019). Older people can experience ageism during healthcare encounters and nurses can perpetuate ageism (Dahlke and Hunter 2021). It felt important to me to explore the human experience of ageing. This topic is of paramount importance to all nurses (Kagan, 2020) and an issue I felt was personally important in view of disproportionate numbers of older people affected by unplanned readmissions.

There is an urgent need for nurses to involve themselves in issues of climate justice and sustainability. As a nurse, I believe that as a profession it is vital that we highlight climate change as a healthcare issue (Butterfield et al. 2021). Since the time of Florence Nightingale questions of the environment have been central to nursing (Chin et al 1985). Nightingale commented on how human existence and the environment are intertwined in her 'Notes on Nursing' (Nightingale 1992). Preventing duplication in the health system and reducing unnecessary encounters, such as the number of people unnecessarily coming to hospital, not only has individual benefits to patients, it also increases efficiency and reduces carbon emissions (NHSE, 2020) which helps support the NHS to fulfil its now statutory duty to reduce carbon emissions (Health and Care Act 2022). In addition, older people are disproportionately affected by climate change (Leyva et al. 2017). Climate change is causing climate sensitive health risks, these include extreme weather events like heat waves, and undermine social determinants of health, such as access to healthcare and social support structures (WHO 2021a). These risks are disproportionately felt by those already more vulnerable in society, including older people (WHO 2021a) and can exacerbate existing inequalities. Exploring and addressing unplanned readmissions to hospital is accordingly also a sustainability issue. These considerations are reflected upon and discussed within this thesis.

My professional identity is affected by the context I am practising in. The current policy landscape is shaped by the NHS Long Term Plan (LTP). A feature of the LTP (NHS 2019) is the requirement to put the "*patient at the heart of the system*" (p.104) and view patient experience as a component of quality care. Patient stories can act as 'light bulb moments', helping clinicians to reflect on the care they provide and prompting them to act on improving care provided (POC 2020). Nursing knowledge must embrace the existential (Hoeck and Delmar 2018) to provide nursing care that supports people to be alive *and* live (Hoeck and Delmar 2018). Thus, nurses need to create knowledge that reflects this, that is, they need to investigate alongside patients and their families and focus on the experiences of patients and families. Thus, I consider patient stories as legitimate and useful knowledge that should be incorporated into healthcare planning and decision making.

3.4.2 Personal background and beliefs

I have been extremely lucky to grow up in a bi-national family, I have a British father and French mother. Even more fortunately, my family ensured we grew up with both languages and cultures very present. Our home was always open and welcoming to family, friends, friends of friends and as such we were surrounded by visitors from around the world, many of whom did not have English as a first language. This influences my research in multiple ways. Alongside the excellent benefit of possessing the ability to speak multiple languages and thus communicate comfortably in many countries, this upbringing reinforced the fact that we all have different perspectives. In addition, it reinforced the idea that people have different experiences of similar phenomena, and that it is important to investigate issues from multiple perspectives to capture this when trying to understand something.

I personally identify as cis female, White, straight, and I have been fortunate to have a relatively comfortable upbringing. Furthermore, since a young age I have described myself as a feminist, hold left wing political beliefs, and am committed to social and environmental justice. These factors all affect my worldview. I understand the world is different for people from different backgrounds and the corresponding need to check my own privilege. This has influenced my research in many ways, some of which I suspect I am not even aware of. To stay alert and conscious about how the self can shape the research process I have sought to be reflexive (Berger 2015), this has involved using a reflective diary and seeking insights from experts by experience.

My feminist beliefs are central to who I am. I recognise that feminism is a wide well-established field in academia and that there is a multiplicity of feminisms such as liberal, Marxist, radical, socialist (Chinn et al. 1985). An extensive exploration of feminism in nursing research, while important, is not the aim here. I have not sought to undertake a feminist piece of research underpinned by a critical theory paradigm rather, I outline how my feminist insights inform my research. The feminism I refer to is one that considers the systematic reasons of injustice based on gender, that questions why there are divisions, considers power and the influence of the current healthcare system on individual’s health and nurses work (Chinn et al., 1985, p.77). The feminism I ascribe to is intersectional (Crenshaw 1989). This feminism recognises that multiple dimensions of identity and human experience, such as race and class, overlap and do not exist independently of each other.

As such, people can simultaneously experience multiple burdens and inequality across a variety of axes, such as sex, race, and class, and these often operate together.

My feminist beliefs influenced my ontology, epistemology, and decisions around how to conduct research. These beliefs are also echoed in nursing practice supporting approaches that involve care, respect, and a commitment to minimise power differentials (Borbassi et al., 2005; Dowling, 2006). The relationships that develop between researcher and participant are carefully looked after, with power differentials minimised as much as possible (Borbassi et al. 2005). Techniques such as informal interviewing (Borbassi et al. 2005), engagement and reflexivity (Dowling 2006) and including stakeholder engagement groups, align with a feminist and nursing approach to research. A feminist stance justifies and values a focus on human experiences and relationships which are central aspects of nursing (Eun-Ok, 2010), highlighting and viewing these as appropriate important issues to investigate. Thus, a feminist perspective aligns with a holistic approach to research which understands that patient experience is not homogenous. Stake (1995) encourages the use of a holistic perspective and thick description so the reader can consider their own reflections, thereby reducing some of the hierarchy that can exist within academic scholarship. This resonated with my personal and professional ideals thus, they also informed the decision to use Stake (1995) as an influence. In addition, use of first person writing where appropriate is used and is legitimate within scholarly nursing work from a feminist perspective, as this approach celebrates the authentic voice and values accessibility (Mitchell 2017). In fact, carrying out nursing research in and of itself is a feminist act in so much as it values ourselves as a profession (Chinn et al. 1985). Thus, a feminist stance justifies shining a light on ‘invisible’ issues central to nursing practice. More specifically, this influenced focusing on the invisible experiences that older people and their families often had of unplanned readmissions to hospital and explains why the topic under investigation was chosen to be examined the way it was.

3.5 Ontology

A relativist ontology was adopted, whereby the search for one 'universal truth' is rejected (Weaver & Olson 2006) and rather an exploration of multiple realities is focused on. Reality is deemed to be constructed (Abma & Stake, 2014), dependant on different peoples' experiences of the world and on the meaning they ascribe to it (Stake 1995). In addition, reality is viewed as relational and experienced in different ways dependent on perspective (Boblin et al. 2013). Reality is explored within relationships and conversations (Delmar 2013) where *how* people give meaning to, describe, and interpret things constitutes their reality (Weaver & Olson 2006). Thus, multiple realities exist, and reality is deemed to be an individual's interpreted experience of phenomena. Undoubtedly, trees and rocks do exist whether we are conscious of them or not, but these objects do not have meaning unless we as humans ascribe them meaning (Crotty 1998); "*It becomes a world of meaning only when meaning-making beings make sense of it*" (Crotty, 1998, p.10). Thus, what is in existence is meaningful when we make sense of it and inherently this depends on the perspectives of the person or people making sense of it, it is context dependent. Context is important and people and situations can change, thus realities are not fixed. Consequently, the aim of research, is to investigate how people interpret what is real and meaningful to them thus it was deemed congruent to include multiple accounts of unplanned readmissions to hospital. These perspectives align with both my personal and professional identities that welcome the varying perspectives different patients bring of their care. Furthermore, there was a desire to centre the experiences of older people as inherently valuable and incorporate them into nursing knowledge.

The question of relativism inherent within constructivism can be problematic (Prins 1995) as it suggests you can be "*nowhere while claiming to be everywhere*" (Haraway 1991 p.191). That is, by welcoming multiple realities there is a risk of merely describing a list of perspectives without synthesising or creating meaning with which to address a research question. On the one hand relativism can to a certain extent enable researchers to respect and value each voice or story within their research and fulfils democratic ideals (Abma & Stake 2014), but it can also mean nothing is questioned or critiqued and wider social issues are overlooked. The potential risks intrinsic to relativism can be mitigated by using a collective case study where meaning is shaped by context, a holistic understanding is prioritised and "*the universal in the particular*" (Abma & Stake, 2014, p.1160) is generated. Thus, multiple realities are incorporated into a contextually dependent 'humanistic understanding' (Stake, 2000) of a phenomenon which can be recognised in other contexts and be useful to making socially useful change (Stake, 2000). Furthermore, this holistic and democratic approach aligns with the nursing values described earlier in this chapter.

3.6 Epistemology

A subjectivist epistemology was adopted, with the corresponding understanding that knowledge is deemed to be co-created between investigator and investigated and that the two are linked "*such that who we are and how we understand the world is a central part of how we understand ourselves, others, and the world*" (Denzin & Lincoln, 2018, p.117). That is, knowledge of a phenomena cannot be separated from the people who know, i.e., those who have experience of this phenomena. Thus, research is conducted *with* knowers, not *on* knowers. The themes generated through co-construction during this research process are co-created between knowers and investigators. Furthermore, the constructions held by knowers need to be uncovered in a way that optimises their abilities to share their constructions. This is consistent with the personal and professional views held by the researcher, especially respect and democracy. In addition, these constructions need to be reflected upon, compared, and contrasted within a specific context (Lincoln & Guba 2013) to generate knowledge.

When acquiring this knowledge, researchers must be aware of power and consider that all knowledge acquisition is a political act as "*inquiry cannot be shielded from the impact of values held either by the inquirer or by the respondents"* (Lincoln & Guba 2013 p.77). Thus, a method that incorporates these steps and values reflection and contextual positioning is required. Central to knowing is the acknowledgement that experiences depend on dynamic wider social structures, which play a role in the constructions (Lofland & Lofland 1995). Furthermore, knowing depends on accepting that different subjective constructions of reality and truth exist and that these should be incorporated. However, not in a way that automatically equates to accepting relativism, or that all views are equal (Stake 1995), rather that knowing is based on the existence of a plurality of views (Baxter & Jack 2008).

This epistemology posits that knowledge is captured through hermeneutics, the interpretation of 'linguistic designations' (Denzin and Lincoln 2018), i.e., words, whether they are spoken or written. Language is the medium which the world comes to be understood (Peck & Mummery, 2018); however, the extent to which a researcher can be sure of what participants really meant with the words they expressed, and thus, whether they are able to fully represent their experience through these words is questioned (Peck and Mummery 2018). To account for this a method that incorporated multiple perspectives of a phenomena was deemed important as was the inclusion of moments of 'accidental ethnography' (Fujii 2015). Field notes of observations and comments on participant behaviours made during interviews can be interpreted and used to generate knowledge (Merriam and Tisdell 2015). In addition, these observations can assist the researcher in understanding wider contextual factors of the larger political and social world in which the research is embedded (Fujii 2015). In summary, this study is based on a subjectivist epistemology that views knowledge as co-constructed between knower and investigator, understands that this process is context dependent and values multiple perspectives of a phenomena to build understanding.

3.7 Interpretivist paradigm, constructivist approach

An interpretive paradigm and constructivist methodological approach were adopted. This is aligned with the research question, provides the structure to interpret experiences within the context they are taking place in, and posits that meaning is co-created within this. As described by Abma and Stake (2014) "*the world does not have meaning on its own, but we make sense of and endow meaning to our world in interaction with others. In line with this tradition, it is not so much the factual world that interests us, but the interactively constructed meanings endowed to the world" (p.1152)*.

A lack of consistency around terminology and categories has been identified as particularly confusing (Corry et al. 2019). There exists confusion and debate around the definitions of interpretivism and constructivism, with some referring to the blurring of boundaries between them (Kelly et al. 2018). For instance, within a matter of pages Denzin and Lincoln (2018) describe: an interpretivist paradigm that includes constructivism as an approach, an interpretivist tradition, interpretive epistemologies that also seems to include constructivist epistemologies, but also refer to both constructivist-interpretivist and constructivist paradigms. Attempts to clearly differentiate interpretivism and constructivism exist. For instance, Cutler et al. (2021) suggest the difference between constructivism and interpretivism lies in how knowledge is used: with constructivism intended to develop and apply knowledge and interpretivism to understand and describe a phenomenon from a conceptual orientation. However, this difference does not appear clear cut when we look at how constructivism is conceptualised in Stake's (2000) work and in Abma and Stake (2014). Stake's constructivist case study work is grounded in the interpretivist 'research tradition', is interested in 'constructed meanings' (Abma & Stake 2014) and wants to both deepen understanding of a phenomenon (a multi-layered and holistic understanding) (Abma & Stake 2014) *and* guide action (Stake, 2000).

Further confusion exits with the terms constructivism and constructionism sometimes used interchangeably and can be poorly defined. The distinction between these terms is deemed ambiguous in the literature (Kelly et al. 2018) nevertheless Crotty suggests there is a defined difference between them stating *"On these terms, it can be said that constructivism tends to resist the critical spirit, while constructionism tends to foster it"* (Crotty, 1998, p.58). However, this difference does not seem sufficient to fully differentiate between these two terms knowing that constructivist thinkers such as Stake do adopt some elements that could be viewed as a 'critical spirit', in that Stake recognises the existence and impact of contextual factors such as structural inequalities and politics (Luck et al., 2006). Furthermore, Stake does purport social change as a desirable outcome of research, noting there is an obligation by researchers to be socially useful and facilitate professional practice (Stake, 2006).

Looking more closely at constructivism, the aim of constructivist inquiry is "*to understand and interpret through meaning of phenomena (obtained from the joint construction / reconstruction of meaning and lived experience); such understanding is sought to inform praxis (improved practice)*" (Denzin & Lincoln, 2018, p.119). That is, constructions are contextually situated and the sense-making that produces the constructions resonates with the values of the voices shaping it, i.e., "*each construction is devised in the framework of the social, cultural, historical, political, economic, ethnic, and gender positions of the constructor*" (Lincoln & Guba 2013 p.58).

Thus, for the purposes of this study, constructivism is viewed as a methodological approach that sits within the interpretivist paradigm. The interpretive paradigm is centred on "*make(ing) the world visible in a different way*" (Denzin & Lincoln, 2018, p.10), includes constructivism as a methodology and aligns with inductive, exploratory qualitative methods.

3.9 Collective case study informed by Stake

3.9.1 Definition

Case studies are particularly useful for answering how and why questions in a real-life setting (Luck et al., 2006). A collective case study informed by Stake occurs when "*one small collection of people, activities, policies, strengths, problems or relationships is studied in detail*" (Stake, 2006 p.vi). The aim is to closely examine several cases that are linked together to explore a phenomenon from multiple perspectives (Stake, 2006). A feature of case study research is that each case must be bounded and described (Luck et al., 2006), that is the boundaries of what is and what is not a case should be explicit. The aim of collective case study is to understand the Quintain, that is a programme or a phenomenon, and cases are used to help better understand the wider phenomenon (Stake, 2006). Cases are not compared, rather, each one is valued in how it can aid a better understanding of the phenomenon under study (Stake, 2006). Thus, by using this approach individual experiences are appreciated and contribute to generating a holistic, context bound, understanding of a wider phenomenon.

3.9.2 Justification for the approach

I adopted a collective case study informed by Stake for the following reasons: It aligned with my ontology and epistemology, it is ideal for answering how and why questions, to explore the "universal in the particular" (Abma & Stake, 2014, p.1160), explore issues where the case cannot easily be separated from the context, and to generate holistic, context bound understanding of the experiences and perceptions of unplanned readmissions to hospital from the perspective of older people and their families. Luck et al. (2006) identifies that case study as an inquiry is useful for studies concerning nursing knowledge with a practical application, and as a nurse this was deemed important and part of the decision making..

This type of case study is in alignment with the constructivist approach taken in this PhD study. This is supported by Lincoln and Guba (2013, p79) who outline that "*the report of a constructivist inquiry is most usefully made in the case study format*" and go on to describe some of the benefits of this approach including the inclusion of vicarious experience via case reports, and thick description and detail that enables readers to consider the case(s) in relation to their own context which facilitates the adoption of findings to other settings (Lincoln & Guba 2013).

This collective case study approach is favoured when there is an interest in examining multiple cases to enable a better understanding of a phenomenon from varied perspectives (Mills et al. 2010). A collective case study enables differences between and within cases to be explored and multiple realities to be encountered (Stake 1995; Appleton 2002). In collective case studies each case is meaningful because it is part of the collective vision of a phenomenon (Casey & Houghton 2010). This collective approach is taken when cases are linked together; in this instance, by the shared issue of an unplanned readmission, and when the phenomena are explored within the contexts in which they take place (Mills et al. 2010). This is consistent with the aims of this study where there is interest in individual experiences and perceptions of unplanned readmissions within a specific context and where there is a desire to identify outcomes that will be useful to society and professional practice (Stake 2006).

There are a range of proponents of case study, including Yin (2009) who also describes ways of conducting multiple case study research. However, Yin (2009) was not deemed in alignment with the ontology and epistemology adopted in this study due to Yin’s theoretical basis being that of positivism (Petty et al. 2012b; Yazan 2015). Yin (2009) comes from a positivist school of thought and the method he describes for conducting multiple case study research follows accordingly, for instance, there is a focus on starting with etic issues and a desire to test hypothesis (Abma & Stake 2014), as opposed to this PhD study where the focus is on including multiple perspectives and generating understanding.

3.9.3 The bounded case

An important feature of case study research is the clear and specific understanding of what is meant by the ‘case’. Furthermore, within the approach there is an acknowledgement that the case and context may be hard to distinguish (Luck et al., 2006). Individuals receiving care often visit different care environments during one hospital visit, such as an Emergency Department, a ward, and a discharge lounge. This reflects the current dynamic and complex nature of a hospital visit in the English NHS. People in effect cross through a variety of care lines during one healthcare encounter (O'Hara et al. 2018). Thus, to understand the phenomenon of patient and family experiences of an unplanned readmission, the boundary of what constitutes a case needs to reflect this reality of movement between care lines. The case boundary needs to be placed in such a way to both capture the individual experience of these movements between environments and ensure the collective experience of the phenomenon could also be recognised. The boundary also needs to reflect clinical criteria inherent within the study, for example geographical location, patient age, being a medical patient and time to unplanned readmission.

As cases must be bounded and described (Luck et al. 2006) the cases in this study are bounded by time, age, and place. Cases are selected according to what can be learned from them and how this can further understanding (Abma & Stake 2014). The aim was to have a range of cases that help understand the phenomenon of unplanned readmission to hospital from the perspectives of older people and their families, occurring in a specific clinical context that is a Trust in the English NHS. Thus, a *case* is defined as an adult aged 65 years or over and who has had an unplanned readmission to the study site hospital Trust within 30 days of discharge. Each case can be viewed from the perspective of the patient, in addition to that of a family member, alongside documents, observations, and reflections. The collective cases help us to understand the phenomenon under study, that is, the c*ase of* experiences and perceptions of unplanned readmissions to hospital within 30 days of discharge situated within this context.

3.10 Methodological limitations

There is not one way to assess quality in qualitative research as the range of methodologies and theoretical bases is vast (O'Reilly and Parker 2013) and different approaches to research have their strengths and limitations. This section will begin by describing and discussing the issue of generalisability which is a perceived limitation of case study research. Then, further misunderstandings of case study will be explored. Wider issues of rigour will be described later in section 4.5 and the limitations of the methods used to collect data will be addressed in section 4.6, both in Chapter 4.

3.10.1 Generalisability

As a concept generalisability is more at home in the positivist tradition where searches for universal laws (Carminati 2018) and a singular truth (Denzin and Lincoln 2018) dominate. Within this approach generalisability is viewed as a quality marker and a desirable outcome of the research process (Carminati 2018) showing that the research findings can be widely applied, and thus, be useful. Thus, a critique of much interpretive research is that generalisability is not possible when the work is relativist, and, that this is inherently a weakness. Even more so for case study research where the case boundary delimits the context of the study and can be perceived by some as limiting generalisability (Merriam 2009) and transferability (Baxter & Jack 2008). Whilst some may view discussing generalisability irrelevant in the interpretivist, qualitative tradition (Carminati, 2018), Stake (2006) addresses it and describes how findings from collective case studies can be applied more widely than in just the study setting.

First, it is worth revisiting the idea that according to Stake there will never be a single reality that can be captured in research (Stake, 2006) and that the world does not have meaning on its own rather humans endow meaning and interpret (Abma & Stake, 2014); consequently no research can ever claim to be generalisable to all humanity. Secondly, Stake (2006) dismisses the assumption that generalisations are inherently useful to professional practice citing the need for detail and context for these to be appropriately and usefully applied. Furthermore, for Stake (2006) generalisations, as described in the positivist tradition, are hypotheses and working positions that can have value but believes they should be viewed alongside contextual factors to be useful. Finally, for Stake (2006) a type of generalisation can emerge from collective case study research, called ‘naturalistic generalisation’ (Stake, 2000), also referred to when noting that an outcome of case study research is the identification of the “*universal in the particular*” (Abma & Stake, 2014, p.1160). Stake observes that “*what becomes useful understanding is a full and thorough knowledge of the particular, recognising it also in new and foreign contexts*” (Stake, 2000, p.22). In this way the reader of the case study takes away learning they feel they can apply to their own context. The complexity of human experience (Abma & Stake, 2014) means experiential, humanistic understanding is valuable. Thus, findings from collective case study are neither reductionist nor overly context specific and can be usefully applied in healthcare settings (Abma & Stake, 2014) when stories illuminated by case studies can act as a “*bottom-up approach*” (Abma & Stake, 2014, p.1158), highlighting what is meaningful to patients.

3.10.2 Misunderstandings of case study research

Difficulties with cases: definition, boundaries, and selection

The difficulties surrounding case description in case study research partly stem from the multiplicity of definitions and approaches that exist (Luck et al., 2006), how cases are defined also depends on the paradigmatic background of the researcher (Appleton & King, 2002; Luck et al., 2006). Criticism of case study research also rests on the potential for inappropriate case definition or non-specific case boundaries (Crowe et al. 2011). Furthermore, there can be a risk of collecting large volumes of data that are not appropriate for the case (Crowe et al. 2011). Consequently, there is a range of research calling itself case study that has different connotations (Casey & Houghton, 2010), outcomes and quality.

To mitigate against these issues within this study there is congruence between the ontology, epistemology and decision to conduct research informed by Stake (1995, 2006). Moreover, the outcomes of background research and the literature review supported the choice of case study definition and thus the boundaries of the study. Furthermore, the selection of cases followed thoughtful consideration; this will be further outlined in chapter 4.

Subjectivity, focus on researcher interpretation

For some, case study research does not have value in and of itself as it is too dependent on researcher values and interpretation (Flyvbjerg 2006). Similarly, there is a perceived value in case study research if it is used deductively as a tool to prove or disprove a hypothesis (Flyvbjerg 2006). Thus, it is the very foundation of case study research as a scientific method that is under scrutiny (Flyvbjerg, 2006). The section in chapter 4 on rigour will go some way to responding to this and will highlight the rigour, and scientific nature of case study research. In addition, briefly revisiting some earlier points from this chapter is helpful here, namely, the idea that no science can truly be called objective. As Stake (2006) states "*there is no value-free science in this world*" (p.85). There is a real benefit to case study research that is proximate to patients and their families, where findings are grounded in their reality and experiences. This ability to identify meaningful outcomes is a strength of case study research in nursing (Casey and Houghton 2010).

3.11 Chapter summary

This chapter began with an outline of the personal and professional beliefs held by the researcher before moving on to describe and discuss the ontology and epistemology adopted in this study. The interpretivist paradigm and constructivist approach taken was described. Approaches considered for this study were described, before a justification for the use of a collective case study informed by Stake (2006) was outlined and methodological limitations were addressed. The following chapter will focus on the methods used for data collection and analysis; ethics, rigour and limitations of methods used will be discussed.

4.0 Chapter 4 - Methods

4.1 Chapter introduction

This chapter will outline the methods used to collect and analyse data for this PhD study. The rationale for their use will be described, including their appropriateness for use within a collective case study that explores the experiences of unplanned readmission from the perspectives of older people and their families. As well as the rationale for their use, this chapter will detail the particular steps taken during this study and discuss decisions made during the data collection phase. The limitations of these methods will also be discussed, then ethical considerations will be outlined, and finally, study rigour will be examined.

4.2 Data collection methods

Collective case study data collection methods are best defined by the research questions posed (Stake 1995). This study focuses on the experiences and perceptions of older people and their families. Interviews were deemed an appropriate method of collecting this data, and as noted by Abma and Stake (2014) within a qualitative case study there is "*a preference for natural conversations and participant observations above data generated from responses to instruments devised by the researcher, such as a test or clinical interview"* (p.1150). Furthermore, interviews with eligible participants enabled me to incorporate multiple realities (Stake 1995) and conceptualise the Quintain whilst valuing individual contributions. The Quintain is defined by Stake (2006) as the phenomenon under study, which in this case are the experiences and perceptions of unplanned readmissions to hospital from the perspective of older people and their families. To build up a picture of each case the patient themselves was interviewed to elicit their experience and perspective on the unplanned readmission. If they had a family member, who may or may not be their caregiver, and who they were happy for me to approach they were also invited to be interviewed. In some instances, the family member was interviewed alongside the patient, other times they were interviewed at separate time points or locations to their family member.

In addition to interviews, I had intended to include a documentary analysis on a range of documents. However, so few patients received written information or could find their copies of documents that it was decided to focus on whether they received it and how they engaged with it. This included exploring whether they found it useful, whether they referred to it or used it in any way, and, whether it was meaningful to their experience or not. This information was documented in notes taken during the interview and was considered in the researcher's reflective diary. This is consistent with the reality of cases study research where initial notions of what will be considered important to the case study may well change during the research process (Abma & Stake 2014) and where data and data collection can change during a case study as researchers reflect on their methods (Stake 1995).

4.2.1 Site selection and number of cases

The aim of a collective case study is to build up a range of information about a phenomenon through information rich cases (Appleton 2002); the learning potential of each case and how it can support understanding of the wider phenomenon is deemed key (Abma and Stake 2014a). Nurse leaders identified a NHS Trust where they deemed there was a particular need to explore unplanned readmissions among older people, thus, this area was selected as a site to identify cases from. There is not a prescribed number of cases to include within a collective case study. This richness and relevance are key, as the concept of data saturation as a quality marker reflecting adequate sampling is contested (O'Reilly & Parker 2012).

Currently there does not appear to be literature describing an optimum number of cases to have within a collective case study. It is suggested that collective case studies should examine at least three different cases (Mills *et al.* 2010). Stake goes on to recommend that a minimum of four cases should be included but cautions the use of more than 10 to 15 cases due to the potential of being overwhelmed by the data (Stake 2005). It is also acknowledged that pragmatism plays a part in the number of cases collected; despite there, theoretically, not being an upper limit to the number of cases that could be included, project timelines and budgets are influential (Mills *et al.* 2010). Thus, it is accepted that a collective case study will be formed of a selection of cases and not *all* cases. It is also noted that more cases and more variability between cases can lead to more "*compelling interpretation*" (Merriam 2009 p.49). In the literature, where a collective case study design has been explicitly used, variability in terms of numbers is noted, ranging from four cases in a study on music teachers (Scheib 2003) to 14 in a study on an educational intervention for nurses and midwives (McDonald *et al.* 2012), to 22 communities in a large study on support services for people who had been assaulted (Campbell & Ahrens 1998). The number of cases suggested in the initial ethics paperwork for this PhD was between 10 to 15, the number of cases recruited as part of this study was 14.

Evidence within qualitative research focuses on "*meaning rather than measurement"* (Holloway & Biley 2011 p.968) and building up a compelling story with rich and relevant data is vital (Stake 1995, Holloway & Biles 2011). Quality of data thus rests on the extent to which cases can help us to understand the phenomenon under study (Stake 1995). To understand the phenomena, rich, in depth and detailed data is required. Searching for cases that can enable this is important, as is the inclusion of cases that may be atypical. This can be done without attempting representation of all possible case characteristics (Stake 1995) as this is not the primary aim of a collective case study, rather the aim is to understand. In this study the researcher believes they have achieved sample adequacy (O'Reilly and Parker 2013) with an adequate number of cases. This decision was arrived at as it was noted that similar themes and topics were coming up in interviews. The 14 cases were deemed to be of high quality as they included rich interviews, that were pertinent to the contributing to an understanding of the phenomenon under study. The corresponding data regarding written information, and reflections made during and after the interviews were substantial enough to answer the research question and to build a compelling holistic story of the Quintain via appropriate within and cross-case analysis.

4.2.2 Recruitment

Potential cases that could be included in this collective case study were patients that had an unplanned readmission to the NHS Trust that is the geographic location of this collective case study. This NHS Trust is based in the south of England and is a large teaching trust. The Trust has multiple sites in both urban and rural areas. The Trust also provides services in smaller centres and in peoples' homes. At the time of data collection, the CQC rated the trust 'good' in all hospital sites. Criteria for eligibility were: Age 65 or over; readmitted to the specified acute hospital trust within 30 days of discharge; medical patient; can provide informed consent. Ethical approval was granted for recruitment to take place in NHS establishments (further details in section 4.4). The benefits of this approach were considered and it was thought that this strategy would ensure potential participants had a comprehensive experience within the case boundary. Furthermore, existing professional contacts could be used to support recruitment. Purposive sampling was used, which is appropriate within a case study (Stake, 2006). Recruitment was a relatively slow process and involved spending a considerable amount of time building relationships with gatekeepers to potential participants.

The study site did not have any formal processes to identify readmitted medical patients aged 65 or above. On discussion with colleagues and specialists within the Trust, including senior members of the discharge liaison team, using specialist nurses to recruit was deemed appropriate in the study site context. Specialist nurses work across healthcare environments within the Trust and had in-depth knowledge of their patients. As teams of specialists, they would often use processes to identify patients, either daily or weekly, that enabled them to concurrently see if any of their patients had experienced an unplanned readmission and could thus be potentially eligible for this study. This did not add to their clinical workload and teams were positive and enthusiastic to take part and were also supportive of my PhD studies as a fellow nursing colleague. They were interested in the results of the study as they could see the relevance to their clinical roles. Once teams showed an interest to take part, I provided training to them in the aims of the study and in participant eligibility criteria. I would then discuss with the team who would then decide on how I should follow up with them, for example, weekly email reminders regarding recruitment or face to face reminders at the start of their shifts. This also kept relationships positive without adding undue pressure to specialist nurses working within a stressful clinical environment.

During the recruitment phase I created a set of ‘aide memoires’ to support a consistent approach to data collection. These took the shape of written lists I kept in my notebook and study file, I found them easy to use and helpful and they illustrate the steps I took during recruitment. Furthermore, I also created a table so I could record which clinical areas I was engaging with and sending recruitment packs to (see Appendix 8). I wanted to ensure appropriate spread across the different sites and clinical areas of the hospital Trust. I used my own knowledge of the Trust to reach out to different specialist teams and asked teams that were engaged to suggest or reach out to other teams to also help identify possible areas for recruitment. Due to operational pressures at the time not all clinical areas were responsive. I deemed it important to strike a balance between achieving a compelling story with respecting and supporting colleagues working in challenging clinical environments. To this end, I reached out either via email or in person. If I did not hear back from a team, I attempted one more time to contact them and if I did not hear back then I did not pursue them further. In two instances teams were initially interested to assist with recruitment, however they then decided they were not in a position to support identifying potential participants due to clinical pressures on their teams. In these instances, I also did not continue to pursue the team to get involved.

Specialist nurses used different techniques to identify potential participants depending on their usual working practices. For instance, the heart failure team had the practice of starting their working day by going through patient lists to identify whether any of their patients had been admitted to hospital. Depending on this, they would then organise their days and arrange visits across clinical areas to see their patients. It was at this point they could identify whether any of their patients had been readmitted within 30 days of being discharged. If this was the case, they took a study information pack with them on their visit and presented it to the patient at the end of their conversation. At this point, once the patient had the information pack, they were free to contact me with any questions and or decide to not reach out to me. The specialist nurses in this team also commented that they were sometimes asked questions about the study by patients and felt able to answer but did encourage the patients to contact me for any further details. Nurses working in other specialist areas used similar techniques to identify potential participants and noted that their knowledge of their own patient group meant this was something they could incorporate relatively simply and quickly at the start of their days. Initial attempts to follow up with teams were not always successful, and it was after I asked the teams how they wanted to be nudged or followed up with that engagement was more fruitful. For instance, with the team working in discharge liaison we agreed a weekly check in via email would be most appropriate, for the heart failure team, this was a weekly early in person visit to the lead nurse before the start of her shift. This also meant I could answer any specific questions there and then which the team noted they found helpful. The time spent building relationships was considerable and is an issue I have reflected on. The strength of this approach was that teams who did engage were enthusiastic and committed and genuinely wanted to support this study. This was particularly the case for teams who had already noted a pattern of readmission among some of their patients. These teams were interested in finding out more about experiences of unplanned readmissions and I believe this was a motivating factor in their involvement.

When speaking to patients who were interested in taking part, I checked whether they had had the opportunity to read through the patient information pack (see Appendix two) and asked whether they wanted any clarification on any of the issues raised. I outlined the aims of the study in lay English and why they had been invited to consider taking part. I then verbally summarised the patient information sheet they had received. This included me ensuring they appreciated the possible benefits and disadvantages of taking part. Potential benefits described were the therapeutic nature of being able to talk about a situation, the benefit to future patients being discharged from hospital as the aim of the research is to improve care, and, to help nurses understand what is important for those experiencing an unplanned readmission. Possible disadvantages highlighted were the potential for participants to feel distressed or disclose having received unsafe or unprofessional practice that is contrary to the Nursing and Midwifery Code of Conduct and or the Trust values and policies. However, I also noted the steps that could be followed in these instances to support them and raise concerns if appropriate. Furthermore, I added a list of potential places people could seek support including Age UK or the Royal Voluntary Service. I also considered that patients and families may view this research as an opportunity to complain about their experiences so I also included a 'Patient Advice and Liaison Service (PALS)' leaflet in the information pack so they could also access this service if required.

Below are the lists I created for myself during the recruitment phase:

4.2.3 Interviews

Face-to-face episodic interviews were used as a data collection method in this study, see below and appendix five which outlines the interview guide. When interviewing in an individual's house, I asked the interviewee where they would like us to sit and used this time to start to build rapport with them. However, if the interview was in a clinical environment (bed space, outpatients department, hospital café) the first thing I did was ensure the participant was happy to be interviewed there, whether they would like to move to a different location, and openly discussed issues around privacy and dignity with them to ensure they were happy to proceed. Only when the participant was amenable to start the interview process did I then seek to gain consent for the interview and begin recording as appropriate. In all instances, once consent had been gained, I began recording using a Dictaphone. I took brief notes in my notebook or on my interview guide about any insights I had during the interview but endeavoured to stay focused on the interviewee and use active listening. The format for the interview structure was consistent and I used an interview guide to prompt myself with relevant questions (See Table Y below). However, the session itself varied slightly depending on interview location and to ensure I could respond to what would make the participants the most comfortable. On three occasions participants asked for the interview to be paused or stopped. On one occasion the patient being interviewed wanted to end the interview as he did not feel well. I immediately stopped recording, asked his nurse to review him, and thanked him for his time. On two other occasions family members being interviewed asked for the interview to be paused and recording was stopped. After some moments both these participants decided they wanted to keep going and the interview continued. Interviews were transcribed by me as soon as possible after the interviews took place. This was a useful exercise and supported with the familiarisation stage of the analysis process.

Readmission to hospital

Exploring the perception and experiences of people aged 65 years and over (and their families or caregivers) of readmission to an acute hospital Trust within 30 days of discharge.

<u>Episodic interview Sheet</u>

Introduction:

Thank you for agreeing to take part in this interview.

In this interview I will ask you to recount your return to hospital / your friend or family member's return to hospital. I will then ask you further questions about this or probe where necessary for clarification.

It should take about 45 – 60 minutes to complete. If at any time, you wish to stop or have a break, please let me know. If you want any questions repeated or clarified, please ask. If there are any questions you would rather not answer please let me know.

Code………………………. (Researcher to complete)

The following interview prompts will be used to guide the interviews:

- First of all, could you tell how old you are? Who do you live with?
- Can you talk to me about your return to hospital? / Can you talk to me about your friend or family member's return to hospital?
- What did this return to hospital mean to you?
- What was the most significant aspect of your return to hospital? / What was the most significant aspect of your friend or family member's return to hospital?
- If you look back is there anything you think might have made a difference to your / friend or family member's readmission?
- Is there a family member/friend/caregiver I could talk to about your readmission?
- Is there anything else you would like to talk about?
- Do you have any questions?

- Would you like me to send you an update on this research when it is available? If so, please let me know the best way to contact you.

Episodic interviewing is a form of qualitative interview, other forms include narrative interviews or semi-structured interviews. An episodic interview centres around asking people to recall and discuss concrete events or moments but are also open enough for people to talk about what elements they want in the form of narrative or description (Flick 2000). This form of interview enables comparisons between interviews to be made (Flick 2000) and contextualises experiences (Flick 2000). Qualitative interviews are congruent data collection methods when exploring people's perceptions, experiences, and their reality in their own words (El-Amir et al. 2011). They are also key to building the "*dialogical engagement*" (Abma & Stake 2014 p.1152) required when exploring experiences in a qualitative case study. Rapport can be built with the research participants and this can enable the creation of rich, detailed data. In addition, some people may find the process cathartic (El-Amir et al. 2011) and appreciate being listened to and heard.

Face-to-face interviews are not without risk; power imbalances must be addressed and, the topic of the interview could be deemed sensitive, as is often the case in nursing research (El-Amir et al. 2011). Many processes can be implemented to ensure participants feel safe and comfortable. These include ensuring the 'space and place' (Gagnon et al. 2015) is appropriate for the participant and considered in the analysis process. In this study, participants could choose the location of the interview and every effort was made to ensure the participant was comfortable and felt secure. Moreover, participants had time to pause, reflect, have a comfort break and to decline to answer any question. I used active, purposeful listening alongside non-verbal cues to help build rapport. After each interview, I reflected, wrote in my journal, and debriefed, if necessary, with a member of my supervisory team to minimise any risk of vicarious trauma (El-Amir et al. 2011). Debriefing when required, whilst maintaining confidentiality, enabled me to share any worries, discuss and identify any possible risks and problem solve if necessary. During data collection no safeguarding risks were identified.

4.2.4 Documentary analysis

Document analysis involves a systematic evaluation for reviewing and evaluating documents (Bowen 2009). Documents can be a complimentary source of data and are often used alongside qualitative interviews (Bowen 2009). Furthermore, Stake (1995, 2005) uses a variety of documents to inform his case studies. Documents can provide context to research (Bowen 2009) and documents can enable researchers to consider what information participants have to base their perceptions and decisions on. Limitations of documentary analysis centre around lack of enough detail and issues of retrievability and consistency (Bowen 2009).

During the interview process I noted if any documentation had been received by the patient or family member. If there was documentation available and it was shown to me, I noted what type of document it was (discharge letter, patient information leaflet etc.), where it physically was placed and what state it was in, and any comments made by the participants about this written documentation. However, whilst conducting the first few interviews it became apparent that there was a lack of documents available, that is, patients did not have documents to show me. Some remembered receiving some written documentation but either did not have it with them, stated they had lost it, or could not remember where they had put it. After some reflection I decided a standard documentary analysis would not be feasible. However, it did open a different component to consider – that is a focus on what meaning people appeared to give any paperwork or written documentation if they did remember receiving some. This enabled me to capture information regarding written documentation whether the participant physically had it with them or not. This also led me to consider and reflect on the reported value of written information from a patient perspective. So, whilst retrievability has been an issue for this study and documentary analysis was not conducted, written documentation is still a component of the data collected as part of this collective case study.

4.2.5 Observations and reflective diary

A research diary where reflection and observations are written is an additional source of data that is incorporated into this collective case study. Notes and reflections were documented after each interview as soon as feasibly possibly. If the interview took place in an individual's home, I wrote notes in the car before leaving. If the interview was in a clinical location, I found a quiet spot to write before I left. Further detail on the specifics of the data collection within my study is outlined in the sections below. These observations included how participants engaged with the written documents, focusing on whether they had any, where they placed it, whether they found it useful, if so how, did they refer to it or use it in anyway, and whether it was meaningful to their experience or not. Due to the flexible nature of collective case study and framework analysis the writing generated within this journal can be used as data. Ortlipp (2008) advocates for the use of such journals as data and views they can be useful tools to show reflection, process decision making, and an audit trail highlighting research rigour and transparency.

My reflections after each interview and discussions with my supervisory team helped me to consider and frame what I had observed. In addition, setting up and running the stakeholder engagement group was vital to the analytic process. I used the journal to write down feelings and thoughts, this helped me to improve on my interview skills which built up over the data collection period. My journal was also used to record thoughts and links I was making between ideas and concepts and having a single point for this was beneficial. I made sure I regularly looked back over my journal during the whole PhD process to help make links between the vast amount of information I had and to see the starting point for ideas I had regarding themes and how I was understanding the phenomenon being studied.

4.2.6 Challenges during recruitment

The clinical context during the data collection phase contributed to some of the difficulties in recruitment as the NHS was experiencing some of its most acute winter pressures. This led to specialist nurses being pulled from their roles to cover clinical shifts on wards - thus meaning they were unable to help recruit for some periods of time. An unexpected benefit of having to spend more time on recruitment was that positive and friendly working relationships were built up over the eight-month period of data collection. As such, the specialist nurses who helped with recruitment became more motivated to help and were able to build positive relationships with potential participants. This led to interviews being conducted with participants who stated they would not normally take part in research, enabling interviews with varied participants.

However, in future I believe having multiple types of recruitment strategies would be beneficial both in terms of increasing speed of recruitment and ensuring a compelling story is built. On reflection, recruitment using social media to reach out to potential participants or including organisations that support older people are techniques that I could have considered.

Creating a table to identify where recruitment packs were going was developed to support me in monitoring the recruitment process and to give me an overview of which additional clinical areas or hospital sites I could consider approaching. The teams I initially approached were purposefully selected for their potential to have contact with older patients and with teams whose specialist nurses worked across multiple Trust sites and clinical environments. This decision was based on the knowledge I held as a clinician working in this site and rapport with teams was facilitated by the fact I also worked as a nurse at the point of care. Over the course of the recruitment period some teams were later identified on the advice of the teams already taking part. Clinical pressures made engaging with these teams more challenging as the months progressed, which is a limitation of the recruitment process. Furthermore, whilst I captured where the recruitment packs were going in terms of the clinical team they went to, I did not create a follow up system to identify which participants had been approached by which clinical teams which I could have recorded when I met with participants. As a consequence, I may have missed opportunities to understand the spread of the recruitment happening across the study site. Thus, on reflection I should have created a system that was more manageable for myself as a researcher who was also working clinically in a challenging environment to support the recruitment process.

Not all returned reply slips led to an interview (Table 4 – Appendix 8 Recruitment information and processes). Out of 21 reply slips received 14 cases were interviewed. The table below outlines in outcomes and comments associated with each returned reply slip and steps taken. However, this indicates that participants felt comfortable to decline an interview and is in accordance with ethical practice. It also further illustrates the reality of recruitment when working with patients and their families who have experienced ill health and hospitalisation.

4.3 Data analysis methods

In this section I outline the methods I used to conduct a multiple case study analysis. This involved me following the suggestions, and ethos of Stake (2006) combined with the tools of framework analysis as described in Ritchie & Spence (1994). First, I describe why this approach was taken by highlighting how the tools of framework analysis assisted in supplementing some of the limitations within Stake's (2006) approach. Then, I describe how both framework analysis (Ritchie & Spence 1994) and Stake's (2006) suggestions for multiple case study analysis have parallels and can be combined. Finally, I go on to outline the process I followed to generate themes.

4.3.1 Rationale for this approach

In Stake's 2006 book there is detailed information on how to conduct multiple case study analysis. This volume outlines specific steps and describes an ethos to conducting analysis. Certain elements are important to highlight as they are specific characteristics of case study research. These include questioning how each case helps to understand the phenomenon being studied within a situated context and lead to a better understanding of the Quintain; the requirement to create case reports to ensure the reader becomes familiar with the cases and is enriched with "*as much of the action and context of the cases as possible*" (Stake, 2006, p.90) and support the reader to understand the situations to which the assertions apply and give them the opportunity to generalise if they so wish (Stake 2006); triangulation by involving people who know of the phenomenon; viewing the Quintain (phenomenon) as a mosaic as opposed to a coordinated system created out of generalisations as "*the study of human activity loses too much if it reports primarily what is common among the several, and universal across the many*" (Stake, 2006, p.88). Finally, in collective case study research "*the common and the unusual are both portrayed, and both are situated in a complex of experience against a local and diverse background*" (Stake, 2006, p.90).

Ritchie and Spence (1994) outline the components of Framework analysis and identify that case study researchers have used their approach. There are benefits to Framework (Ritchie & Spence 1994) that I believe assist researchers in conducting multiple case study analysis and that do not appear explicitly addressed by Stake (2006). Ritchie and Spence (1994) highlight the usefulness of being able to use a framework as a tool to organise and manage data. Additionally, this framework then becomes a manageable document that can be scrutinised, gone back to, and is a place where the whole collection of cases is visible. Furthermore, the familiarisation stage they describe is a useful step to follow before writing case reports and enables the researcher to get a sense of the whole.

Framework analysis (Ritchie & Spence 1994) addresses and complements some of the weaknesses I perceived of Stake's (2006) description of multiple case study analysis. Furthermore, Gale (2013) identifies the usefulness of Ritchie and Spence's framework analysis for health research. Stake (2006) acknowledges that case reports can become an "*oversimplification*" (Stake 2006 p.41) or reductive (Stake 2006). Thus, having a Framework created inductively from all the included cases enables the researcher to keep going back to the un simplified data. Additionally, the examples provided in Stake's (2006) book are of multiple vast programs of work being examined. I needed to find a way of staying true to the ethos of Stake’s (2006) analysis method whilst being pragmatic and translating this to my collective case study which was smaller in scope and size and where each case was not a program of work but involved up to two individuals. The benefit of reducing a large program of work to a manageable case report in Stake’s (2006) description of the method appears necessary to be able to make sense of all the data. However, for my study I wanted to be able to come back to and “see” the whole when required, thus, using an inductive framework made this possible.

4.3.2 Parallels between Stake’s analysis approach and the Framework method

This section will describe the parallels between Stake’s approach to multiple case study analysis and the Framework method. In collective case study analysis transcripts are re-read multiple times, sometimes to look for ‘issues’ and at other times to look for new ones. The issues become codes and are used to guide attention. This is done within and between each case to understand the case and cases (Stake 1995). The aim of analysis in a collective case study is to see the whole and understand the phenomenon under study from multiple perspectives (Stake 2006). To illustrate these two aspects of the collective case study, and to ensure there is enough of a descriptive element to the collective case study – important to enable readers to consider the cases and how they can relate to their own context – both descriptive and interpretative findings are generated. The descriptive element focuses on describing each case within the collective – that is the within case analysis. The interpretative element shows how the phenomenon as a whole is understood via an exploration of themes – that is the across case analysis. Thus, each case is scrutinised and to identify how it can enable the researcher to better understand the wider phenomenon (Stake 1995, 2006).

Matrices can be used when conducting analysis of multiple cases (Stake 2005). In addition, Stake uses the term 'assertions' and 'Quintain' when describing his analytical approach. The 'Quintain' is the collective, the phenomenon as viewed from multiple perspectives. 'Assertions' are defined as "*the researcher's findings about the Quintain*" (Stake 2005 p.41). I have interpreted this to mean that 'assertions' are themes that help us to understand the phenomenon within the particular context of the study. This is not a search for big generalisations rather a contextual exploration of a phenomenon that is described in enough detail for readers to translate these experiences to their own context (Abma & Stake 2014).

Framework as an analytic method lends itself to collective case study and has been applied in case study research (Ritchie & Spencer 1994, Houghton et al. 2015). It enables the researcher to systematically explore each case separately and view the cases together as a whole. Furthermore, it facilitates mapping of phenomena (in this case, perceptions, and experiences of unplanned readmission) and finding associations (Ritchie & Spencer, 1994). It is also flexible and different types of data can be incorporated (Ritchie & Spencer 1994), including interview transcripts, notes taken during interviews and the researcher reflective diary. The framework approach is mirrored in Stake's (1995) suggestions of how to analyse case studies, for example, when he suggests using initial ideas of themes or topics in mind as a starting point for cross-case analysis. Furthermore, the steps and methods in framework analysis (Ritchie & Spencer 1994) correlate with Stake's (1995) claim that "*understanding each one [case] requires an understanding of other cases, activities, and events but also an understanding of each one's uniqueness*" (p.44).

Ensuring the centrality of participant voice within the analysis is an important factor in this PhD project, and the stages used to conduct framework analysis lend themselves to ensuring this happens. One of the key features of framework analysis is that it is grounded and driven by original accounts and observations (Ritchie & Spencer 1994) this is also a feature of collective case study and Stake notes that cases have "*their own stories to tell*" (Stake 1996 p.VI).

The correlation is illustrated below to show how the steps suggested in framework analysis correspond to aspects of collective case study analysis:

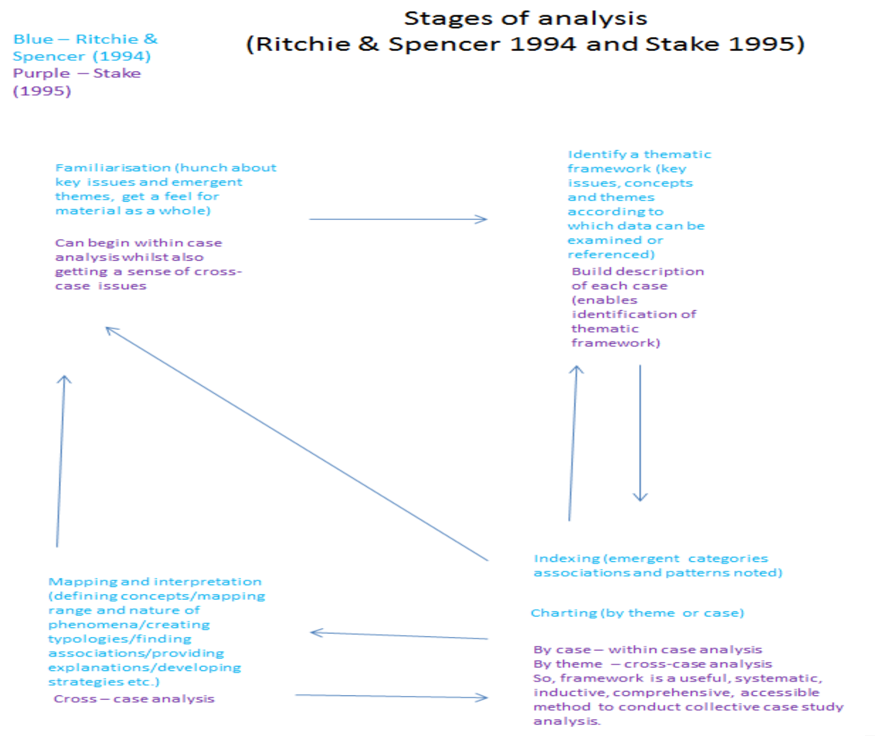


Figure 3: Stages of analysis

4.3.4 Process followed to generate assertions about the quintain

For Stake (2005) analysis can start during the data collection phase and occur throughout the study. It consists of giving meaning to both first impressions and more sophisticated and reflected upon thoughts (Stake, 1995). Reflection and seeing other points of view is a vital part of the analysis (Stake 1995) and Stake does not suggest only one analysis method should be used when wanting to analyse a case study (Stake 2005; Yazan 2015). Creativity is inherent in analysis (Lofland & Lofland, 1995) and it is thus more than a mechanical following of steps. Deep thinking and revisiting the data multiple times and finding the right environment to do this in is how your understanding can creep forward and analysis takes place (Stake, 1995).

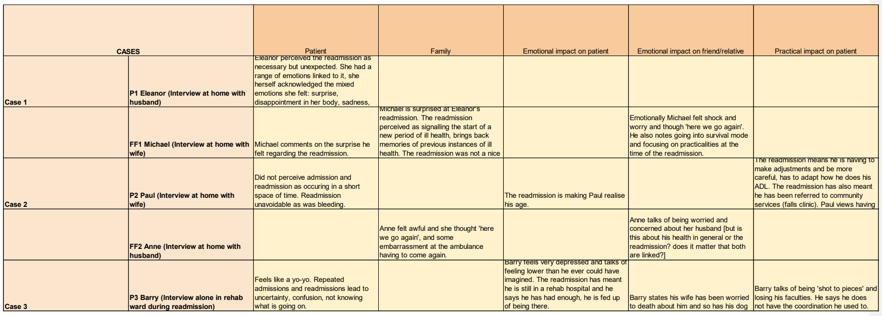
The steps followed in the analysis process are outlined here, however, it is important to note this was not linear and an iterative process was followed where there was a regular back and forth as illustrated in the analysis image (Figure 3: Stages of analysis). Despite there being identified and delineated steps outlined by both Stake (1995, 2006) and Ritchie and Spence (1994) the reality of the qualitative process is not that clear cut or simple. Data analysis requires the researcher to go back and forward and find ways to be creative and think flexibly (Lofland & Lofland 1995). First, the analysis really started at the very first interview when reflections and ideas were noted. These were returned to throughout the analytic process. These reflections and ideas were kept in notebooks with dates, times and pseudonyms of interview participants noted down. The right hand page was used for these notes and the left hand page was kept blank so I had space to write down reflections at later dates or draw diagrams or pictures. This process supported the development of the assertion relating to a ripple effect. Along with the matrix (described in section 4.3.5 below) the reflective notebooks were important tools in the analytic process. By reviewing notes and reflections and literally mapping out impacts I was able to conceptualise these using the idea of ripples. The familiarisation stage involved multiple steps. Firstly, I personally transcribed the interviews verbatim then read and re-read them multiple times. Secondly, I brought together the observation notes and reflections for each case and information regarding the relationship patients and families had towards any written documentation they may or may not have received. Once this had been completed for each case included in this collective case study, case summary reports were pulled together for each case. This was done using Stake's (2006) suggested headings: Synopsis, situational constraints, uniqueness among other cases, findings, excerpts (as quotes) and finally, there is space for brief commentary. Creating these case descriptions forms part of the analytic process and are viewed as descriptive findings. Alongside these case descriptions, the interviews and notes were revisited in order to code them and 'clump' these codes into categories a process referred to as categorical aggregation (Boblin et al. 2013).

4.3.5 The creation of the matrix

The within case analysis conducted as part of this collective case study can be viewed in the case summaries for each of the 14 cases included (a selection is available in Chapter 5, the rest are in the appendix, please see appendix one). As previously noted, individual case summaries were written up to explore how the phenomenon of experiences and perceptions of unplanned readmission from the perspective of older people and their families appears in each individual case.

The categorical aggregations developed from the codes and case summaries were used to create the inductive matrix. Table five (in appendix 8) illustrates how categorical aggregations were created from codes derived from the data. Grouping together of instances in this way supports interpretation and a search for meaning. The categorical aggregations were listed along the top of the matrix. Cases were listed down the left-hand column of the matrix. Then, relevant summary information from each case was inputted into the relevant sections of the matrix or left blank if there was no corresponding data.

Then followed the indexing and charting phase whereby data from the interviews and notes were inputted into the framework. Information gleaned from the stakeholder engagement group supported these phases. During the mapping and interpretation phase Stake's dialectic questions were asked to assist in identifying how each case helped increase understanding of the wider phenomenon. This detail could come from interview transcripts, the reflective diary, and included comments and information on the written documentation. Once complete, the matrix enabled the categorical aggregations to be explored across all the cases. The Assertions (findings about the Quintain (Stake, 2006)) were then constructed and developed from this, these are described in Chapter 6. An excerpt of the created matrix is presented below.



CASES		Patient	Family	Emotional impact on patient	Emotional impact on friend/relative	Practical impact on patient
Case 1	**P1 Eleanor (Interview at home with husband)**	Eleanor perceived the readmission as necessary but unexpected. She had a range of emotions linked to it, she herself acknowledged the mixed emotions she felt: surprise, disappointment in her body, sadness,				
	FF1 Michael (Interview at home with wife)	Michael comments on the surprise he felt regarding the readmission.	Michael is surprised at Eleanor's readmission. The readmission perceived as signalling the start of a new period of ill health, brings back memories of previous instances of ill health. The readmission was not a nice		Emotionally Michael felt shock and worry and though 'here we go again'. He also notes going into survival mode and focusing on practicalities at the time of the readmission.	
Case 2	**P2 Paul (Interview at home with wife)**	Did not perceive admission and readmission as occuring in a short space of time. Readmission unavoidable as was bleeding.		The readmission is making Paul realise his age.		The readmission means he is having to make adjustments and be more careful, has to adapt how he does his ADL. The readmission has also meant he has been referred to community services (falls clinic). Paul views having
	FF2 Anne (Interview at home with husband)		Anne felt awful and she thought 'here we go again', and some embarrassment at the ambulance having to come again.		Anne talks of being worried and concerned about her husband [but is this about his health in general or the readmission? does it matter that both are linked?]	
Case 3	**P3 Barry (Interview alone in rehab ward during readmission)**	Feels like a yo-yo. Repeated admissions and readmissions lead to uncertainty, confusion, not knowing what is going on.		Barry feels very depressed and talks of feeling lower than he ever could have imagined. The readmission has meant he is still in a rehab hospital and he says he has had enough, he is fed up of being there.	Barry states his wife has been worried to death about him and so has his dog	Barry talks of being 'shot to pieces' and losing his faculties. He says he does not have the coordination he used to.

Figure 4: Excerpt from the matrix used for cross case analysis

The idea is not to simply compare cases, rather see how they can increase our understanding (Stake 2006). For this reason I felt it was necessary to take stock of each case again to set up a "*case-quintain dialectic*" (Stake 2006 p.46) by asking myself the rhetorical question: *What does this case tell us about the phenomenon?*. In this instance, I asked myself what the case could tell me about the phenomenon of unplanned readmissions to hospital within 30 days of discharge. The insights developed through the stakeholder engagement group were extremely valuable and incorporated in the development of assertions. Furthermore, the use of a stakeholder engagement group reinforced the co-constructed element of this analysis. In particular, by incorporating the insights of the participants in this group considering how they prioritised issues that assertions revolving around communication and misaligned need were developed. Finally, assertions were generated which are, in essence, the findings about the how unplanned readmissions are experienced and perceived by older people and their families in the context of this collective case study. These steps are summarised in table 6, in Appendix 8.

As noted by Stake, patience, reflection, and a willingness to see other points of view are central to good quality case study (Stake 1995). The framework method to analysis takes time so this tool gave me space to consider a variety of viewpoints and return to the raw data. As part of 'theory triangulation' (Stake 1995 p.113), codes and initial categories were discussed with the supervisory team and members of a stakeholder engagement group. This further enabled the search for additional interpretations (Stake 1995) and ensured my understanding of the phenomenon was rich and more informed (Abma & Stake 2014).

Description of the stakeholder engagement group session

One of the ways multiple perspectives were considered as part of the analysis was through the creation of a stakeholder engagement group. My own critical reflection during data collection highlighted the sense I felt during interactions with patients and families that I was very much viewed as a healthcare professional, and I thus wanted to ensure that the research findings were not solely centred on my interpretations as a nurse. A stakeholder engagement group of older people with experience of unplanned readmissions was a way of interrogating my own taken for granted assumptions about older peoples' experiences (Flores-Sandoval and Kinsella 2020); further reinforcing the need for and involvement of multiple perspectives and, illuminating the lived experiences of older people themselves. The aim of this group was to explore what the group volunteer participants perceived as meaningful within the interviews, to find out what their thoughts and ideas were on the issues raised by patients and families. In essence, what did they perceive to be the priorities or of most importance to understand the wider phenomenon under study?

This group was open to willing volunteer stakeholders who were in the target age group (aged 65 and over) and who had experience of being hospitalised and/or readmitted or who had supported a family member who had been readmitted to hospital. Information about the group was circulated via university channels and six possible volunteers responded wanting further information. A total of four volunteers were both willing and able to attend the one-off session. Stakeholders received lunch and refreshments as a thank you gesture for taking part and their transport costs were covered where required.

An informal approach, with an element of creative evaluation methods, was favoured to facilitate enhanced engagement and to identify issues in a relaxed and enjoyable manner.

Creative evaluation methods have been shown to elicit new perspectives or themes, generate rich data and be empowering for participants (Daykin 2015). The creative elements of this session included the opportunity for stakeholders to interact with printed copies of transcripts and letting them place them how they wanted in concertina books, and use sticky notes and stickers to help with thinking and prioritisation (see figure five). The concertina books were notebooks created for this session. They are of landscape format and the blank pages that they are made from are linked end to end so they can be opened up in a concertina fashion and all the information contained within them can be viewed at the same time. The session took place in an accessible room at one of the university sites. The session started with lunch and informal conversations to enable the stakeholders to get to know each other. It also meant I was able to get to know the stakeholders. The other people present were two supervisors, both of whom took notes during the session to enable me to focus on facilitating the session.

After the lunch, transcripts were discussed; there was a comfort break between discussing the transcripts and refreshments were available throughout. Each transcript was discussed in the following manner: stakeholders were asked to pick out a sentence or word that stood out to them on each page of the transcript. Then, this sentence or word was discussed by the group. Themes, thoughts, and ideas were written on sticky notes, and these were stuck around the sentence/word. These were stuck in large format concertina style workbooks. At the end of the group discussions the workbooks were spread out in full, participants then spent some time discussing and thinking about which themes/ideas they deemed most important. They used gold and silver star stickers to identify these points along with time to step back, have a look, and reflect. Thus, by the end of the session what the volunteers deemed to be important to understanding experiences of unplanned readmission had been discussed in depth. Furthermore, there was a visual representation (sticky notes and star stickers) to highlight these points and the priorities given to them.

After the session I reflected on the discussions, on what the stakeholders had deemed important, meaningful and a priority. This session also shaped how I felt about the research, giving me a renewed sense of the importance of understanding these experiences and using this study as a starting point for further quality improvement. This session was extremely valuable in my search for understanding and helped to focus my vision of the data and what I noticed within it.

Figure 5: Completed concertina books at the stakeholder engagement session

4.6 Methodological Limitations

4.6.1 Recruitment

As noted, the recruitment strategy combined with winter pressures at the Trust meant recruitment was relatively slow. In future multiple recruitment strategies should be considered when conducting this type of research, this would potentially speed up recruitment and open recruitment to a more diverse base. Other researchers focusing on older people have also experienced challenges with recruitment (Chatters et al. 2018) and suggest multiple strategies that include reaching out to older people directly and engaging healthcare professionals to support recruitment. Thus, on reflection, some strategies that could have worked well in this context were the use of social media and snowball sampling through a variety of older people's organisations.

4.6.2 Interviews

Face-to-face interviews do have limitations; firstly, there are the potential risks for both participant and researcher (El-Amir et al. 2011). Secondly, the content of the responses given to the interviewer is the choice of the interviewee. This means issues around recall should be considered alongside an appreciation that there can be differences between what people say they did and what behaviour they expressed. Thus, for some research topics observational methods are more appropriate. In the context of this PhD however the focus being on patient perception and experience data collection using episodic interviewing was deemed suitable. It enabled participants to discuss what was important to them and meant the research could focus on their insight. Thirdly, social desirability (Baxter & Jack 2008) plays a part in the answers that can be given in interviews. I was keenly aware of my role as both a researcher and nurse working clinically in the study setting. However, I critically reflected on how my presence and role could have an impact on the answers given after each interview. Furthermore, I made it clear to participants that their answers would remain confidential and anonymous. They were also supported to contact the Trust via their Patient Advice and Liaison Service (PALS) network if they did have any concerns to raise, and information on further sources of support was included in the participant information sheet (see appendix two).

4.4 Ethical approval and processes followed as part of this research

Appropriate processes were followed and ethical approval for the study was granted by my University and the NHS: FREC 2016/32; IRAS REF 221137; REC REF 17/LO/1073; R&D REF 13044. Please see appendix six for approval letters. Furthermore, relevant institutional data storage and security processes were followed. In addition, during the recruitment phase my study was selected by the University Ethics Committee to be audited. This process involved a member of the University research ethics team reviewing all of my paperwork and processes and interviewing me about these. Feedback received during this process included: "*I was most impressed with the organisation of your research files and the steps you have taken to ensure the confidentiality of those taking part in your research*" and concluded that "*I can therefore confirm that the research is being carried out in accordance with the research protocol and the conditions of ethics approval*". This was a beneficial process that gave me confidence in the decisions I had been taking to support an ethical research process, and in respecting patients and their families throughout, and indicates that I was following through on the plans developed at the start of the study to ensure an ethical process.

All participants approached to participate were fully informed of the study (for the invitation letter please see appendix four), the purpose, the process, and the outcomes. Potential participants were given an invitation and information sheet which clearly outlined the purpose of the study, what their involvement would be and the benefits and risks of the study. A consent form was discussed and explained with the potential participant and signed if they consented to proceed (please see appendix three). It was made clear to participants that their participation was completely voluntary, and they were free to withdraw from the study at any time without giving a reason and that this would not affect their care in any way. The interview setting was for the interviewee to decide on and were conducted in participant homes, hospital wards, hospital cafes and outpatient departments.

Discussing readmission to hospital or episodes of ill health may cause distress or anxiety to patients, thus these were issues considered during the ethical approval process. This risk was addressed in the patient information sheet so that people could consider this before participating. As a registered nurse that continues to practice clinically at the point of care, I have experience working with distressed patients and have the necessary skills to help people in these situations. Plans were put in place to support any distressed participants. For example, if a participant became upset, the interview would be stopped until they felt ready to continue or would be postponed or abandoned. Signposting to local and national organisations or helplines was also provided within the paperwork provided to potential participants; and professional clinical judgment was used in determining what support the participant may require and this would be discussed verbally with them as necessary.

Another ethical issue was the possibility that the research could reveal poor clinical practice. If this was identified the following processes were in place: I would consult my supervisory team to discuss the issue confidentially without disclosing identifying details. I would also follow guidance in the NMC Code (2015) and relevant Trust procedures for Raising Concerns would be followed. The Trust has a “Freedom to Speak Up” Guardian who could be contacted. This research could be viewed as a way of airing complaints by patients and/or their family. Participants with these concerns were encouraged to contact the Patient Advice and Liaison Service (PALS) and contact information and their leaflet was included with the participant information sheets.

The question of pseudonym selection involves issues of power, race, and gender in the decision making (Lahman et al. 2015). A name is not simply a name, it can carry deep personal meaning for someone which must be respected. For many, a name symbolises cultural heritage and background and if a participant gives a researcher permission to choose their pseudonym this must be done sensitively and thoughtfully. Others may prefer their own name used, they do not want a pseudonym, they want to tell their story using their name (Lahman et al. 2015). However, safety and confidentiality and ethical codes need to be considered. As a researcher who has been given ethical approval for this study with the caveat that participant anonymity be respected, I needed to find a way to balance these ethical requirements, reject paternalism, racism, classism at all costs and include a participant's own wishes. To do this, I asked questions of myself: Are pseudonyms representative of the participants personality and who am I to choose what part of the participants identity be reflected in a pseudonym? I resolved these questions by asking people if they wanted to choose a pseudonym. If they stated they were happy for me to do so I attempted to do it in partnership with them to give them the opportunity to agree or disagree with the selection. If they did not want to engage with the name selection, I created one during the transcription process. Names used can affect how a reader interprets a story (Lahman et al 2015) so I was as careful as possible to reflect their actual name when considering pseudonyms without breaching any confidentiality.

4.5 Ensuring maximum rigour

Researchers have long been engaging with how to define rigour in qualitative research (Parahoo 2014). Strategies suggested for quantitative research are not appropriate for qualitative work, however, parallel terms and strategies can be employed (Parahoo 2014). Furthermore, it is important to determine rigour and ensure that quality and trustworthy evidence is being generated.

The vocabulary used to describe these strategies can differ (Houghton et al. 2013). Greenhalgh (2016) suggests the terms ‘trustworthiness’ (“*where researchers go beyond a superficial approach to collecting data to provide rich detail*” (p.6)), ‘plausibility’ (“*the account rings true and allows the audience to enter the world of the research subjects*” (p.6)) and ‘criticality’ (“*the researcher shows a high degree of reflexivity, questioning their own findings and considering alternative interpretations for them*” (p.6)). These terms correlate with how others have conceptualised rigour, for instance Lincoln and Guba (1985) who refer to ‘credibility’, ‘dependability’, ‘confirmability’ and ‘transferability’. In later work (Lincoln and Guba 2013) highlight that credibility is also dependent on how readers may interpret the information available to them. These terms also incorporate issues determined as important by Stake (2006) namely that the reader can also play a part in determining the rigour and quality of research (Freshwater et al. 2010) with Stake (2006) noting collective case study authors should *“enrich the reader’s experiential knowing with as much of the action and context of the cases as possible”* (p.90), hence the need for thick description and the inclusion of the case summaries. Lincoln and Guba (2013) make a similar point noting the need for readers to experience vicarious experience and test any personal constructions they are developing as they read. They go on to note that any assertions about ‘truth’ depend on what information is available to audiences and are context dependent (Lincoln & Guba 2013).

Within this collective case study, the readers of the study, and in the context of this thesis they include supervisors and examiners, have been provided with case descriptions and participant quotes to support them in determining rigour and quality and whether they could make similar assertions. Alongside this, the author’s world view and methodology have been outlined so the reader can determine congruence of thought and ideas. Further activities to support study rigour are outlined here:

Using a collective case study thus viewing unplanned readmissions from multiple perspectives and using different forms of data allowed this study to go beyond the superficial and provide rich detail, and activities which also ensure trustworthiness. Building rapport with participants and stakeholders to ensure they felt as comfortable as possible and were in an environment conducive to their participation supported the communication of these valuable and meaningful experiences and ensured a conducive environment to support the co-construction of these ideas. Interviews were audio recorded and transcribed verbatim and notes were kept in a systematic fashion. Additionally, each case has been described to allow the reader to get a sense of the experiences and perceptions felt by patients and families. Assertions about the Quintain have been synthesised and are presented using a range of verbatim quotes permitting rich detail and participant voices to shine through, which also supports plausibility. To further strengthen plausibility, transparent and clear descriptions of the research process and methods were recorded and have been described in sections above. Moreover, clear aims, methodology and method have been developed and summarised. Multiple activities were followed to ensure criticality. For example, the researcher regularly engaged in peer review through a variety of means: by publishing work based on earlier elements of this study the researcher engaged in blind peer review. Furthermore, the researcher actively sought opportunities to engage in scholarly conversation, critique and learning with peers and educators by attending three European Academy of Nursing Science Summer Schools, during university seminars for PhD students and when presenting at national and international conferences. Moreover, formal processes organised by the university: such as annual progress monitoring and regular supervision were additional opportunities for critical reflection and review. Other opportunities for criticality include the delivery of the stakeholder engagement workshop where stakeholders could directly comment on a selection of data collected and provide alternative interpretations and insights to be incorporated into the analysis. By using a reflective journal, issues around documentary analysis were identified in a timely fashion and this could be addressed and recorded in a manner that conformed to the methodology chose and was agreed with the supervisory team. An important element of ensuring rigour reflexivity is further commented on below.

Reflexivity

In and of itself noting a researcher was reflexive is not sufficient to support rigour, as noted by Lynch (2000) "*reflexivity in general offers no guarantee of insight or revelation"* (p.47). Neither is it helpful to conceptualise reflexivity from a positivist standpoint by merely describing it as a tool to reduce or eliminate bias or researcher influence (Oliphant and Bennett 2020) or even to support 'bracketing' (Dowling 2006). Some critiques of reflexivity must be acknowledged. Whether it is possible to 'hear' what is happening can be questioned (Berger 2015) and thus our ability as researchers to truly identify the elements that participants are telling us are meaningful (Peck and Mummery 2018). Consequently, being reflective when we may overemphasise or ignore what is communicated to us by participants is not straightforward. Furthermore, techniques commonly used to explore and report reflexivity, such as journaling, can be culturally specific (Oliphant and Bennett 2020) so it may be harder for some researchers to even have their reflexivity recognised.

This does not mean we should remove reflexivity from our research processes, rather we must be aware of its limitations and incorporate mitigating factors. For the purposes of this study, reflexivity was viewed as a useful process to become self-aware about the influence of the researcher-participant relationship (Oliphant and Bennett 2020), to identify how the self and researcher position is shaping the creation of knowledge (Berger 2015), notice power differentials, and support problem solving when the research process was not going as anticipated (Oliphant and Bennett 2020). Done thoughtfully and systematically, reflexivity can enhance the quality of research (Berger 2015). To avoid merely being a device that gives studies an appearance of rigour (Dowling 2006) the components of the reflexive process should be made explicit. Within this study, the following was conducted as part of this process: a journal was kept throughout the design, data collection and analysis phases. This supported me to identify my emotional reaction to the research and problem solve when I was having challenges with recruitment. It also gave me a space to consider how my professional nursing identity was presenting and from this I concluded I could not separate my nurse identity from my researcher identity. I revisited notes made earlier in the research process and reflected on how my viewpoints had changed or developed. The stakeholder engagement group supported me to question what I was overemphasising and helped to frame my analysis.

Research can never be value neutral, so, reflexivity conducted in the way described was deemed important. This way, I continue to be explicit about my conscious influences and opinions, whilst enabling opportunities during the research process for critique and different opinions to be given consideration. This ensured my unconscious had time to process information which supported intuitive leaps during the analysis (Meek 2003).

4.7 Chapter summary

This chapter has outlined the different research methods use to collect and analyse data as part of this collective case study. This chapter has described the rationale underpinning these methods and delineated the specific steps taken in both data collection and analysis. These methods are appropriate to the research question posed and congruent with the personal, professional, and philosophical bases of this study. Limitations to these methods have been discussed, ethical considerations have been detailed and approaches to rigour have been described. The following chapter (Chapter 5) will outline the context of the collective case study, detailing pertinent information regarding the study site hospital trust, the discharge processes used there, and other contextual issues impacting the study site and interviews will be described. In addition, Chapter 5 will
showcase a selection of the collective case study descriptions.

5.0 Chapter 5 - Description of the cases

Chapter Introduction

This chapter aims to describe the cases and the context they were in at the time of data collection to provide background for the subsequent analysis and findings. Outlining these case descriptions fulfils several elements of case study reporting and analysis. They provide the reader with a description of each case so they can consider their own thoughts or reflections on the data (Stake 1995). Furthermore, they form part of the analytical process (as described in Chapter 4 and later in this Chapter). The case descriptions shaped the framework created for the analysis, they enabled each case to be valued in, and of, themselves and form the different pieces of the mosaic that is the Quintain. The case descriptions included in this chapter showcase the individual experiences and perceptions of patients and their families, in relation to unplanned readmissions. This is combined with reflections on the meaning ascribed to written information ascertaining whether and how patients and families received, engaged with, and used these documents.

5.1 Context of the collective case study

5.1.1 The Hospital Trust

The hospital Trust central to this study is one of the largest NHS teaching trusts in the country (England) and is recognised as a centre for excellence in many clinical areas, as well as in teaching and research. As part of England's NHS system, care in this Trust is provided free at the point of use and according to clinical need. Some private services are provided within this Trust; however, these were not the focus of this study and all the services, clinical areas and staff described as part of this study were providing NHS care.

The Trust has four hospital sites as well as services delivered in smaller locations and in peoples' homes. The Trust became a Foundation Trust in 2015; this means its direction comes from local decision-makers and patient representatives as opposed to central government (DH 2005). Across the Trust's four sites there are 1185 beds across 60 wards and during 2018/19 the Trust provided 1.4 million patient contacts. The Foundation Trust received 92% of admissions from people domiciled in the county it is based in, thus 8% of admissions were from people outside of the county. Admissions from the county the Trust is based in comprised 73% of the Trust's total admission activity (CQC 2018). In addition, people come to this Trust from a variety of different counties in the surrounding area and from overseas. Within this county, 16% of the population is aged 65 and over (CQC 2018).

5.1.2 Discharge processes

Around the time of study conception and data collection the Trust employed 3779 nurses and midwives, 1829 doctors and 1622 healthcare support workers. Among the nursing staff across the Trust, there are a variety of specialist nursing teams; these nurses cross all four hospital sites to provide specialist care. The Trust also has specialist teams of nurses that provide care in people's homes and there is a team specialising in the safe and timely discharge of patients. This discharge liaison team focus is on discharge processes, identifying suitable beds in the community and working with the wider hospital leadership on patient flow. However, their involvement with nurses at the point of care and with patients and families is less clear. As part of the Trust best practice guidelines for discharging patients, it is stated that written information should be provided to patients and that furthermore, families should be involved in the discharge process. The type of written information the Trust suggests supplying is a standard discharge letter. This is completed using a pro-forma on the electronic patient record system. There are sections for the medical and nursing teams to complete. However, the role of this written information is not clarified, there is little guidance on how to present this written information or clarity over whether it should be a complement to a discussion with the patient and their family, or who has the responsibility to have this conversation. Furthermore, there is no guidance around the need to check for patient understanding and how to do this.

5.1.3 Study context

Data collection took place between September 2017 and June 2018. This covered a period of acute winter pressures across England that had an impact on the study area. Pressures on staffing resulted in beds across the Trust being closed and many specialist nurses were required to minimise their specialist duties and return to bedside nursing. Later in this period day case areas were used as wards and staff moved around to cover there. In addition, elective procedures were postponed, and the pressure was put on medical and nursing staff to discharge patients as soon as they were deemed ‘medically fit for discharge’ and staff were encouraged to make decisions on patient discharge at multiple set points during the working day. During the weeks between December 2017 and March 2018, the pressure on the Trust was such it was running on Operational Pressure Escalation Level 3 and 4.

In summary, the context of the study for patients and their families was as follows. Patients and families were treated in a large and busy hospital trust. Specialist teams, both medical and nursing, were available and patients could come from a wide geographical area for this care. The Trust did have processes in place to support patient discharge via the discharge liaison team and existence of information leaflets, however, it was not clear what processes were in place to translate this to patients and families at the point of care and whether wider nursing staff were aware of their roles and responsibilities in relation to this. Finally, this is set against a period of high stress and pressures on staff and resources with the potential to disrupt care and have repercussions on staff, patients, and families.

5.1.4 Context of the interviews

Interview locations depended on the choice of the person being interviewed. In some instances, both interviewees were interviewed one after the other in a chosen location. In other instances, the patient and family member were interviewed in separate locations, or the interviewee wanted to be interviewed in a separate room to their family member. Fifteen of the 22 interviews conducted took place in people's homes. The interviews that took place in a hospital setting varied - they were either in a ward environment at the patient's bedside or in another hospital location such as an outpatient waiting room or café. There were benefits and challenges to interviewing in each location however the range of settings indicates that participants made decisions on the location of the interview according to what worked best for them and where they would be most comfortable.

5.2 Description of the cases

5.2.1 Case summaries

In total 14 cases are included within this collective case study. In eight cases both a patient and family were interviewed. The relationships of the family member to the patient were as follows: in four cases they are spouses (1, 2, 5, 13), in three cases they are children (4, 7, 14), and in one case they are friends (9). The age range of patients represented in this study spans the older age ranges and includes people classed as being 'oldest old'. The youngest patient participant was 72 and the oldest 97. No patient participants were in their mid to late 60s. Both male and female patient participants are represented in this study, equally, there is a gender mix of family members. Each case included in this collective case study will be described below or be included in appendix one (and please see table seven for demographic characteristics of patients and families), and a summary table is included to provide a brief overview (table eight). Case summary reports written for each case use headings suggested by Stake (2006) on what to include in this type of report. A selection of case summary reports which reflect the range of patient – family relationships included within this study are presented below in section 5.2.2, the others are included in the appendix. Pseudonyms are used throughout for both the names of patients and the family members.

Table 7: Demographic characteristics of patients and families

Case Number	**Name of patient / family member & their relationship Pseudonyms used throughout**	**Age of patient**	**Interview location**
1.	Eleanor (Patient)	77	Home
1.	Michael (Spouse)	Not recorded	Home
2.	Paul (Patient)	86	Home
2.	Anne (Spouse)	Not recorded	Home
3.	Barry (Patient)	82	Hospital
4.	Patricia (Patient)	89	Home
4.	Stewart (Son)	Not recorded	Home
5.	Toby (Patient)	79	Home
5.	Phyllis (Spouse)	Not recorded	Home
6.	John (Patient)	89	Hospital
7.	Betty (Patient)	88	Hospital
7.	Stew (Son)	Not recorded	Home
8.	Neil (Patient)	86	Hospital
9.	Grace (Patient)	89	Hospital outpatient department

9.	Milo (Friend)	Not recorded	Hospital outpatient department
10.	Henry (Patient)	87	Home
11.	Evelyn (Patient)	97	Home
12.	Joan (Patient)	78	Hospital café
13.	Catherine (Patient)	72	Home
13.	Matthew (Spouse)	Not recorded	Home
14.	Violet (Patient)	85	Home
14.	Laura (Daughter)	Not recorded	Home

Table 8: Summary description of the cases in the collective case study

Cases[2] ↓	Reason(s) for unplanned readmission	Summary of patient/ family experiences and perceptions of the unplanned readmission(s)	Reported written or verbal information provided
1. Eleanor (p), 77, home	GP sent Eleanor to the hospital after a follow-up appointment. At the GP appointment they reviewed notes, blood results and decided to send Eleanor to the hospital that same day due to low Hb and a history of cardiac issues.	Surprise, disappointment, sadness. Also, a feeling that the unplanned readmission means Eleanor is being looked after and that the issue was spotted and dealt with. Feels grateful for this. Readmission viewed as necessary. Accepts hospital admissions as part of senior life.	Eleanor remembers being given a written list of medications after her first hospitalisation and a discharge summary after her readmission, does not recall being given anything else. She has a copy of the discharge summary at home. Eleanor was not given any written information regarding lifestyle or other discharge instructions.
1. Michael, spouse, home	GP summoned Eleanor into the surgery after a routine follow-up phone call regarding Eleanor's medication. The GP then sent Eleanor to the hospital due to low Hb.	As part of 'normal life' as Eleanor has previously had multiple stays in the hospital with various conditions (cardiac). This unplanned readmission viewed with shock to him, and as a way of Eleanor receiving further tests.	No information provided
2. Paul (p), 86, home	A second fall in the home. Paul and his wife live in a retirement community so they activated their pendant alarms, carers came to assess and they are the ones who called an ambulance that led to Paul's unplanned readmission.	As needed to get better. As part of getting older, means things are changing.	After the first visit, no information was received on discharge, nor was paperwork received after his unplanned readmission. Paul stated the most advice he received was from his private neuro physiotherapist. He remembered there was information about needing his GP to conduct a medication review and refer him to the falls clinic but he was not clear about the processes that should make this happen. No information was received about his dressing. At the time of the

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[2] Case number, name of participant, (p) = patient / (f) = family, age, interview location. Ages were only collected for patients.

			interview, he was waiting for a GP medication review and falls clinic.
2. Anne, spouse, home	Because her husband had another fall.	Felt embarrassed to have to call for an ambulance again. Resigned to these incidents. Views unplanned readmissions as signifying her husband is getting slower and losing confidence, that he has deteriorated.	Anne seems to remember receiving some information in the form of a copy of the discharge letter their GP received – Paul only recalled this letter after Anne noted she remembered it.
3. Barry (p), 82, hospital	A fall on the same day or the next day after his return home from his first admission. He is unable to remember all the details clearly.	He was discharged too soon and was not cared for properly. Makes him feel like a yo-yo and feels depressed, low, and confused.	Barry states he did not ever receive any written information or any verbal explanation about what was going on or any plans for his care.
4. Patricia (p), 89, home	Patricia states she cannot really remember what happened especially as she does not like remembering bad things	As something she had to do to get better.	Patricia does not remember receiving any written or verbal information during her time in hospital or her discharge.
4. Stewart, son, home	Patricia was admitted to hospital due to a possible infection and severe pain associated with her leg ulcers. She was then discharged home, three days later her son Stewart called the GP again for a review as Patricia had not been able to get out of bed. The GP reviewed Patricia and arranged the unplanned readmission as Patricia's blood pressure was so low	As a result of his mother being discharged too soon, Stewart viewed the readmission due to his mother being rushed out the first time. Stewart notes many wider impacts, on his mental health, anger, feeling low, losing wages, being a link person for his relatives, feeling stressed.	Stewart noted that Patricia received a discharge letter with the medication list included after the first discharge. He noted that no results or extra information were on that letter. He stated they received no written information after the second discharge. Furthermore, he could not find a copy of the discharge letter to show me during the interview.
5. Toby (p), 79, home	Toby had a heart attack and was admitted. Two weeks later an ambulance was called due to difficulties breathing so he was readmitted, medication changes were made. He went home after two days in hospital. Then, he experienced chest pain so he was readmitted. Again after a few days at home he experienced pain in his left side and was again readmitted. The day before Christmas eve he was told he could go home.	Viewed his unplanned readmissions as lifesaving and necessary to put things right. Simultaneously, one of the unplanned readmissions viewed as due to being discharged too soon.	Toby noted that in one of the letters (combined with a verbal interaction with a doctor) it was made clear what expectations he should have of his own recovery - this then had a positive impact on his experience of his own health and recovery. This was after the last unplanned readmission; he has not been in hospital since he had that experience.

5. Phyllis, spouse, home	No information provided	Viewed that in some instances Toby was discharged too soon. Readmission viewed as a relief as Toby was not well.	Phyllis had a folder with all the letters and written information received over Toby's times in and out of hospital, all neatly organised in chronological order, easy to access and refer to.
6. John (p), 89, hospital	Readmitted after four days of discharge due to a cardiac condition and blood results that were not satisfactory. Readmissions prompted by intervention from carers, DNs or GP. John did not feel unwell and he was unsure on the specifics surrounding his readmissions. Carers put in place after first hospitalisation.	Very accepting and stoical of unplanned readmissions, viewed them as part of life and ageing, has had three hospitalisations in the past six weeks. Regarding the latest readmission, says he saw it as a way of sorting out the things that were wrong.	John has not received any written documentation and noted in the interview that he did not remember receiving any advice even verbally on what to do when home.
7. Betty (p), 88, hospital	Betty felt chest pain, told her son (whom she lives with), her son called an ambulance and Betty was readmitted.	Betty views the readmission as just another stay in hospital, as a break (a bit like a holiday).	Does not remember receiving any
7. Stew, son, home	His mother was discharged, but even at discharge he did not think she was 'cured', he did not think her breathing was good enough. The next morning his mother complained of chest pain so Stew called an ambulance which prompted the readmission.	The readmission was viewed as a result of his mother being discharged too soon the first time. Thinks his mother should have been 'cured' the first time but that the ward she was on first did not care for her properly.	Did not understand the written information and does not remember where he put it.
8. Neil (p), 86, hospital	Readmitted same day as discharge, so within a few hours. Neil had a fall and had been admitted after the first fall. Then, after being discharged home, he fell at home again and was readmitted that same day. Both times he was taken to hospital via ambulance.	Neil was still in hospital after his unplanned readmission and was in considerable pain, he was waiting for answers, he was unsure what was going on. He also had a history of heart failure and leg ulcers. Viewed the readmission in a stoical way but also noted feeling frustrated and was missing home.	Does not remember any written information.
9. Grace (p), 89, hospital	First admission was for intravenous antibiotics due to a lung infection and prompted by her GP. Grace was discharged home and went to stay with her friend. She	Grace did not want to go to hospital or be readmitted but viewed the readmission as necessary, there was nowhere else for her to go with her broken arm.	Had some written information on caring for her cast that she did refer to.

outpatient department	took a sleeping tablet that evening and when she woke in the night as she needed to go to the bathroom, she felt dizzy and ended up falling over and injuring herself. Her friend called an ambulance and Grace was readmitted, she was first sent to the emergency department and had a plaster cast put on and then went to a ward for a few days.		
9. Milo, friend, hospital outpatient department	Knew very clearly that Grace would need to go back to hospital with her broken arm, recognised it was broken and called for an ambulance.	Readmission viewed as necessary.	No information provided.
10. Henry (p), 87, home	Went to the emergency department but was sent home the same day. On getting home from the emergency department Henry experienced breathlessness and stated the next evening he was in hospital. He noted he could not remember how long he was in hospital before being discharged. Henry was at home for a few days and then needed to be readmitted due to symptoms linked to heart failure. It was his cleaner who prompted for Henry to be readmitted. He was in hospital for about two and half weeks during the readmission. Prior to the readmission Henry had an alert bell on his wrist and that is how he called for ambulances.	The admission and readmission were viewed as lifesaving. Readmission also viewed as having improved his symptoms though he noted wanting to be fully cured after his readmission instead of being sent home.	Did not remember receiving anything after he was discharged from his first admission. Had a pile of paperwork on a table in his living room, this was behind his comfy chair. There was a pack of written information from the community heart failure team (an envelope of information and medication that he can take if his symptoms deteriorate) and a leaflet on how to use an inhaler spacer. Unclear on when this information was received (i.e pre or post unplanned readmissions). Henry noted the amount of paperwork felt overwhelming and that he did not understand it. He was aware of the existence of the medication and when he should use it.
11. Evelyn, (p), 97, home	First admission to hospital due to possible heart attack, stayed in for six days. Readmission to ward via emergency department and stayed in for two days. First admission prompted by Evelyn calling daughter who came round	Felt reassured by readmission, also expected to be in and out of hospital at her age.	There was a pile of written information on a coffee table in the living room: A discharge letter from the first admission and discharge letter from the unplanned readmission, copies of medicine

	and then called GP who then called ambulance. After this admission home care was arranged for Evelyn (two nights later she was back in hospital, Evelyn had a total of two weeks' worth of home care planned). Readmission prompted by healthcare professional providing a check-up (not sure what team or what type of healthcare professional) and then calling for an ambulance.		information leaflets (copies of what would be found inside each box of medication), a hospital at home leaflet, an Age UK leaflet and a signed purple DNACPR form. Evelyn said no one had gone through the written information with her when she was in hospital, she did not understand the content of the letters or other documents.
12. Joan (p), 78, hospital cafe	First admission was for an exacerbation of COPD/pneumonia and a fall. As a result of the fall sustained a knock to the head and was now using a walker. After a few days at home readmitted due to diarrhoea. Both times Joan did not remember how she came into hospital, thought one of her children called for an ambulance.	Stoical about unplanned readmission, also very relieved to be readmitted as she did not think her daughter was coping with caring for her at home.	Had discharge letters, they were crumpled, in a bag, not referred to for information.
13. Catherine (p), 72, home	Admitted on the night of Saturday to Sunday via ambulance and emergency department (999 call made by husband). Stayed in over the weekend and was then discharged on the Monday. Catherine stated she did not feel better, in fact she started to feel worse. Called the GP on the Wednesday who come to do a home visit, the GP then called for an ambulance, and Catherine was admitted to a ward via the emergency department. When we met there was still no confirmed diagnoses, but Catherine believed she had had a type of stroke.	Readmission wanted as felt worse than when she was discharged and felt the only option in this case was to go back to hospital. Relieved to be back to get treatment, but also disappointed this was required.	Received written information on the rehabilitation exercises to follow, was using this resource.
13. Matthew, spouse, home	Called the GP who visited and arranged for an ambulance back to hospital. Was unsure and unclear on what processes to follow and wondered whether they should have called 999 directly instead of the GP.	Unplanned readmission viewed as very unpleasant, and upsetting, but very necessary and lifesaving. Also viewed as a way of Catherine accessing further tests and getting more information and support. Felt like he learnt about processes and who to call in any similar events in the future.	Information not provided

14. Violet (p), 85, home	The story was quite complex and both Violet and her daughter appeared to have 'lost track' of each separate admission and unplanned readmission. The unplanned readmissions were linked to Violet's heart failure and needing to adjust medication and treat symptoms (fluid retention, difficulty breathing, & a possible heart attack).	Violet got used to being in and out of hospital. Viewed the visits as necessary, felt resigned to them.	Written information was received but they did not have copies to show. Discharge letters received after each admission. On the last unplanned readmission received specific information from the heart failure team. Violet noted she received leaflets and a phone number on the last unplanned readmission, and a list of medications (Violet's medications were changed many times over the multiple readmissions).
14. Laura, daughter, home	Over four unplanned readmissions in the last few months, according to Laura, Violet had been in and out every two weeks since March so unplanned readmissions generally took place within two weeks.	Felt the unplanned readmissions were partly due to her mother not receiving a stent when she was first unwell, so, due to not receiving adequate care during her first admission. She also felt her mother was routinely discharged too soon. She got a stent during her last readmission and since then had improved enormously. The last readmission was also a way of getting further information and community support set up.	Placed her mother's discharge letters in a bag ready packed for the next admission – does not have these letters to hand.

5.2.2 Example case summary reports:

Case 4 – Patricia (Family relationship - Mother and Son)

Synopsis

Patricia, Female, 89 (and Stewart her son). Interview location: Own home. Readmission within approximately three days of discharge. Most of this information regarding the readmission came from Stewart's account as Patricia commented that it was hard to remember things, and that she did not even want to remember the experience. Stewart was able to describe the events surrounding Patricia's readmission to hospital. Patricia was admitted to hospital due to a possible infection and severe pain associated with her leg ulcers. She was then discharged home. Three days later Stewart called the GP again for a review as Patricia had not been able to get out of bed. The GP reviewed Patricia and arranged the readmission as Patricia's blood pressure was very low.

Patricia does not remember receiving any written or verbal information during her time in hospital or her discharge. Stewart described the written information received in between recordings. He noted that Patricia received a discharge letter with the medication list included after the first discharge. He noted that no results or extra information were on that letter. He stated they received no written information after the second discharge. Furthermore, he could not find a copy of the discharge letter to show me during the interview.

Situational constraints:

- Patricia admitted she did not want to recall negative experiences and did not want to say much

Uniqueness among other cases:

- Home setting was in one of the most deprived parts of the city
- Some positive descriptions of care in hospital

Findings:

- Discharge took place too soon; Stewart felt his mother rushed out; Patricia was not cured.
- Poor and unclear communication, not knowing plans or what is going on, messages/information changing at the last minute
- Negative impact (emotional, practical, financial, physical health) of unplanned readmission on Patricia, her son (caregiver), close family and wider (son's work colleagues, wider family…)
- Negative experiences of stay in hospital (for both Patricia and Stewart), being in hospital you are removed from your everyday
- Family not listened to
- Home environment changed since readmission (bed downstairs)

Excerpts (quotes):

Patricia: "*um… I don't know I …. I can't really remember now I tries to forget all those sort of things...the things that I don't really like, like going in hospital and staying in hospital I tries to forget them"*

Patricia: *"I didn't like the idea of having to go back into hospital but then if I had to I would if you know what I mean to get better".*

Patricia: (re stay in hospital) "*I'm away from all my friends and family and I just sort of in hospital you know just waiting for something to happen if you know what I mean" … "I worry about the ones I've left behind just hoping they are getting on alright you know with their own help instead of me helping them as well"*

Patricia: "*they were all very pleasant, they were all very nice, well the ones that I've you know been with...they'd come and talk to you if you sort of feel a bit frightened or anything like that... You need someone to talk to sometimes don't you...and you can talk to them if you want to like you know".*

Stewart: *"I'm not having a go at any particular people most of the nurses there were fine they was uh willing to help and this sort of thing like I say apart from the first one up in WARD who like I saw walked away when I was half way through a sentence about her treatment and that she needed, she's virtually blind in one eye and got cataracts in the other so the eye drops are important which I was trying to explain but she just wasn't interested"*

Stewart: "*...I didn't think she should have been out the first time, they promised us more the second time she was still released early but she was actually physically fit the second time she come out, first time she wasn't"*

Stewart: "*So I come over here and not sleep very well cos I'm worrying about what is happening and the less sleep I get the more tetchy I get so it has come out at work when I've sort of lost me temper I've been a bit snappy with people I shouldn't be so it has affected my way of life as well*"

Stewart: *"..we've brought the bed downstairs so when she wakes up it's a different view so that's a little bit confusing.."* (Stewart, Patricia's son Case 4)

Commentary:

The experience of being readmitted to hospital for Patricia was one she purposely appeared to forget. She acknowledged and understood the need for her to go back into hospital to receive care and treatment. She also noted that she had received care and kindness from nurses whilst she was there. However, overall, the experience was not deemed 'nice' and as such Patricia was actively wanting to forget it. The experience and perception of the unplanned readmission was described more fully by her son and he had a very negative perception of it. He viewed the unplanned readmission as being due to his mother being rushed out the first time. He did not experience quality clear communication from healthcare professionals and felt that he did not have any answers to what was going on. The impact of the unplanned readmission was substantial, he noted the impact on his own health, his job and colleagues, and his wider family. A positive impact of the unplanned readmission was that his mother was now in the receipt of District Nursing care - something she had not been having previously. This is viewed as a positive by Stewart as it means there is more communication between community and hospital care.

Case 09 - Grace (Family relationship – Friends)

Synopsis

Grace, Female, 89 (and her friend Milo). Interview location busy outpatient's department (waiting room and clinic room as per Grace's requests during the morning). Readmission within 24 hours (according to Grace), Milo comments it was about three days. First admission was for IV antibiotics due to a lung infection. Then, Grace was discharged home and went to stay with her friend Milo. She took a sleeping tablet that evening and when she woke in the night as she needed to go to the bathroom, she felt dizzy and ended up falling over, then her friend called an ambulance and Grace was readmitted, she was first sent to the emergency department and had a plaster cast put on and then went to a ward for a few days. Milo suggests the readmission took place after about three days.

Information regarding the cast was given. They did not have any of the paperwork with them as we were in an outpatient department.

Situational constraints:

- The interview location was noisy, busy. We kept moving throughout the morning to accommodate Grace's appointment needs (waiting room, clinic room, waiting room again).
- The setting also impacted on my ability to concentrate as it was noisy, public and quite stop/start with multiple changes of location

Uniqueness among cases:

- Family in this case is chosen family

Findings:

- Readmission catalyst for thinking about the future, and their age.
- Impact of condition on daily living back home (not being able to use arm), relying on others
- Communication issues
- Unplanned readmission not wanted but accepted and viewed as necessary, nowhere else to go.

- Needing to advocate for self / family (local anaesthetic vs general anaesthetic), not always being listened to (pulse oximeter, food), Grace didn't always feel able to advocate for what she wanted or what she knew to be required (sling)
- Understanding contextual issues i.e that NHS is busy whilst highlighting instances when care was not good enough (pulse oximeter, pressure to eat)
- Family support important
- Perceptions differing between patient and family: family prompting memories in patient (impact of sleeping tablets)

Excerpts (quotes):

Grace: "*I knew that I'd done something and I tried to call Milo but of course he was in another bedroom in another part of the building and so I crawled back to bed on my hands and knees and just stayed there until the following morning."*

Grace: "*well I was on a trolley for about seven hours but mind you I was not unattended I mean I was... People were very good if I wanted anything they came..."… "I suppose I don't get angry because I know they're so busy".*

Grace: "*I said well it isn't that, it's because I've still got a few marbles left and I don't want to lose them under a GA* *laughs* *which was quite true, when you get older these things have a greater effect*"

Grace: "*I felt communication could have been better than it was except for this young doctor who phoned Milo and um he tried to keep me in touch with what was going on in the orthopaedic section...the next day when I saw him he apologised and said he didn't have the information at that time so that was rather nice"*

Grace: "*and it did hurt this push pulling but I thought I'm not going to say anything *laughs* I want this to be done as soon as possible".*

Grace: *“...when I went to the plaster room to have it the cast off he came in and he apologised and he said ‘well I think one things forgotten amongst others is that you should have had your hand up in a sling anyway”*

Grace: “*but I think at my age I do accept quite a lot of things that perhaps if I was younger I would probably be complaining about”*

Grace: “*I mean I knew they were incredibly busy and um so the second time around I knew that I would have to come back as there was nowhere else to go ...and er I would have to put up with whatever was waiting for me”.*

Grace: “*I’ll just have to be careful in the future*

Milo: *“took it as it came, it wasn’t frightening no no I’m not phased by that, I’m a vet so I’m used to seeing animals breaking things”*

Commentary:

Grace appears to be quite accepting of her readmission. She did not want to go back to hospital - or even necessarily go in the first time - however she could appreciate why she needed to go both times. The experience of care received was generally positive though some specific moments are noted around communication and care that could be improved. Both Grace and Milo note their age, the impact their age has, their desire to ‘keep their marbles’. This readmission is also a reminder for them to be ‘more careful’ and has made them think and reflect on their time ahead.

Case 10 – Henry (Family relationship – Patient only)

Synopsis

Henry, Male, 87. Interview location: Henry's home. Readmission within a few days. First, Henry went to the emergency department but he was sent home the same day from the emergency department. Then on getting home from the emergency department Henry collapsed and could not breathe well and went to hospital. He cannot remember how long he was in the hospital before being discharged. Henry then talks about being at home for a few days and then needing to be readmitted. It was his cleaner who prompted for Henry to be readmitted. He was in hospital for about two and a half weeks during the unplanned readmission. Henry lives alone and has an alert bell on his wrist and that is how he called for ambulances. Henry did not want me to contact his daughter for an interview.

Received a discharge letter and a pack from the community Heart Failure team. Neatly piled up on a table behind him. Not in his line of vision. In the interview Henry says he did not receive anything after he was discharged from his first admission but he did receive information after being discharged from his unplanned readmission. Since his unplanned readmission Henry has also received letters for specialist follow up, these letters are also in the same pile of papers. Henry does remember being told when leaving hospital after his unplanned readmission that it would take six to eight weeks for him to feel better.

Recording paused at one moment as he wanted to make a cup of tea and talk through his appointment letters. During this time, he mentioned his frustrations with logistics of getting to hospital and parking. We discussed a couple of possible options for him and he appeared happy with them. He then invited me to look at other letters and leaflets, and the information he had received. There was a standard discharge letter and Henry said he did not understand it so we discussed it. There was also an information pack from the community Heart Failure team. There was also a leaflet on how to use an inhaler with a spacer chamber and an information leaflet about the District Nursing (DN) team but he did not mention having had any visits from them. Henry also noted how many pieces of paper he received and how he did not know if he was ‘coming or going’ because of all the information.

Situational constraints:

Uniqueness among other cases:

- Henry only participant who had an initial hospitalisation on the same day as being discharged from the emergency department, then had a subsequent unplanned readmission after this

Findings:

- Communication not adequate, things not explained, plans not kept (testing), not feeling listened to
- Discharged when still felt unwell (weak, diarrhoea), expectation would be ‘cured’ before discharge
- Impact of lack of communication post readmission = Henry accessed GP as still had unanswered questions (diarrhoea)
- Puts own self into perspective (others are worse off)
- Hospital setting not comfortable & noisy, moved around within the hospital felt unsettled
- Home preferred, wants and tries to be as independent as possible
- Unplanned readmission was lifesaving, has also resulted in follow up by specialist team

- Paperwork not being used, referred to or deemed useful. Some verbal advice recalled and useful (re: expectations).

Excerpts (quotes):

Henry: “*I’ve got some stuff on the table there what they give me but as I say I’ve got so much paperwork I don’t know whether I’m coming or going”.*

Henry: “*nothing was said to me.” And “nothing seemed to be done. I had to get my own Dr out and er to get some tablets to cure it. ''*

Henry: “*I’m getting there I think now, you see I’ve got spinal stenosis that’s why I have to use the cane and I gets pains in my back terrible but people are worse off than me, that’s how I put it yeah”.*

Henry: “*you can’t beat your own bed can you”*

Henry: “*Mr X you’ve got the flu. And that’s as far as it went”*

Henry: “*I personally thought that I wasn’t going to make it...I knew I had to go into hospital to get something done. If I’d stopped home, I don’t think I would have made it”*

Henry: “*I don’t think it’s a complaint really like you know but uh I would have thought they would have tried to cure it* [the diarrhoea] *in the hospital you know”.*

Henry: “*I’ve got it all wrote down but there’s so much to remember”*

Henry: “*I mean they’ve got a hard job anyway and er as I say there’s a lot of people hundreds of people worse off than ever I am. I’ve had a good innings anyway”*

Henry: “*As I say I cannot fault the nurses at all they did their job they made sure I was clean and washed in the morning and everything like they do”*

Commentary:

Henry appears to be a proud strong independent gentleman. He views the hospital as a place where his life can be saved and his health issues can be cured, thus his unplanned readmission is framed in this way. He is disappointed to have left hospital still having diarrhoea. Despite this, he was given some information to help manage his expectations and does not appear to feel he was discharged too soon. His readmission appears to have set in place further help and support for Henry, from carers and from specific teams i.e., community heart failure team. The paperwork he received was after his unplanned readmission but it does not appear to be very meaningful to him or useful - he finds it too much to take in and does not really know where to start with it all.

Case 13 – Catherine (Family relationship – Spouses)

Synopsis:

Catherine, Female, 72 (and her husband Michael). Interview location in own home (Catherine and Michael were interviewed separately and in a private room in the house at both their request). Unplanned readmission within two days. Admitted on the night of Saturday to Sunday via ambulance and emergency department (999 call made by husband). Stayed in over the weekend and was then discharged on the Monday. Catherine states she did not feel better, in fact, she started to feel worse. She called the GP on the Wednesday who come to do a home visit, the GP then called for an ambulance, and Catherine was admitted to a ward via the emergency department.

A considerable amount of paperwork from the rehabilitation team (physiotherapy and occupational therapy) with information on various exercises and progression points. These were in full view (on dining table and coffee table) and being used regularly. Discharge letters received, not in view, not to hand.

Situational constraints:

Uniqueness among other cases:

- Only family who wanted to be interviewed separately and privately
- Most affluent address visited

Findings:

- Hospitalisation and unplanned readmission a shock, future plans drastically changed, role changes within the family (husband & caregiver; being on sick leave from work)
- Unplanned readmission provided more knowledge and more treatment and care and home support (physiotherapy and occupational therapy), and more understanding of hospital/healthcare processes and system (would use the word 'stroke' not 'dizzy' when calling ambulance)
- Unplanned readmission a relief for family
- Disappointment in own body and self
- Aware of contextual factors, the NHS having limited resources, other people being sicker, not wanting to use resources inappropriately, feel fortunate to have a NHS
- Hospital not somewhere to convalesce
- On reflection family wonder whether patient discharged too soon but at the time were happy to accept advice and decision making of professionals

Excerpts (quotes):

Catherine: "*"Every day I wake up get out of bed and feel wobbly .. so… that's my attitude. I want to wake up and feel normal *laughs* but everyone who I meet says ooh you look wonderful and I feel like saying well doesn't feel so wonderful …..you know…"*

Catherine: "*Well, I think the main strain has been on, as well as on me has been on my husband because it's a terrible shock to him and he's had to do everything as my carer since I've come from the hospital."*

Catherine: "*and as a result of being back in the hospital for six days I've subsequently had extremely good physiotherapy coming at home*"

Catherine: "*Well everyone else is pleased with me but I'm still I suppose disappointed in myself, I keep hoping that I'll just wake up and feel normal but it hasn't happened yet"*

Catherine: "*so as far as I was concerned I wasn't glad to be back in hospital from the point of view of having something wrong with me but I was glad to be back where they could do the required treatment."*

Catherine: "*I thought well it's no good sitting around here with all these terribly ill people all much worse than I was I've got to make an effort and go home"*

Michael: "*well it was very upsetting really, it was all the uncertainty about it and the uncertainty was generated because they were unable to give the first time around a diagnosis, a detailed diagnosis because the MRI and CT scans didn't show any...uh evidence of a stroke".*

Michael: "*When Catherine thought she was at death's door and this was it and we'd never experienced that before it was uh very upsetting for both of us, so, was, were we going to go through that again all over again come the Tuesday, she went back in on a Wednesday didn't she yeah so we were a bit more aware of what was involved but it's still upsetting for us both.*"

Commentary:

For Catherine her illness and readmission have been a shock, she has felt let down and disappointed in her own body, she is frustrated, and there was a lack of understanding of the system and what to do when discharged home and before the unplanned readmission. Catherine has made the decision to use the word ‘stroke’ if she feels her symptoms relate to this instead of talking of feeling ‘dizzy’ to make sure her call is prioritised. She is talks of having called her GP instead of 999 when she felt unwell after her first discharge because she did not feel she could ring 999 a second time in a few days - this is something she has reflected on and she now feels she would call them and sooner. This also leads her to feeling disappointed in her own decision making and makes her wonder what would have happened if she had called 999 a day earlier. The unplanned readmission was a relief for her husband and for her in the sense that she was getting the care she required and more knowledge and information was received. However, it was also viewed negatively as it meant she was still unwell. The illness has caused a shift in the roles they each play with Matthew becoming a caregiver and Catherine having to pause her professional role. It has also meant they have had to reassess their future plans. Catherine’s sense of self also appears to have been affected.

Case 14 – Violet (Family relationship – Mother and daughter)

Synopsis:

Violet, Female, 85 (and daughter Laura). Interview location in own home. Multiple unplanned readmissions within 30 days over the last few months. Unplanned readmissions take place within two weeks of discharge. The story was quite complex and both Violet and her daughter appeared to have ‘lost track’ of each separate admission and unplanned readmission so even when probing it was hard to get a clear picture of the number of unplanned readmissions, what had happened, and what each separate one was like. The unplanned readmissions appear to be due to complications with Violet's Heart Failure and needing to adjust medication and treat symptoms (fluid retention, difficulty breathing, possible heart attack).

Written information was received but they did not have copies to show me - Violet and Laura mentioned they had received discharge letters after each admission. On the last unplanned readmission, they had also received specific information from the heart failure team. Violet noted she received leaflets and a phone number on the last readmission, and a list of medications (Violet's medications were changed many times over the multiple unplanned readmissions). Laura notes she has put all the discharge letters in a hospital bag ready for if her mother needs to get readmitted again.

Situational constraints:

- Initially, Laura was being interviewed with her mother Violet present. She only opened-up once her mother moved to another room as her friend was visiting.

Uniqueness among other cases:

- Case with the most amount of unplanned readmissions

Findings:

- Different experiences and perceptions between patient and family
- Significant impact of unplanned readmissions on life and wellbeing of family
- Unplanned readmissions deemed inevitable

- Unplanned readmission expected due to age
- Some unplanned readmissions key to securing adequate support and care in community
- Number of unplanned readmissions mean experiences are a blur
- Experience during hospitalisation
- Some discharge information helpful if it has specific point of contact and how to access i.e phone number and name/advice/community support/if it is recognised as a resource by patient and family
- Unplanned readmissions experienced as traumatic by family, many repercussions on wellbeing, health (mental health), work (being signed off), relationships.
- Lasting effect of unplanned readmissions (worrying each time phone rings)
- Discharged too soon,
- Poor communication
- Not being listened to
- Understand contextual factors, pressure on NHS, limited beds
- Needing to advocate for your family

Excerpts (quotes):

Violet: "*I've been in and out.. I don't really know"*

Violet: "*I mean they were wonderful in there the doctors and the nurses they were so lovely they really were, can't fault them at all any of them, really good, really good."*

Violet: "*well I got used to it* [the readmissions] **laughs* now I think you know,* I, *I'm not frightened of hospitals like some people are.."*

Violet: “*I think when my time comes it’s come and that’s it. I’m a firm believer you’re allotted time on this earth *laughs* but um you know I just don’t worry about going in again at all...don’t want to but um you know it doesn’t worry me hospitals as I’ve said before.”*

Violet: “*I’m grateful for that you know, I mean they’ve been very very good this last time haven’t they they have...They’ve given you know the options of everything I’ve never had that before but this last visit they offered all these things”.*

Laura: “*that um obviously things weren’t going to be OK that time and um I think it impacted every time she went in it sort of had more of an impact on me… yeah I worried…”*

Laura: The unplanned readmissions were “*a traumatic time”* and “*happening too often”*

Laura: “*I mean yeah you just every time the telephone goes you jump just in case…”.*

Laura: “*I felt they sent her out too quickly”*

Laura: “*..it hasn’t been til we’ve been in this last time um on this day thing that we’ve really got all the info and everything else um… I felt quite relieved when we were going and the heart failure nurse came to see her”*

Laura: “*they don’t listen to what anybody else is saying according to the book you should have this that and that but this that and that might not suit and obviously mums blood pressure usually runs a little bit higher than they would like but the reason is if it runs too low she faints”.*

Laura: “*it’s just sometimes I think they could perhaps say things in a different way”*

Laura: “*I think they do tend to treat everybody a little bit the same” … “I think the main thing for me is that um probably not to have criterias and look at the person rather than go to a book and say ‘oooh you’re not quite there yet’”.*

Laura: “*she don’t like bothering anyone” ... “she’s terrible she hates bothering people even the GP tells her off”*.

Commentary:

Violet's perception appears to be that that these unplanned readmissions are something to get used to and to be expected at her age, her attitude is rather stoical. She also notes that the only specific written information she got that helped was received after her final unplanned readmission before that she only got generic discharge letters. Laura appears to experience her mum's readmissions in a different way. Her mum's delirium is experienced in a traumatic way and the whole series of admissions and unplanned readmissions have affected Laura's health and wellbeing, even leading to her being signed off from her work. Furthermore, Laura has experienced not being listened to in hospital settings and feelings of uncertainty, it is only after the last unplanned readmission that Laura felt there was adequate follow up and support in the community for both her mum and herself. Communication issues have been picked up by Laura (linked to not being listened to and having to advocate a lot for her mum) however Violet did not mention having issues with communication.

5.2.2 Patients and families within the collective case study

The case summaries presented created during this phase of the analysis of the collective case study provide rich, nuanced descriptions of the experiences and perceptions that older people and their families had of their unplanned readmissions. There is a diversity of experience present. There are multiple different clinical reasons for the unplanned readmissions ranging from acute episodes linked to accidents through to what appear to be exacerbations of chronic conditions and a clinical need to address symptoms, in some instances life threatening ones. In addition, some families describe their experiences based on one unplanned readmission, whereas others provide accounts of a series of multiple unplanned readmissions occurring regularly over the course of a few weeks or months. The written information and documents referred to during the interviews also varies. There are occasions where no written information is recalled, other times specific documents are described. There does not appear to be a regular pattern to what type of written information people were provided with, perhaps reflecting the multiplicity of clinical conditions and experiences presented here. However, in some instances it took the prompting of a family member for the patient to recall having received some. Similarly, there were differences between patients and family members surrounding the recall of the timings of when events occurred, for instance how long someone was home before they were readmitted. Across the collective case study there were instances where patients and families expressed worry about the other, signalling unplanned readmissions could be perceived as a concerning time. Thus, this collective case study is informed by a multiplicity of diverse experiences of unplanned readmissions. This has captured a range of different family set ups and clinical conditions and illustrates the real range of older people experiencing unplanned readmissions to hospital within 30 days of discharge within the context of this study site.

5.3 Chapter summary

This chapter has summarised contextual factors the study was conducted in, describing the hospital Trust, discharge processes and issues occurring during the data collection phase. The 14 cases have been summarised, with brief details presented in a table. Alongside this, a selection of case summary reports has been provided along with a brief outline describing the multiplicity of patients and families depicted within this collective case study. The next chapter will present and explore with richness and detail the Assertions about the Quintain, that is, the findings that help us to understand the phenomena that are the experiences and perceptions of unplanned readmissions within the context of this collective case study.

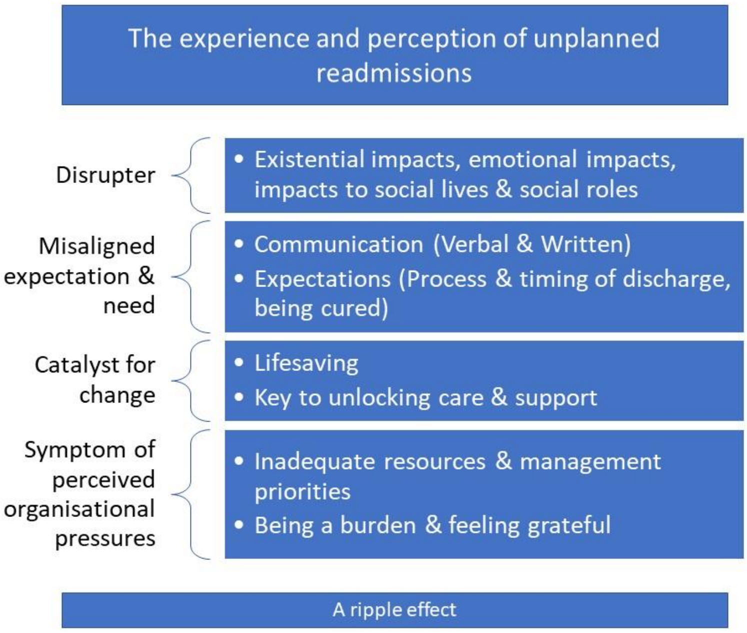
6.0 Chapter 6 - Findings or ‘Assertions about the Quintain’

Chapter Introduction

This chapter sets out the findings of this study in the form of themes. Stake (2006) refers to study findings as ‘Assertions about the Quintain’ that is, what the collection of cases studied contribute to further understanding of the phenomenon, that is the experience and perception of unplanned readmissions from the perspective of older people and their families. These Assertions about the Quintain act like a mosaic, they present a picture of the experiences and perceptions of unplanned readmissions, however, each tile, or case, is still centred and celebrated. Thus, the stories of the older people and their families should still be visible when the Assertions are described. All the names of patients and family members in this chapter are pseudonyms that have been used throughout this thesis.

To understand the experience and perception of unplanned readmissions the analysis presented in this study conceptualises them as a phenomenon that is disruptive to the lives of patients and their families. They are characterised by a misalignment of expectations and needs between patients, families, and healthcare professionals, and viewed as catalysts for change. Finally, unplanned readmissions can be perceived as a symptom of organisational pressures. A cross cutting element of these themes is how their impacts can ripple out across peoples’ lives not only affecting those directly experiencing the unplanned readmissions but also wider networks which have the potential to affect future experiences of healthcare encounters. The diagram below, Figure 6, provides a summary of these findings.

Figure 6: Diagram of the Assertions about the Quintain as themes and sub-themes



6.1 Unplanned readmissions as a disrupter

An unplanned readmission was experienced as a disrupter by patients and families. This centred around existential disruptions (to self, their relationship with their ill body) that prompted reflections on age, ageing and death; emotional disruptions linked to ill health, hospitalisation, and unplanned readmissions; and disruptions to social lives and social roles with impacts in personal, professional, and environmental spheres.

This first theme sets the context from which to view the subsequent themes and helps to explains how the themes generated within this study support the contention that unplanned readmissions have a ripple effect. Multiple returns, especially those within a short timeframe, appear to intensify the effect of the disruptions.

In the context of unplanned readmissions, this study suggests disruptions associated with ill health and hospitalisation are compounded. Their repeated nature and the uncertainty linked to when, why and how the unplanned readmission will take place appear to be important. Certain cases within this collective case study are indicative of this and illustrate the intensity of experiencing multiple unplanned readmissions. Michael (Eleanor's husband, Case 1) noting, with shock stress and disappointment, "*here we go again"*; Stewart (Patricia's son, Case 4) highlighting the financial and emotional impact of repeated time off work; and Laura (Violet's daughter, Case 14) noted "*I think it impacted every time she went in it sort of had more of an impact on me… yeah I worried…"* underlining how deeply affected by the uncertainty and repeated nature of her mother's readmissions she was, so much so that she has been signed off work, also point to this being of particular relevance to family members.

6.1.1 Existential impacts

Unplanned readmissions appeared to cause patients and their families to reflect on age, ageing, sense of self and death. The unplanned readmission was viewed as an unsurprising part of age and ageing. The hospitalisation was sometimes viewed an inevitable aspect of getting older, and age was cited as a reason for why the impact of the unplanned readmission was experienced the way it was. Despite people feeling an unplanned readmission was to be expected during this time of their life they signalled a time of change and of needing to adapt, and not all participants were accepting of this.

When asked about what the unplanned readmission meant to him Paul (Case 2), the patient who was readmitted, replied: *“I suppose they [the readmissions] mean that I’m getting on a bit and I have to adjust myself to fit in with them”* (Paul, Case 2). Paul notes he needs to adjust and compensate for his ageing and the effects of his readmissions. Similarly, Eleanor (Case 1) viewed hospitalisation as part of her life now as an older person: “*I just have accepted it as being part of my senior life that occasional visits to hospital are going to be needed*” (Eleanor, Case 1). John (Case 6) also felt that going in and out of hospital, as he had been doing for the past few months, was part of life as an older person:

“*Yes, I have to accept that this is part of ageing as you say, there’s no point railing against it and saying why does it happen to me, it happens to everybody at my time of life….I’ve had 25 years of retirement and the early part of that, the major part of it I’ve been able to lead an active life so I’m grateful for that. It’s at only the last ten years or so that life has been more restricted*” (John, Case 6).

Among those who described unplanned readmissions as being a part of life and ageing, some took it in a more stoical and accepting way than others. John (Case 6) described his philosophical attitude to life which he applied to how he viewed the unplanned readmissions: "*Well, I just take it, I just accept it as life, you know, I've got to the stage where I take a sort of philosophical life, attitude to life, accept what comes and if I have to go to hospital I accept that*" (John, Case 6). John (Case 6) was not alone in having an accepting attitude to life and getting older, Violet (Case 14) discussed her thoughts, she was clear about taking life as it came and not worrying about her visits to hospital or any future readmissions:

"*I just take things as they come, what comes comes and what don't you know just, I don't worry about it sort of thing I just sort of accept it I suppose really I don't um you know don't worry about is it going to happen again I don't worry about that at all I think when my times come it's come and that's it...I'm a firm believer you're allotted time on this earth but um you know I just don't worry about going in again at all .. don't want to but um you know it doesn't worry me hospitals as I've said before.."* (Violet, Case 14).

However, this stoicism and acceptance was not necessarily the whole picture, for example despite John (Case 6) mentioning multiple times how accepting he was of the need to go back to hospital, he referred to his deteriorating health that led to these unplanned readmissions as indicating that "*… the rot set in…*". He also said "*I don't feel like doing anything. I feel a general lassitude...I would normally read when I was at home and so on but um since I've been in hospital I don't feel like doing anything…if I'm restricted to bed or sitting down all the time life is going to be uh more difficult"* and described not being able to cope with jigsaw puzzles anymore and not having the energy or desire to read anymore, an activity he previously enjoyed, pointing to potential low mood. Catherine (Case 13) was conscious of her age but noted how much she used to do, *“walking five miles, swimming 40 lengths etc”* and contrasted that with how she felt after her unplanned readmission *“Every day I wake up get out of bed and feel wobbly .. so… that’s my attitude. I want to wake up and feel normal *laughs* but everyone who I meet says ooh you look wonderful and I feel like saying well doesn’t feel so wonderful ….you know…”* which again points to a more complex emotional picture and that not everyone was as accepting of their changing bodies or needs. Thus, for some an unplanned readmission was an expected feature of older age, and whilst some appeared to stoically accept this, for others there were hints of more complex emotions.

The impact of the unplanned readmission was partly framed around patients’ ageing self, for instance, Evelyn (Case 11) noted she felt more tired than before her unplanned readmissions, but she felt these processes and feelings were linked to ageing: “*I don’t I just don’t feel I’ve got quite the energy as I had before I went in but I just put that down to age, I can’t expect to keep going …*” (Evelyn, Case 11). Betty (Case 7) commented something similar but in her case, it was her sister giving her this reminder:

“So, she (sister) said next time if you should go in um which is like now, um, don’t keep on about going home give yourself a chance to pick up again because of course I’m 88 now, these things don’t work so quickly when you’re older. She said you’ve got to make allowances so ... here I am allowing” (Betty, Case 7)

For the participants in this study having one or more unplanned readmissions in quick succession acted as an indication that life was changing, was being disrupted, and much like it was viewed as a sign of ageing it also moved thinking to death and the idea of being on ‘borrowed time’ until death. After describing what prompted his unplanned readmission “*on the Saturday night I was getting my tea out of the oven and I had another bad fall which cut me head and um made me nose and arm bleed and hurt me back and here I am today”* Neil (Case 8) referred to each new day as “*a bonus*” carrying on saying he did not think he would be alive this long. Betty commented about how lucky she is to have this extra time whilst also having a stoical attitude to life: “*I’m now on borrowed time so I’m fortunate with the extra time that’s the way I look at it but that’s something that you can’t do anything about you just have to accept your lot and that’s it*” (Betty, Case 7). Previous unplanned readmissions and ill health reinforced this idea, Michael (Eleanor’s husband, Case 1) noted: “*we know we’re always sort of working on borrowed time really don’t we*”, and the more recent unplanned readmissions indicated this pattern was continuing “*then this one [unplanned readmission] appeared and that means oh gosh has it really started that all over again*” (Michael, Eleanor’s husband, Case 1). He went on to note the challenges surrounding this and appeared tired when discussing this. Another family member, Matthew, Catherine’s husband (Case 13) similarly highlighted the upset and challenge of their partner having an unplanned readmission: “*I mean for both of us it was the, the first time round, whenever it was four o’clock on that Saturday morning when Catherine thought she was at death’s door and this was it and we’d never experienced that before it was uh very upsetting for both of us, so, was, were we going to go through that again all over again come the Tuesday, she went back in on a Wednesday didn’t she yeah so we’re a bit more aware of what was involved but it’s still upsetting for us both …”.* Thus, unplanned readmissions were experienced as a disrupter to life and impacted on patients’ views of their age, ageing, and prompted thinking about life ahead and how much time was left. Family members also experienced elements of these existential disruptions.

6.1.2 Emotional impacts

Unplanned readmissions provoked emotional responses for a variety of reasons. As seen above, unplanned readmissions were symbolic of ageing and engendered thinking around life and death. Emotional impacts were also due to other factors associated with the disruptions linked to unplanned readmissions, such as, reflecting on sense of self, identity, but also stresses and emotions linked to practical issues.

Participants' sense of self was impacted by unplanned readmissions, and this was not necessarily linked to ageing. For instance, it provoked moments of reflection on self and identity. Catherine (Case 13) described being disappointed in her own body and feeling shocked at the need to go into hospital:

"*Well I'm disappointed in my own body, I'm 72 years old and I'm historically a quite fit person, um, I said to the doctors normally when I'm well I can walk on a five mile walk no problem, I can swim 40 lengths at the pool which is a kilometre, and um I can ride a bicycle without falling off too often, although I did fall off about three years ago and broke a bit of my arm but um and so I'm shocked*" (Catherine, Case 13). This was then compounded by the unplanned readmission and requirement to work hard at rehabilitation: "*Well everyone else is pleased with me but I'm still I suppose disappointed in myself, I keep hoping that I'll just wake up and feel normal but it hasn't happened yet*" (Catherine, Case 13). In addition to the physical impact, Catherine's identity as an academic and a professional woman was affected as she was not able to work, compounding her feelings of disappointment and shock.

For Barry, his sense of self was affected by a long stay in hospital. He was readmitted to hospital shortly after discharge, had been there for several weeks and was finding it challenging. Thus, his sense of self was affected by the disruptive result of his unplanned readmission which had corresponding emotional impacts. As a man who spent a lot of time outdoors with his dog, not being able to go outside for several weeks took its toll on his mental health as did being away from his wife and dog. This was worsened by his lack of understanding over why he was deemed unwell and what his care plan was. Barry said: "*But I've been here over a fortnight I'm just so fed up with it … and I never thought I could get down as low as I've got just lately ….*" (Barry, Case 3). In this instance, Barry's emotions and wellbeing were affected by the complex interplay of disruptions caused by his unplanned readmission, instigating him to feel lower than he has ever done in his life.

There was a complex combination of emotional and practical impacts, whereby practical impacts could have emotional disruptions and vice versa. For instance, emotional impacts were linked to practical situations such as requiring a to learn a new skill, for instance how to learn to walk again (Catherine, Case 13), or how to navigate using a space, such as when Paul (Case 2) learnt how to use his kitchen again. Paul (Case 2) described this stating:

Paul: *"I still have to get from where I am to where I'm going to be and do things, I walk along supporting myself on the worktop all the time and um if I need to go back I will go backwards supporting myself with the worktop all of the time and then putting the things from the worktop onto the um trolley"*

This account from Paul and Anne highlights the extent of the learning required to use his kitchen space again. Later in the interviews Paul notes he is required to adapt, mentioning he is "*probably more careful when doing things um when I sit on the toilet, I sort of remain there for about three minutes or something to let myself settle*" and that now *"I walk very carefully around the house".* Anne comments she continues to be concerned at the risk of Paul falling again. Matthew required to learn how to navigate health systems (which service to call for what and when to do so). Matthew (Catherine's husband, Case 13) commented on the need to do so quickly making it a stressful and challenging experience: "*So it's been a very rapid learning process really you always think it it you know it happens but you never think it will happen to you*" (Matthew, Catherine's husband, Case 13). Stew (Betty's son, Case 7) has found the whole experience stressful, it ripples out to the relationships he has with family and has been compounding his existing mental health issues: "*Stressful cos I suffer with stress anyway um I had a bit of an episode so a few years ago and I'm still on citalopram now and it was something I could have done without um but you know you just have to get on with it I suppose it was just the fact that I couldn't get information…Yeah it's just the stress and not knowing what's going on and you try and deal with your family outside and and trying to give them information and you can't you, you don't know what's going on".*

For Stewart there was a clear ripple effect from his mother's unplanned readmission to hospital, which had become a disruptive wave in many aspects of his life and had extended to affect wider family and his colleagues at work. Stewart talked of not sleeping well due to the stress and starting to drink again during the week. He has also been taking home less money due to the need to take extra days off work to deal with his mother's hospitalisations, discharges home, and subsequent unplanned readmissions. This led to him being angry at work, something which his colleagues had noticed, thus the ripple is moving out from him as an individual and out to the wider community. Describing coming home from visiting his mother in hospital Stewart noted:

"*So I come over here and not sleep very well cos I'm worrying about what is happening and the less sleep I get the more tetchy I get so it has come out at work when I've sort of lost me temper I've been a bit snappy with people I shouldn't be so it has affected my way of life as well*" (Stewart, Patricia's son, Case 4).

This illustrates the situation for many when faced with their own or their families unplanned readmissions. There are emotional disruptions related to disappointment in their own body, and what the physical changes can represent to themselves, to reactions and feelings related to what is happening to them or their family, and an interplay between practical and emotional disruptions. These can also ripple out to wider people not directly affected by the unplanned readmission.

6.1.3 Impacts on social lives and social roles

The impacts associated with unplanned readmissions affected social lives and included practical, financial, or logistical consequences, impacts on social roles, plans for the future being modified, and changes to the physical home environment. Whilst these are noted as practical impacts which disrupted participants' lives, they could also contribute to the emotional and existential reactions to unplanned readmissions.

Stark words from Stewart (Patricia's son, Case 4) illustrate the financial disruption unplanned readmissions could have for people: "*So I only had half my wages this week…and this is all because I thought she was sent home too early the first time*" (Stewart, Patricia’s son, Case 4). Stewart was having to change his working pattern at the last minute and was not able to make shifts causing him a real financial strain, this coupled with his feelings of anger was leading to issues with sleep and had been affecting his behaviour when he was able to work. He needed to arrange and plan care and visits for his mother between other members of his family. He lived with his mother and so also needed to liaise with carers and deal with the uncertainty of plans, what was happening and whether his mother might need to be admitted again. This points to tensions between his professional role, his role as son, care giver, and role coordinating information within his family. This indicates the breadth of disruption that can be linked to unplanned readmissions. Stewart was not alone in describing these impacts that extended out further than the immediate family unit. Laura describes how the multiple unplanned readmissions her mother had experienced meant she had been to her GP to be signed off from work:

“*Yeah and that is only the last two weeks because I’ve been off work since eight weeks I think now cos I just couldn’t cope with going back um… having a telephone call at work cos work was not that understanding .. it’s my boss ...oh dear she’d be more understanding if I’d gone back this week but she’s not… I just wanted to make sure that mum was getting better rather than go back and something else happen um cos it’s not obviously easy so…*” (Laura, Violet’s daughter, Case 14).

Here Laura notes how she could not cope with receiving yet another phone call at work to say that her mother had been readmitted to hospital again indicating how unplanned readmissions have been having real disruptive impacts on her life. This has also affected her relationship with her boss and how she feels about work. Thus, the disruption associated with unplanned readmissions extends out of the family unit and into the social and professional world of families of patients who have experienced unplanned readmissions and the roles they play in these spheres.

The repeated nature of unplanned readmissions can compound this, and the practical requirements of having to deal with the home environment and going back and forth to hospital can become extremely stressful, as well as being a key point of contact for wider family or health and care professionals, indicating that the practical impacts of unplanned readmissions can also prove emotionally draining: *“Apart from that um because obviously there’s all the um running the house etc when she’s not here and the toing and froing and visiting and the joys of parking up at the [hospital] um you know all amount to to a lot of stress so you know”* (Stew, Betty’s son, Case 7).

Another area where the disruptive element of unplanned readmissions was illustrated is when plans needed to change. The unplanned readmissions and ill health associated with these impacted on how people could travel or plan for future leisure activities or hobbies. They also affected their social lives, how the future was envisaged and what was perceived as possible in the future. Toby was unable to go to a competition abroad despite representing the UK in his hobby: “*Yeah I mean there was an outside chance we would have gone but um obviously I’m not going after having had a heart attack they won’t let me go there so I just got to wait and see what happens*” (Toby, Case 5). He noted at length during his interview how important his hobby is for him and how much he had been looking forward to being able to represent the United Kingdom at this international competition. However, he was still able to participate in his hobby and took great pleasure in it. His series of unplanned readmissions had impeded his plans to travel but he was still able to do his hobby, in this sense he could continue to take part in activities that were meaningful to him. This was not the case for everyone. Catherine was having difficulty walking and using her hands after her ill health and unplanned readmission:

"*I don't yet feel totally confident that I will be back completely to um there's things I was planning to do this year that I might not plan to do like climbing up a couple of thousand feet of a mountain*" (Catherine, Case 13)

This was a trip she had previously taken with her husband many years ago. They had been discussing wanting to do it again before they got too old or unwell and they noted with sadness that this had occurred, that they would not be able to go, and that for Catherine just walking a few metres to the local pub was now a challenge. Eleanor (Case 1) mentioned throughout the interview that her unplanned readmissions led to her not being able to drive *"I was sent home by taxi from the surgery as not allowed to drive"*. After the interview Eleanor reiterated that this was perceived as an important issue for her, especially as she lived in a rural area with little access to public transport.

In addition, unplanned readmissions takes people away from being at home, and from being able to participate in their social lives at home. For some this was a social setting they had a desire to be back in, even if they recognised the clinical need to be in hospital. Neil (Case 8) commented in the interview he had been in hospital for a few weeks *"Still here since now that's what three weeks ago"* and later noted he missed being at home, where his daughter could check in on him and where he could watch TV without having to pay, though he equally wanted his pain to be managed and recognised the need to be in hospital. For Barry (Case 3) being away from his home environment means he is not there for and with his wife and dog, neither can he enjoy the outdoors as he would, he yearns to go home and "*take my little dog for a walk with my missus and I know I can't walk very far"*. For Patricia (Case 4) being in hospital meant she could not fulfil her role as mother and friend, commenting that "*I'm away from all my friends and family and I just sort of in hospital you know just waiting for something to happen if you know what I mean…I worry about the ones I've left behind just hoping they are getting on alright you know with their own help instead of me helping them as well".* Thus, unplanned readmissions, and the ill health associated with these, had repercussions on peoples' social lives and social roles.

The practical impacts of the unplanned readmission rippled out to affect family with stress and uncertainty occurring when a loved one was at home because there was the constant fear of them going back to hospital: "*I think it's the dread of getting that telephone call um all the time … we haven't been abroad since last year because of that reason um yeah I think it does .. you keep going and then and then you suddenly break don't you yeah um…*" (Laura, Violet's daughter, Case 14).

Participant's professional worlds could also be affected with practical implications for the whole family. Catherine's (Case 13) ability to work was severely affected and her husband also had to make changes to his social roles as his caring responsibilities increased. Catherine (Case 13) noted the disruptive impact the readmission, and her health condition, had on her husband Matthew's life:

"I think the main strain has been on, as well as on me has been on my husband because it's a terrible shock to him and he's had to do everything as my carer since I've come from the hospital…so whatever else he's been doing he's had to drop and um…he cancelled some meetings he had in London and he had to just let people down" (Catherine, Case 13).

Matthew noted that friends and family were rallying around and becoming present in their lives, but also commented that Catherine's professional life would perhaps be changing forever, saying: *"I don't know whether she'll do much more research herself, I don't know … we'll see..."* which again highlights the practical disruptive effect and uncertainty brought upon by unplanned readmissions and ill health and the impact on social roles.

Grace and Milo viewed the practical impacts and disruptions as to be expected, in fact this was something they had already envisaged may be a feature of their lives, reinforcing the idea that unplanned readmissions, for some, were viewed as part of older age. They had made an agreement to look after each other after their respective spouses died and were quite matter of fact about how the readmission was affecting them:

"*Well, no real problems really. We're both retired, and we have an undertaking to look after each other so we're looking after each other so we just enjoy life, between us we've probably got about ten years on the clock left, five years each is what we've arranged so we're enjoying those five years, so no no I just look after her as she would do me, it's not a problem*" (Milo, Grace's friend, Case 9)

Unplanned readmissions, in some instances, could herald changes to the physical home environment due to the impact of the condition(s) requiring hospitalisation or as a condition of being discharged. This resulted in seeing a familiar environment in a different way after the unplanned readmission. For Patricia's son Stewart (Case 4), Patricia's health deterioration has meant their house has had to change: *"We've brought the bed downstairs so when she wakes up it's a different view so that's a little bit confusing."* (Stewart, Patricia's son Case 4). His mother's bed has been brought downstairs into the living room and she now has a strip wash in front of the downstairs sink, these mobility issues have also added to Stewart's stress levels. It also meant his mother was confused by the new home environment.

For Catherine (Case 13), her home environment became different after her unplanned readmission as she could not get around as before, her usual environment had changed because of how she interacted with it: *"Actually I remember my grandmother using her stick for all sorts of things actually you know opening windows and things I've been doing that a bit myself."* (Catherine, Case 13). Catherine interacted differently with her home as she found it more challenging to navigate. Paul (Case 2) learnt how to navigate his kitchen differently after his readmission. Paul and his wife made changes and came up with systems to help make the home environment easier for Paul after multiple readmissions, disrupting their usual environment, he described his morning routine to illustrate this:

"Um, in the kitchen in the morning um getting my breakfast um sort of park the stick safely in a corner so it doesn't fall on the ground, very often I walk along to where the Weetabix Anne put it in a bowl or the egg for boiling she's put by … I walk along supporting myself on the worktop" (Paul, Case 2).

Multiple unplanned readmissions could compound these environmental disruptions. For instance, Laura (Violet's daughter, Case 14) changed her mother's environment by placing a hospital bag packed ready for her mum near the door: *"…we have a bag ready to go just makes it easier and like you put the discharge letter in there so that .. for next time.."* (Laura, Violet's daughter, Case 14). She had done this, so it was ready for the next unplanned readmission, a behaviour started due to her mother's frequent unplanned readmissions and indicating how the future in her mind was being modified due to these readmissions.

The practical impacts of unplanned readmissions were wide ranging affecting finances, daily living, work, organisation, plans for the future and the physical home environment. These could also influence the emotional responses to unplanned readmissions. These impacts were disruptive on a variety of levels rippling out temporally and across wide networks of people beyond the immediate family unit with the potential for longer lasting impact.

6.2 Misaligned expectation and need associated with unplanned readmissions

The experience and perception of unplanned readmissions was characterised by misaligned expectations and needs of both patients and families in relation to the care and processes they went through. This was described by them through accounts of encounters where communication, both verbal and written, was not effective. They also described confusion and surprise around their belief they would be cured after one hospitalisation, the timing of the discharge home, and hospital processes.

6.2.1 Communication

Verbal communication

Patients and families reported not feeling listened to, they noted they felt ignored, their expertise and opinions were not considered, and a lack of interaction with healthcare professionals meant there was a lack of opportunity to be listened to. Thus, the experience and perception of unplanned readmissions is affected by the experiences before, during and after, and especially during the times of hospitalisation.

Barry (Case 3) noted he was ‘stuck in a corner’ and that no one would listen to him. “*Nobody listened to you, they just stuck you in a bed and pushed you over in a corner they you are that’s where you can stay, nobody gave me any answers*” (Barry, Case 3). Barry went on to say he felt that people did not want to listen to him, that his expertise of his own self was not being considered. He felt that his knowledge of himself was not valued or counted as knowledge by the healthcare professionals. In addition, he felt something was wrong but that this was not listened to by the healthcare professionals when they made decisions about his care, including his discharge:

“Nobody wants to listen to you...Is more what I was trying to say ...um they don’t want to listen to you cos you don’t know anything. But the trouble is you know there’s something wrong” (Barry, Case 3)

Other patients also noted their own knowledge of themselves was not considered. For instance, Grace (Case 9) was not listened to by nurses who insisted she eat more than she wanted and kept checking her oxygen saturations using a finger pulse oximeter as opposed to an ear probe, despite Grace noting that with her medical condition, her fingers were not appropriate for the pulse oximetry probe as it would not read accurately. The only person who appeared to listen to Grace (Case 9) was a medical student:

“Well he wasn’t qualified but he was a medical student nearly at the end and um he came and talked to me quite a lot, and he took the oxygen measurement from my ear and of course it was 94% and I before I left I said to somebody on the ward um one of the staff if

you have a patient with rheumatoid arthritis do the oxygen measurement from the ear" (Grace, Case 9)

Grace was very kind about staff throughout her interview, but she selected this moment to emphasise when she felt listened to as a real contrast to her other experiences. Barry and Grace were not the only patients who did not feel listened to. Both Toby (Case 5) and Henry (Case 10) described having very brief or non-existent interactions with doctors during the ward rounds and this leading to them not feeling listened to. Henry commented that:

"..Well I think it was more or less every time a doctor came round someone came to see me you know but um I mean like they just ask you how you are today one thing and another and that was it" (Henry, Case 10)

Henry's account points to a situation where he was not made to feel valued as a participant in his own care and it did not appear, he felt, like professionals were trying to build a relationship with him, which may explain why he left hospital not feeling 'cured'. Henry (Case 10) noted "*nothing was said to me…nothing seemed to be done. I had to get my own Dr out and er to get some tablets to cure it''.* Similarly, Toby (Case 5) noted he did not feel like a participant in his own care noting that:

"..that's one thing, the doctors are always very late coming to see you if they see you because um obviously because my heart was racing away they decided what medication and they could do nothing until that medication started working so but you don't get told this and so you see the doctor come he walks straight by and you think hey he can't see me.." (Toby, Case 5)

In addition, Joan (Case 12) had worries around her information not being communicated effectively between the healthcare professionals looking after her and how she did not like having to repeat her information "*I do like to see the same person each time because otherwise, I mean they have swarms of them and how things don't get passed on or do get passed on that was the only thing that worried me…I didn't want to repeat everything".*

In effect, the lack of consistent interaction meant there was a lack of opportunity to be listened to or to have a conversation to find out and understand what was going on, thus minimising opportunities to feel valued and an active participant in their own care. For some people, this affected how they experienced being discharged and readmitted, framing it as a result of not being cured or being discharged too soon.

Stewart (Case 4) felt he did not get answers when trying to speak to healthcare professionals, instead his query was passed on to someone else. Similarly, Laura (Case 14) was marked by an experience where a doctor did not value or recognise the knowledge she had of her mother or the expertise Laura had around her mother's medications and reactions to them, Laura felt this doctor was not considering her mother as an individual but rather saw her as a series of symptoms that he needed to treat according to information he found in a book:

"*Yeah, yeah I think … so I felt and they just look at what medication they think is best for the condition but don't look at the wider picture really … but every time I said them oh that's what the heart failure team like we don't like that in here but listen because then she won't blow up with water so yeah just little things like that*" (Laura, Violet's daughter, Case 14)

In addition, Laura (Case 14) felt a nurse did not take her seriously when she brought up her mother's ankle swelling, in essence Laura's expertise was not valued and subsequently her mother had an adverse incident during her stay in hospital:

"*Um, and she wasn't breathing right and I said to the nurse before I left her at nine o'clock at night I said um you know she's filling up with fluid - holding her ankles - and I said her ankles never ever swell and she said 'well eh' and and at two o'clock in the morning she had to press the bell and it was an emergency so I do feel sometimes they need to listen a bit more to someone that knows the patient you know*" (Laura, Violet's daughter, Case 14)

For both patients and families there were descriptions of chaotic, disorganised communication and processes. Michael (Eleanor's husband, Case 1) spoke of a "muddle of communication" and how he felt that he never knew what was happening, who to speak to, and felt that the outcomes of processes were unclear as they were still waiting for some information, noting: *"...but it was always where do we go from here and as always when is she coming out and there's certainly a lack of communication about that or a muddle of communication… as far as the hospital is concerned it's the thing about communication and the communication is still bad because we haven't had various things… which in both cases, both times in hospital Eleanor was told this was going to happen and we still haven't heard officially so that's not proper I don't know where the delay in the process is but it's not good for anybody"*. For Barry (Case 3) this was described as not being kept updated about information or processes *"we would like to be kept in the loop...we're not kept in the loop if there ever was a loop"* adding the stress this caused his wife back at home, commenting that the multiple readmissions: "*it was worrying my wife to death and I couldn't see what was going on with me if you see what I mean".*

Barry's wife was not the only person who experienced this with other families finding the lack of communication difficult, especially not being able to get information and having to wait for different professionals who did not appear to have talked to each other. Stew described this at length at multiple points in his interview, saying:

"*I can't fault any of the treatment she received um you know and the people up there but it just seems communication is not the prime thing. It always seems to fall down whoever you talk to it's a different someone else then you add people with different opinions about who what and where whereas if you could sort of keep to roughly the same sort of um people looking after them because I found that was the thing you always had to go and find out advice there was no one about to sort of talk to you always had to ask and invariably whoever you spoke to would be on a different shift sort of thing and you can't get to speak to them which is er a bit of a problem*" (Stew, Betty's son, Case 7).

For patients themselves, there was a sense they did not know what was going on with their own health or their own care. In addition, there was a sense they were being missed out or being moved around the hospital without knowing why. Communication on these issues was lacking, there were Instances when a healthcare professional would say something would happen but then it did not, and patients felt there was a lack of feedback on how a situation was unfolding. Barry felt this lack of communication quite deeply and felt that people were hiding or withholding information; he wondered whether this could be due to his working-class background:

"*Alright I was only a working fella but all the same I'm surely due something over this it's like now I don't really know what was up with me but you see these people won't tell you anything*" (Barry, Case 3)

Henry (Case 10) felt unsure what was going on: *"…I was, when I went in there I was shifted from one bed to another don't tell me where I went, I was upstairs, downstairs …"* (Henry Case 10) He was understanding about the need to be moved it just felt unsettling as he did not get told why or where he was going. An account by Toby (Case 5) further highlights this; he was not told why he could not walk to the toilet alone and felt confused by this. Additionally, he did not know why the medical teams were missing him out during ward rounds, he felt he was not being given information.

"...I don't find anything that I would object to in hospital except that maybe its lack of knowledge of what they're trying to do … um you get a different doctor come round some walk straight by…" (Toby, Case 5).After a few days he discovered that the teams were waiting for his new medication to start settling his heart condition and Toby was understanding; however, he would have liked all this information earlier. Some patients had a lack of clarity over why symptoms were occurring. Neil (Case 8) was aware there were still tests running but he did not feel clear as to why these things were happening to him.

*"…other than that they couldn't find nothing else but I'm still getting a lot of terrible back pain so they've tried me on different tablets *has difficulty breathing* they tried me on some different tablets to see if they can ease it more only I can't hardly walk ..."* (Neil, Case 8).

As a response to being in this context of care where communication was not effective and misaligned with need some participants noted they needed to learn a new language or way of navigating these spaces. This is illustrated in the examples of family learning what they need to do to advocate for their loved ones, for example, waiting at the bedside in the hope of meeting a healthcare professional. More distinct examples were described, for instance, by Grace (Case 9) who was in pain during a procedure but decided against saying anything as she did not want them to stop.

"*Also, they gave me some gas that I could inhale which apparently, they use when people are having babies, I couldn't get this, I wanted to breathe through my nose all the time so I didn't have any effect from this er but em and it did hurt this push pulling but I thought I'm not going to say anything I want this to be done as soon as possible.*" (Grace, Case 9)

Grace had waited a very long time in the emergency department to get to this point and was concerned if she said something her care would be paused or moved to a different time. She was aware of how busy things were and was learning that she needed to fit into the hospital processes to get the care that she wanted despite her pain not being managed. Similarly, Catherine (Case 13) and her husband both talked about learning through the process of Catherine's admission and readmission, of needing to learn to navigate the different systems but also the vocabulary to use:

"I suppose I mean in future if I have any kind of collapse, inability to talk or anything, I didn't know that was associated with a stroke, I would say 'I think I've had a stroke' and then I think they would come quicker if you see what I mean so… ah you learn something everyday

as they say" (Catherine, Case 13)

There were fewer accounts of patients or their families describing being listened to; however, when they were it was very much appreciated. These examples highlight moments when caring relations were built, and people's contributions were valued, and they could participate in decisions. Laura (Case 14) described one moment she was listened to by healthcare professionals: "*they wanted to put a catheter in in um A&E and I begged them not to because my grandmother had a heart attack after a catheter in in hospital so it's just but they did listen they did listen...*" she went on to note this helped alleviate her stress and that she felt heard. Similarly, Both Grace and Milo (Case 9) were very clear they were listened to about not wanting Grace to have a general anaesthetic, Grace did not want to "*lose my marbles*", a local anaesthetic was used, and they were relieved. These experiences were the exception and not being listened to was manifested in a variety of ways, from patients feeling ignored to family feeling their expertise was not considered. These accounts further highlight that when asked about people's unplanned readmissions the time they are hospitalised features in these accounts and appears to be part of the whole experience.

Experiences and perceptions of unplanned readmissions were characterised by misaligned communication needs, whereby people did not feel listened to, they felt their knowledge of their self or family was not considered, they did not feel part of care processes, there was a distinct lack of communication, and a requirement to learn how to navigate the system as a result. The ineffective communication reported took place at various moments during the different healthcare encounters that were referred to as part of the experience of unplanned readmissions whether these happened before, during or after the specific moment of readmission.

Written information

Many of the participants could not remember receiving any written information. When asked whether she remembered receiving any information Patricia (Case 4) replied: “*oh, um I tries to forget all those sort of things and not remember them*” (Patricia, Case 4). There was also no visible paperwork or documentation at her home. Amongst those who remembered receiving written information few were able to locate it, show it and explain how they had used or referred to it. Throw away comments were used by some to indicate they knew they had received something but could not remember where it was. When interviewed Betty (Case 7) said she did not receive any written information. However, her son, Stew noted they received a discharge letter and some leaflets on discharge; however, he could not find it or remember where it was.

“*Yeah, we got a load of paper and all that but you don’t tend to look at that do you, I mean it’s better if you can sort of talk through*” (Stew, Betty’s son, Case 7)

The preference he had to be able to talk things through meant he was very frustrated as he felt communication, both verbal and written, was lacking and inadequate. Thus, his needs were not responded to and the written word was not enough to support him to understand what was happening; this highlights a misalignment in need between patient relatives and hospital processes.

For those who could locate their paperwork, it was not necessarily used as intended, i.e., as a reference for after discharge. Paul and Anne (Case 2) recalled receiving a letter after Paul's readmission, they could recall receiving a letter but had not used it or referred to it *"...they sent me a copy of the report that they had sent to my GP and that letter I remember that*" (Paul Case 2). Joan (Case 12) could locate it but it was crumpled and at the bottom of her handbag: "*Oh I'm sure I did…I might even have got some of it here...I don't know, what discharge … [looks through paperwork] ...I mean that's my list of drugs on discharge…*" (Joan Case 12). When she took it out to show the letters, her understanding about which letter was from the admission and the readmission was confused, and her attitude towards the letters appeared to indicate these were not useful or important to her.

The physical placing and appearance of the paperwork was not necessarily indicative of how well, or not, information contained in it was understood or used. There were cases when paperwork was kept carefully on a table or in a neat pile however it did not necessarily indicate it had been understood – Evelyn (Case 11) had taken care of all the paperwork she had received, it included discharge letters, a purple Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form, and an Age UK information booklet and a leaflet from the hospital at home team. However, she was not aware of the significance of the DNACPR and commented she had not looked through any of it because she had been waiting for someone to go through it all with her. Evelyn went on to say that *"You've been more help over my tablets than anybody else!"* (Evelyn Case 11). This was not an isolated example and others also had similar experiences of keeping the paperwork but not understanding the letters or content of them. Henry (Case 10) felt similarly: *"Oh yes they just gave me, I've got some stuff on the table there what they give me but as I say I've got so much paperwork I don't know whether I'm coming or going"* (Henry Case 10)

Henry found the amount of paperwork overwhelming and did not understand the content of it which added to his confusion. Henry (Case 10) had a pile of paperwork including documents from the heart failure team, despite feeling overwhelmed by much of the paperwork, he did understand the emergency medication pack he had been left. Henry had been visited by a community nurse from the heart failure team and he was able to relay the information they had discussed and in what circumstances to use the medication and when to seek further help – this interaction with this nurse made sense to Henry and appeared to meet his informational needs and helped him to understand his care. However, Henry still found the volume and content of the rest of his paperwork overwhelming and he was not able to explain any of the other paperwork included in the pile on his table, further suggestive of misalignment of need between the creators, distributors and users of the written information provided. It appears that the written communication received by participants in this study was not viewed as a useful resource, it was not something they could use as a reference point, especially as clear plans were not evident, thus it was not meaningful to them.

6.2.2 Expectations

Expectations around hospital processes and timing of discharge

The accounts of what it was like to experience unplanned readmissions included in this study point to a variety of situations where there was a misalignment between expectations and needs of patients, families, and decision makers in hospital. Hospital processes and timing of discharge were illustrative of this. Whilst effective communication leading to clear understanding of expectations around hospital and care processes and outcomes did occur accounts of this were limited. Henry (Case 10) was clear about the time frame within which he should feel better in terms of walking and breathing, he mentioned "*Well I'm determined to get there they told me when I come out of hospital to get over this it would probably take six to eight weeks, and it's six weeks today*". He was not clear who told him this but he was aware he could not expect to be in hospital for the six to eight weeks it was predicted his recovery would take. Similarly, during his latest readmission Toby (Case 5) and his wife had a discussion with a doctor, followed with a letter, clearly explaining the expectations he should have for when he should feel better:

"*If there is any frustration it's the frustration that you are not getting better very quickly. Um in fact I've got a letter somewhere and the doctor says that um I realise that I can't do that walking suddenly and I got to be patient and they said four weeks didn't they?*" (Toby, Case 5)

At the time of the interview Toby and his wife Phyllis were both able to discuss this with a healthcare professional and felt supported and clear about this care: "*He did send a document and most of it was on it and also the fact that it would probably take me another four weeks before I really felt any better*" (Toby Case 5). Toby went on to explain that he was starting to find walking around the house easier and this tied in with the four-week window the doctor had suggested would be normal for him to feel better. In this situation effective communication supported a patient and family to understand the situation they are in and align the expectations of healthcare professionals and patients.

For most cases, however, there was a misalignment between what patients and families expected and experienced. For instance, they did not know who to speak to or where to find members of staff. They perceived that plans changed quickly for arbitrary or unknown reasons that they were not involved in. Furthermore, they had difficulty getting information and had a lack of understanding around how to get the information or how hospital processes worked. Stewart (Case 4) was told on a Friday that his mother would stay in over the weekend to ensure she could get further tests on the following Monday and a care package could be arranged, only to be called on the Sunday afternoon to be told his mother was being discharged. This impacted on him in multiple ways, he did not understand why this was happening, he felt stress, and subsequently received less pay that week as he needed to take emergency time off work.

"When she was in the first time um they kept saying she'd be kept in a while waiting for a care package … they said they'd be keeping her in for a few days and then it came as a shock when they phoned me up and said she can come out today..." (Stewart, Patricia's son, Case 4)

He did not understand how plans that were communicated to him as thorough and fixed could be so suddenly changed and that his mother could be deemed medically fit for discharge so soon. In addition, when discussing his mother's time in hospital he perceived there to be a lack of input from medical consultants as they were not visible to him.

"*I left the hospital thinking everything was going well and then from then on we hardly see any of the consultants again that were downstairs because the doctor had actually changed we had a different doctor who was up on the ward they didn't know about the drug for the pain*" (Stewart, Patricia's son, Case 4)

Stewart did not get any explanations for the causes of his mother's ill health and he spoke of a lack of communication between departments and doctors, feeling he did not get any answers to his questions. He would get passed around between different professionals each saying the other would know about something. He could not find the right people to speak to and he felt healthcare professionals were not proactive in coming to talk to him. These experiences in hospital framed how he experienced and perceived his mother’s unplanned readmission.

The expectations participants had of the healthcare encounter foresaw it as a situation where they or their family would receive the necessary care and support to get better and where messages would be consistent and clear. This did not necessarily occur, patients and their families did not appear to receive adequate communication or help to understand what was happening, thus the caring relationship between patients, their families and the healthcare professionals looking after them was sub-optimal.

The timing of the discharge from hospital was noted when participants felt they or their family member had been sent home from hospital too soon. Barry (Case 3) remembered going home then coming straight back to hospital in an ambulance and this situation reinforced his impression that he had been discharged too soon. Barry mentioned he did not think anyone had really done anything to make him better and so wondered what the healthcare professionals could have put on their notes:

“And um god knows what they put down on their paperwork they must have put a load of lies because as I say they sent me home and before that ambulance that took me home had got back to [city] I was waiting for another one”. Barry (Case 3)

The misalignment in expectations can also be illustrated in Henry's accounts, where he describes understanding why it was not appropriate to spend more time in hospital but still not expecting to go home feeling the way he did: "*I can understand the six to eight weeks period, I don't expect them to keep me in there for six to eight weeks to get over it like you know but eh, I wasn't, well I felt as weak as a rat when I came home*" (Henry, Case 10). For others like Stewart (Patricia's son, Case 4), he felt his mother was not physically fit and there was no support for her to go home and so should not have been discharged when she was the first time:

"*...I didn't think she should have been out the first time, they promised us more the second time she was still released early but she was actually physically fit the second time she come out, first time she wasn't"* (Stewart, Patricia's son, Case 4).

Stewart noted the practical and financial impact of his mother's early and unexpected discharge and makes it clear he believes it contributed to her unplanned readmission. He and his family had to physically change things in their home, and he required unpaid leave which had a severe effect on his life. His needs as caregiver, family member, and worker did not appear to be considered when the professionals made the decision to discharge his mother home, and there did not appear to be a rationale explained to him, highlighting misalignments between his needs and expectations and those of the decision makers in hospital:

"*then she's suddenly been released early so everything's had to change like they told us, told me Sunday half past two I think it was she's being released we thought Monday was* *going to be the earliest...we were going to see her again Monday so we hadn't even got the bed down yet so we had to rush about getting all that sorted get the bed down get the stuff ready for her to come home and then go up the hospital to pick her up and then like I said bang three days later everything's changed again she's rushed back in in the ambulance I'd run out at work so obviously all the time off I'm not getting paid for so I only had half my wages this week so financially it's not helping us and this is all because I thought she was sent home too early the first time*" (Stewart, Patricia's son, Case 4).

The misalignments of expectations and needs illustrated here point to the perception by participants that there was inadequate preparation or timing of the first discharge and a corresponding range of subsequent impacts on peoples' lives.

Expectation that the initial hospitalisation will result in being cured

These misalignments continue to be observed through participants accounts of their expectations they or their family member would be cured during their initial hospitalisation. A tension arose when their expectations were not fulfilled, leading some to feel confused, angry, and let down. Henry (Case 10) had an expectation he would go home cured of his symptoms before he was sent home, however, this did not happen, and it caused him some concern:

"*The only thing I would have thought they would have cured my diarrhoea before I came home. I was a bit concerned as I say when I got in my son-in-law's car*" (Henry, Case 10)

In some instances, this expectation was described via patients not perceiving anything had been done to make them better, like Barry (Case 3) who was disappointed in the care he received, he did not feel that anything had been done to make him better, saying of the moment just after his initial discharge:

"*Oh I don't know what the words are…nobody sort of cares anymore …but they never bothered to focus on anything, they did their usual checks. Put him over there he'll be alright. They kept me in there for two or three days then said well you can go home...but they hadn't done nothing to put anything right"*

For family this was also a consideration, Matthew (Catherine's husband, Case 13) found it upsetting that his wife's initial hospitalisation could not provide answers in the form of a formal diagnosis, "*well it was very upsetting really, it was all the uncertainty about it and the uncertainty was generated because they were unable to give the first time around a diagnosis, a detailed diagnosis because the MRI and CT scans didn't show any...uh evidence of a stroke".* For Betty's son Stew (Case 7) he was very confused as to why his mother was not cured after her initial hospitalisation. He had clear expectations that during his mother's first hospitalisation his mother should be cured and not go home as bad as she went in: "*…expectations are you go to hospital to be cured and not to come out as bad as you went in…*". Stew reiterated this point throughout his interview and wanted hospital staff, and the NHS more generally, to consider what the impact of this might be like for patients and their families: "*but as I say I'd just say it needs more thinking on what's the patient and like I say their family going through rather than just let's get them out the door …um just you know they get the job right first time*".

The misalignment of expectation and need between patients, families and healthcare decision makers has been described via accounts of communication experienced and expectations of hospital processes, discharge timing and being cured. Whilst the degree of misalignment varied, the impacts of these experiences and perceptions all had the potential to ripple out onto future encounters and spread wider than the readmitted patient and their immediate family. Furthermore, these moments were described as part of the wider phenomenon of unplanned readmissions even if the communication issues or misaligned expectation took place at other time points and not specifically at the point of unplanned readmission.

6.3 Unplanned readmissions as a catalyst for change

Alongside being disruptive and experienced as moments of misaligned expectations, unplanned readmissions were viewed as lifesaving or forces for good. In this sense, the unplanned readmissions were perceived as catalysts for positive changes in people's lives despite the challenges and disruptions also associated with them.

6.3.1 Unplanned readmissions as life saving

Whilst hospital was not a place that participants necessarily enjoyed being, they acknowledged it was a necessary place to go when unwell, viewing being readmitted as lifesaving, and hospitals as settings with experts who cured and cared for you. Michael (Eleanor's wife, Case 1) highlighted this saying "*that was the experience which wasn't a nice one but it came, it came out with the right result anyway, as soon as the infusions and the transfusion had happened Eleanor had got to being practically where she was before*". Toby (Case 5) acknowledged the lifesaving role of the hospital reflecting on how he would not have survived had it not been for prompt care: *"The one thing that does stick in my mind is the fact that if they didn't take me in when I had that heart attack I might not be here now"*

(Toby Case 5). This is mirrored in Henry's account of the first of his unplanned readmissions saying that "*I personally thought that I wasn't going to make it. Like you know, um, it didn't because I knew I had to go into hospital to get something done. If I'd have stopped home I don't think I would have made it.".*

Hospital was viewed as a place to go and get immediate help, to get treatment, get better and to be in the safe hands of experts and unplanned readmissions was a way of accessing this. Evelyn (Case 11) mentioned "*I had wonderful treatment I've got no faults at all with anything, the treatment I had couldn't have been better if I'd been private it was excellent, it didn't matter what you asked, as it happened you didn't have to ask for much but they're so friendly".* Violet (Case 14) said: "*I'm not scared of hospitals or doctors or anything like that at all I just feel they're there to help you and they do they really do help and get you better"* and this was an expectation of a place you would go to 'get' better'. Barry (Case 3) viewed this in terms of hospital being the place you go to get 'put right' and John (Case 6) felt it was a place you go to get cared for by experts who know best: *"I just feel that um whatever's necessary in the way of treatment the hospital will give it to me, they know best".* Even if the experience of unplanned readmissions could be challenging, unplanned readmissions could still be associated with some positive meaning if they were perceived as necessary, lifesaving or curative.

6.3.2 Unplanned readmissions as a key to unlocking care and/or support

The wide-reaching impacts of the unplanned readmission was viewed as a force for good in peoples' lives. There was the sense that the unplanned readmission was the key to unlocking further care or getting answers for people when they are their family had reached a crisis point. Thus, though the experience of the unplanned readmission could be disruptive and unpleasant it could also be perceived as a helpful, even positive, event.

Violet (Case 14) noted how it was only after the last unplanned readmission she received options never before offered to her "*I mean they've been very very good this last time haven't they they have.. They've given you know the options of everything I've never had that before but this last visit they offered all these things…*" (Violet Case 14). This information was something also discussed with her daughter Laura, and her relief contrasted with how she had felt on previous discharges where none of this information had been provided, this final unplanned readmission was viewed as the key to finally accessing the help and support Violet required.

This occurred in other cases where the unplanned readmission meant further care and support was arranged for patients outside of hospital. For instance, Henry (Case 10) was set up with appointments and was then followed up by a community team. John (Case 6) had formal carers arranged to come in to see him multiple times a day after an unplanned readmission. Similarly, after his unplanned readmission, Paul had some appointments set up for him to review his medication and have an assessment at the falls clinic:

"…they referred him to what they call falls clinic…and apparently, they check the medication there or something" (Anne, Paul's husband, Case 2)

Stewart (Patricia's son, Case 4) finds the unplanned readmission has meaning and finds that there is a positive to be taken from his mother's latest unplanned readmission, because his mother received care from the District Nursing team in her own home, meaning he and his mother had more much needed help and crucially a care plan was established:

"…so we have to have a district nurse to come in so which is a bit better because they're more in contact with the hospital side of things I think and err they've got their own plan as to do a certain couple of weeks of treatment if that's not working they'll discuss it and try another method so that was the only good thing about going in the second time we got a bit more help in trying to sort out what is going on in trying to cure the ulcers" (Stewart, Patricia's son, Case 4)

The unplanned readmission also paved the way for further tests and care in hospital, in some cases leading to more answers and knowledge, or even relief. Neil (Case 8) had more extensive tests done in hospital during his readmission, without which a plan for his ongoing care and support could not have been made. Joan (Case 12) was extremely relieved as the unplanned readmission meant her daughter no longer had to care for her at home, and she perceived that hospital was the better place for her to be, she stated *"Uh….well I suppose relief that [daughter] wasn't going to have to look after me and I don't know why I was having the diarrhoea I mean my tummy was all obviously upset from what I don't know and what pills I was on you know, um, no nothing else. OK, I'm just going back in"*. Despite the stress and worry linked to Catherine's condition, Matthew (Catherine's husband, Case 13) found significance in her unplanned readmission, and was grateful to have better knowledge and understanding around what was happening to her:

"What was the most significant aspect… well I suppose that they did more tests and they perhaps discovered that there may well have been some form of minor stroke which I

wouldn't say was reassuring but at least there was improved knowledge about what what maybe the cause of the of the problems and also I mean the, it's very reassuring having seen the professionalism of all the people in the stroke unit you felt she was in very good hands…" (Matthew, Catherine's husband, Case 13).

Thus, unplanned readmissions can be viewed as lifesaving and a crucial factor in unlocking further care and support. The unplanned readmission is viewed as having facilitated much needed in hospital care or testing and can be viewed as vital in having home and community-based care established and there can be a real sense of relief or significance linked to this.

6.4 Unplanned readmissions as a symptom of perceived organisational pressures

Unplanned readmissions were perceived as a symptom of organisational pressures, where inadequate resources and management priorities were contributing factors, and sometimes put ahead of patient and family needs. Linked to this, patients and families also commented they felt like a burden on the system alongside feeling grateful and acknowledging the quality of the care they received. The impact of these experiences had immediate repercussions to how patients and families perceived healthcare more broadly and have the potential to ripple out further impacting on future healthcare encounters.

Describing the experiences he had with his mother's unplanned readmission, Stew (Betty's son, Case 7) viewed his mother's discharge as being too soon and due to 'a numbers game' all to do with NHS figures and the pressures to free up beds:

"..yeah that was the only one downside I can really say was the fact that whether it's sort of the numbers game they're pushing people out too early to get figures down or whatever but I was quite disappointed the fact that she was released that first time" (Stew, Betty's son Case 7).

Stew later commented he was aware of pressures on staff but wondered whether if people got the 'right' treatment first time they would not need to come back. Laura (Violet's daughter, Case 14) felt similarly. Her and her mother had experienced multiple discharges and unplanned readmissions and Laura felt this narrow focus on releasing beds to the detriment of those being discharged contributed to unplanned readmissions: "*They don't look at the wider picture of it and I think that's that's something that needs to be .. yeah they probably do need the beds but this is at the same time why you're going to keep on having these readmissions if you do that and there was a few other people in there was a bay of four and there was a couple of other people that had been in and out*" (Laura, Violet's daughter, Case 14)

Despite feeling discharged too soon patients and families sensed other patients may have had more urgent needs than them and acknowledged the fact that the NHS has finite resources. Patient participants and their families appeared to have understanding and compassion for others in similar situations to their own. For some, such as Phyllis (Toby's wife, Case 5) this helped them accept why their family member was sent home when they were. Phyllis stated she understood why her husband was sent home, even though she felt it was too early, because there was a lack of beds in the hospital and the bed was needed for someone else:

"But I can understand why they were sending him home because of the bed situation but he would have been..if he could have stayed in for longer it might have helped whether...but it seemed to me that he was coming home too soon…he was shuffling about and his breathing wasn't right...once he was here I thought well I don't know perhaps he's not as well as he should be to come home. That was my only um sort of thing that I felt he wasn't quite right" (Phyllis, Toby's wife, Case 5)

Catherine and Matthew (Case 13) were both very aware of the people and systems around them, Catherine noticed people around her seemed worse off and more ill than her and she was very aware that the NHS needed to prioritise certain people over others depending on clinical need and that there are endless patients to deal with. Catherine mentioned *"I was a little bit wobbly but then by the time it came to Monday I thought well it's no good sitting around here with all these terribly ill people all much worse than I was I've got to make an effort and go home and I didn't feel strong certainly um and I felt very very tired at that point but again you don't stay in hospital because you're tired do you?*". Matthew noted he felt very fortunate to live in the UK with its NHS, especially as they had lived overseas where healthcare systems are very different:

"I mean the people when they do come were very professional, we're very fortunate having been lived in third world countries and frequently travelled the world it's one doesn't like to complain because we realise what a fortunate position we're in to have access to such excellent facilities so close to hand" (Matthew, Catherine's husband, Case 13).

Matthew was conscious of using up scarce medical resources and appeared very grateful over the quality care his wife received. However, he experienced uncertainty and stress and did question whether his wife was sent home too soon: *"...it's not an answer really but if she hadn't had been sent home would she, was she sent home too soon that's the question, but I'm not medically able to judge that really..."* (Matthew, Catherine's husband, Case 13).

Despite occasions when patients and families acknowledged they were part of a wider society of people who required healthcare, participants described unmet needs and moments when they were not supported to understand their care: "*I appreciate at times the hospital has got to fit people where they can but you've also got to sort of cure them as well that's a good thing*" (Stew, Betty's son, Case 7). These incidents could also bring patients to view themselves as a burden, as Paul (Case 2) mentioned when describing his fear and emotions experienced when thinking about the next potential unplanned readmission. This was captured in observations from the interview in the form of notes made in the reflective diary. Paul had been showing me around his flat after the interview when he alluded to feeling fearful about the potential for a further unplanned readmission and he appeared emotional when mentioning this.

The examples in this section illustrate how the experience of an unplanned readmission can be framed as a symptom of wider organisational issues and viewed in that context, with both patients and families showing understanding and still feeling gratitude for the care they received. The examples also illustrate the potential repercussions of how future healthcare encounters could be framed and experienced by patients and families because of the unplanned readmissions already faced by patients.

6.5 Chapter summary

The Assertions about the Quintain, that is, the findings about the experiences and perceptions of unplanned readmissions to hospital amongst older adults and their families in this collective case study, conceptualise unplanned readmissions as disruptive. In addition, there is misalignment of expectation and need associated with these experiences of unplanned readmissions, and this is in part viewed as symptomatic of wider organisational pressures. The unplanned readmissions are viewed as catalysts for change which resulted in further care and support, thus, a crisis was required for care to be unlocked. The impact unplanned readmissions had on the patients and families within this collective case study point to unplanned readmissions being a phenomenon that transcends the specific moment of the unplanned readmission. Instead, it ripples out to wider networks and moments in time, with varying degrees of disruption, and yet, in some instances can be viewed positively as a catalyst for required changes.

7.0 Chapter 7 – Discussion and recommendations

7.1 Chapter Introduction

This chapter reviews the findings co-created as part of this PhD study and highlights the unique contribution this study makes to the field of nursing. The findings are then contextualised and explored in relation to theory, literature, practice, and the literature review (Chapter 2). This discussion is an opportunity to shine a light on the experiences of unplanned readmissions from the perspectives of older people and their families and explore them in the context of embodiment, ageism, theories of ageing and considers the implications for the development and delivery of quality nursing care with an age friendly, family centred focus. Recommendations for nursing practice, research, education, and policy are then suggested.

7.2 Summary of findings

The question explored within this study was "What are the experiences and perceptions of unplanned readmissions to hospital within 30 days of discharge from the perspectives of older people and their families within an English NHS". This question was explored using a collective case study informed by Stake (1995, 2006) involving interviews with patients and their families, observations regarding written information they may or may not have received during their hospitalisation, all in the context of an English NHS hospital Trust. The observations around written information included whether participants had received any paperwork, if they kept it and if so where and how, and, finally whether they referred to it, or found it useful. The analysis explored how participants experienced, perceived, and made sense of their unplanned readmission to hospital. The Assertions developed in response to the research questions suggest the participants in this study viewed unplanned readmissions as disruptive, as key to unlocking care, as a highlighting challenges with communication and expectations, and they understood some of this as being part of wider organisational issues.

These Assertions are described via themes and sub-themes in Chapter 5: Unplanned readmissions as a disruptor with existential and emotional impacts and impacts on social lives and social roles. Misaligned expectations and needs associated with unplanned readmissions, with associated issues with verbal and written communication, and, misaligned expectations surrounding hospital processes, timing of discharge, and being cured. Unplanned readmissions as a catalyst for change, that can be viewed as lifesaving and a key to unlocking care and/or support. Finally, unplanned readmissions as a symptom of perceived organisational pressures. Overarching these themes, the experiences and perceptions of unplanned readmissions can be viewed as transcending the specific point in time when an unplanned readmission occurred. Additionally, the impacts of unplanned readmissions ripple out to wider networks and moments in time with varying degrees of disruption.

The image [Figure 7: Elements comprised within the Quintain] below illustrates how unplanned readmissions can be conceptualised and described within this PhD study. Factors taking place before the unplanned readmission, the perceived impacts stemming from the readmission as well as any outcomes ascribed to the readmission all contribute to the experience and perception of the unplanned readmission and how it is framed by patients and families. Thus, this PhD study also identifies that unplanned readmissions can be viewed as broader than a discrete event and this is developed further to incorporate the wider impacts and outcomes of an unplanned readmission whilst also considering the unplanned nature of the readmission.

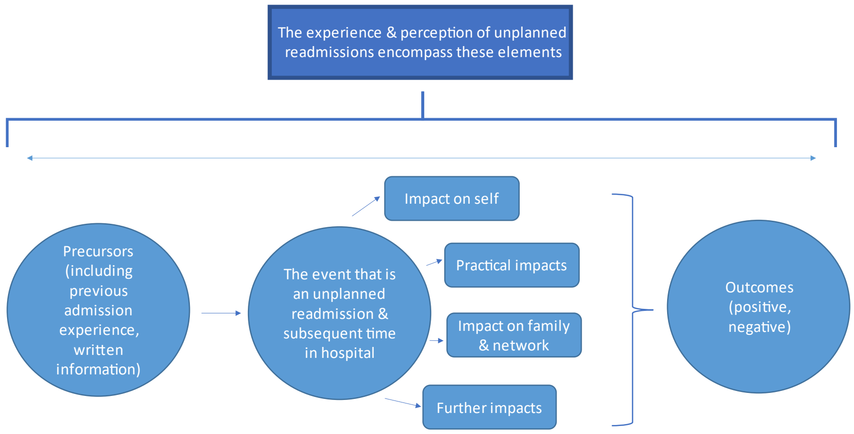


Figure 7: Elements comprised within the Quintain

An unplanned readmission was often experienced as a disrupter by patients and families. There were disruptions to their existential condition which precipitated thoughts on age, self, and death. Disruptions had emotional and practical impacts which influenced their current situation or future life plans, including affecting social lives and social roles. The experiences and perceptions of unplanned readmissions were characterised by the misaligned expectations and needs of both patients and families in relation to their care and the processes they went through. This was described through accounts of encounters where communication, both verbal and written, was ineffective. Participants also described confusion and surprise over the timing and planning of their hospitalisation and discharge home feeling they had been sent too early as the expected to be cured before going home. Alongside being disruptive and experienced as moments with misaligned expectations, unplanned readmissions were also viewed as lifesaving or forces for good. In this sense, the unplanned readmissions were perceived as catalysts for positive changes in people's lives despite the challenges and disruptions associated with them as they unlocked further care or support. Third sector organisations have highlighted the social impact of unplanned readmissions, pointing to emotional harm distress and worry (Healthwatch 2015) depression, frustration (Age UK 2019) anxiety (Royal Voluntary Service 2015) and trauma (Ombudsman 2016), which are all issues reflected in my study findings. My study contributes to this picture and highlights the wider ranging and longer-term impacts that result in experiences of unplanned readmissions having a ripple effect.

Unplanned readmissions were often perceived as symptomatic of organisational pressures, where inadequate resources and management priorities were contributing factors, and sometimes prioritised ahead of patient and family needs. Linked to this, patients and families also commented that they felt like a burden on the system alongside feeling grateful and acknowledging the quality of the care they received. The impact of these experiences had immediate repercussions on how patients and families perceived healthcare more broadly and had the potential to ripple out further, thus impacting on future healthcare encounters.

7.3 Unique contributions

This study findings provide a unique contribution to our understanding of the experience and perception of unplanned readmissions, within the context of this collective case study.

The unique contributions to this understanding are enumerated here. Each one of these areas will then be discussed in further detail in the remainder of the chapter below.

1. The findings from this study present a deeper and richer understanding of experiences and perceptions of unplanned readmissions to hospital among older people and their families. This study has presented the magnitude of the disruption and illustrated how the impacts of these unplanned readmissions can ripple out across time and wider society.

2. Nuance around the experiences and perceptions of unplanned readmissions have captured the fact that as a catalyst for change they can be viewed as key to unlocking care and support. This suggests older people and their families are reaching a type of crisis point before things change for them.

3. This study's findings involving the experiences and perceptions older people have of their unplanned readmission offer contextually bound first-hand accounts of the lived experience of being older and accessing healthcare, which contributes to diversifying the narrative around older age and supports combatting ageism.

The implications for nursing practice, research, education, and policy will be discussed below via discussion and recommendations will be suggested.

7.4 Magnitude of the disruption: Implications

Viewing unplanned readmissions as a disruptor, provides the background context to the experience and perception of unplanned readmissions within this study and provides broader understanding of ageing and embodiment. Whilst the disruptive nature of hospitalisation and illness is not new this study does contribute to our understanding of experiences of older age and views us all as embodied rather than humans who 'have bodies' (Draper 2014) by providing a deeper and richer illustration of the magnitude of the disruption. The review of the literature conducted at the start of this PhD process did not identify the magnitude of this disruption. The review findings pointed to older adults feeling uncertain and at times vulnerable when required to adapt to a new normal as a result of unplanned readmissions. However, this PhD study presents a deeper, richer understanding of these experiences. Unplanned readmissions acted as a disrupter in the lives of older people and their families and were moments when they reflected on the self and their identity. The accounts shared by participants help to give a sense of what was important to them during their experience of unplanned readmissions.

7.4.1 Embodiment and Disruption

Embodiment

Participants in my study often framed their experiences within the understanding of their own bodies and its functionality which aligns with embodiment theory. In essence, embodiment views bodies as vehicles for our sense of self (Draper 2014) not solely as physical entities, and this is because our bodies and minds are inextricably combined. We experience life, health, and illness through our body (van Rhyn et al. 2021). We cannot separate the body from our sense of self (van Manen 1998) and so when our body does not do what we want or behave the way we expect, our body becomes centred in our mind. In a study of narratives written by older people, Jaggers et al. (2022) describe how personhood is conceptualised by the 'oldest old' who are not experiencing cognitive decline. They note that the older people in their study construct a maintained self throughout the aging process: "*personhood is a continuous state that is not lost but rather negotiated in later life through the construction of the narratives that older adults tell*" (Jaggers et al., 2022, p.3) thus, their sense of self was supported through the stories they told of themselves.

When considering the ageing self, the duality between body and mind can appear more noticeable in so much as the body, as external object, experiences more changes, which may or may not be reflected in how the internal embodied self feels (Gilleard 2022 p.2). This is reflected in recent work by van Rhyn et al. (2021 & 2022) who explored the phenomenology of the body after 85 years. Van Rhyn et al. (2021) found that older peoples' experiences linked to their bodies challenged their sense of self, and noted experiencing their bodies as unreliable, uncooperative, unpredictable and at times unfamiliar, their "previously taken-for-granted body is largely lost" (van Rhyn et al., 2021, p.231). However, additional work by van Rhyn et al (2022) with the same cohort of older people also suggests that when focusing on their self, older age brings evolving ways of being that can be positive, joyful, creative, and resilient. These studies focused very generally on the experiences of being older and did not focus on experiences of health or hospitalisation. The findings from my study suggest that whilst it may be expected for older people to reflect on their aging self and body, experiences of unplanned readmission can push this to the forefront. In Gilleard's study on the ageing body they note the alienation between body and mind can be more pronounced in older age, noting the 'body drop' whereby the "*embodied self is let down and the body fails its duties as the self's agent*" (Gilleard 2022 p.894). There are parallels to this in my study illustrated through the participants' views that unplanned readmissions emphasised their bodies were ageing, that things were changing, and for some the unplanned readmission was identified as a moment of 'body drop'. That is, unplanned readmissions were a moment when the difference between the body and the self was noticed. This could be seen through descriptions of what their bodies could do before and after their unplanned readmissions and this contrast meant they did not feel normal or themselves, the expectations they had of their body were not met; their body had failed as the self's agent.

The negative experience of the ageing body was reflected in other studies that found the body being unreliable or unfamiliar in contrast to people's sense of self (van Rhyn et al. 2021). Whilst this may be disruptive it may also be experienced as a 'normal abnormal' associated with age (Gilleard 2022). Both the disruptive and 'normal abnormal' were experienced by participants in my study. The unplanned readmissions were viewed as an unsurprising part of ageing or even inevitable by some, whilst others did find this harder to accept. This illustrates that experiences of ageing and responses to ill health are varied; thus, experiences of older age are heterogenous.

Thus, as nurses we have a requirement to be aware of this and incorporate it into how we approach our clinical care. Based on this, discussions around personhood among older people can support us in considering how to support older people in clinical practice. In their study of personhood and older people, Jaggers et al. (2022), note that "*the main finding is that all older adults in this study articulate personhood through constructions that illustrate a maintenance as opposed to a reconstruction of self and identity over time*" (p.7). From this work on personhood, a way of supporting older people is to support them to find ways of maintaining aspects of self and identify they have held throughout their life (Jaggers et al. 2022) whilst acknowledging changes that may be occurring to their physical bodies. Increasing opportunities for older people to talk, to tell their stories, can support them to construct their identity and assign meaning and make sense of what they are experiencing, and is a tool for their own self-understanding (Jaggers et al. 2022). Furthermore, Jaggers et al (2022) note the importance of reinforcing the continued value of older people in society. As nurses we could incorporate these moments when we are delivering care. There is no expectation that these moments should necessarily be lengthy so offering opportunities during the delivery of nursing care for older people to identify what is important to them, share how they are feeling, and explore how their qualities and relationships can be maintained during their changing circumstances could make a real difference to how older people feel when experiencing hospitalisation and nursing care.

My study illustrates that unplanned readmissions emphasised the discombobulation and expectations of body brought upon by the clinical reasons for the unplanned readmissions, whether acute or chronic. Thus, unplanned readmissions can be viewed as a feature of chronic illness, and in some instances even acute episodes of illness. A loss of self can occur when experiencing chronic illness, which can stem from sources of suffering that include having a more restricted life, being isolated, ignored, or devalued, and feeling like a burden (Charmaz 1983). van Manen's (1998) notes "*Indeed, it is the broken, disrupted or disturbed relation with the body that seems characteristic of almost all experience of injury or illness*" (p.3), suggesting that all experiences of illness whether acute or chronic have the ability to engender feelings where body and mind are unsettled. Sartre noted our body passes by in silence [« passé sous silence »[3]] until disruption occurs (Draper 2014), that is we may 'forget' we have a body until something does not work as we expect. In my study, unplanned readmissions themselves were identified and viewed as moments that signalled

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[3] Sartre J-P (1943) *L'être et le néant Essai d'ontologie phénoménologique* Éditions Gallimard, Paris, France.

a time of change and bodies were loudly noticed. As noted in the paragraph above this has implications for nursing in how we talk with older people in our care and can prompt opportunities for them to describe what is meaningful to them and by building a therapeutic relationship, support them to have a smoother connection between their body and self.

The intersection between experiences of ageing, illness and of unplanned readmissions had a particular impact on the participants in my study. Unpicking precisely which experiences are linked to which element at this intersection appears challenging. However, nursing has a role in restoring the 'smoothness of forgetfulness' (van Manen 1998) that occurs there. As noted previously, this can occur through thoughtful conversations during clinical practice that gives space to older people to explore their feelings around their self and body. Student nurses and qualified professionals could benefit from awareness of what is meaningful to older people, especially the oldest old, as described in their own words. This PhD study contributes to this, as does other work (van Rhyn et al. 2022), where the diversity, richness, changing identity and inner world of older people are recounted, to help us 'see' older people in their complexity, viewing not from a deficit model but a strengths-based view.

For there to be meaningful person-centred care, nurses must have "*an integrated view of the body and embodiment*" (Draper 2014 p.2239), be aware of the multiple factors influencing this and, be able to nurse in environments that facilitate and support working in a holistic, person-centred manner. This is dependent on healthcare professionals, educators, managers, and policy makers having a thorough understanding of ageism, the impact of ageism on health, theories of ageing, gerontological competence, and, have an ability to critically reflect on care delivery and how hospital processes are organised. These are issues that will be further explored during later sections of this discussion.

Disruption

People's sense of self being affected or disrupted by illness has been written about as far back as 1623 when John Donne described illness as a change in religious faith (Frank 1993). Through the ages, illness has been viewed as a moment to reflect on the self and as a time when changes can be made (Frank 1993). Frank (1993) makes some helpful assertions regarding the different ways disruptions because of illness can result in change, via "cumulative epiphanies" (Frank 1993 p.42), and highlights the embodied experiences of illness, such as when he describes the loss of self-recognition brought upon by illness. However, by viewing illness as solely an individual experience Frank (1993) ignores the disruptions experienced by family how this can impact on both patients and families. Participants in my study noted multiple ways in which they, as patients, were disrupted by their unplanned readmissions and the illnesses associated with these. Additionally, families also experienced disruptions and their own senses of self were impacted upon, for instance in their social roles and by the ripple effect of the unplanned readmissions.

Chronic illness has been conceptualised as a biographical disruption (Bury 1982) but also, similarly to GIlleard's conceptualisation of the 'normal abnormal' disruptions associated with illness or hospitalisation, can be viewed as part of one's "*on going life story*" (p.244) as in Faircloth et al's 2004 work on exploring experiences of stroke recovery. The disruptive nature of unplanned readmissions is consistent with disruption experienced from chronic conditions or hospitalisations and has been noted in other work on unplanned readmissions among a broader age group (Considine et al. 2019). With unplanned readmissions being a feature of a chronic illness for some, or, associated with a specific episode of acute illness, it would appear reasonable that unplanned readmissions would be experienced and perceived as disruptive in a similar way that chronic illness or acute illness can be. Compounding this disruption was the misaligned expectations and needs experienced by participants in my study, viewed through challenges with communication, both written and verbal, and the expectations around care not being met, which will be explored in the section below. Whilst the disruptive nature of unplanned readmissions was a finding generated through the literature review conducted at the start of this PhD study (see Chapter 2) the full extent of the misalignment of need was not captured in such a rich manner by the literature review. For instance, the included studies noted patients questioning their readiness for discharge and communication challenges centring around feelings of powerlessness and being disregarded, this PhD study goes further, pulling together a richer picture of these misaligned expectations and needs from both the patient and family perspectives.

Discharge from hospital

The timing, processes and communication surrounding hospital discharge were widely discussed by the participants in this study when referring to the experiences of unplanned readmission. An emphasis on discharge planning and enabling shorter stays in hospital appear to be a current policy focus, especially in discussions around care of older people, whilst unplanned readmissions no longer appear at the forefront. As part of this is a push for personalised care and shared decision making across the whole patient population (NHSEI, 2019). One of the aims is to support people to stay well in their home or care home and reduce time spent in hospital (NHSE, 2019). A central tenet of personalised care is that care is planned, and delivered based on ‘what matters’ to them, and this is set within an integrated system of care and support (NHSEI, 2019). More recently, a new national discharge taskforce has been established (DHSC, 2022), they will contribute to the refresh of the Long Term Plan (NHS, 2019). One of their first outward facing activities has been to encourage hospitals across the system to put into practice ten best practice initiatives as part of a ‘100-day challenge’ (NHSE, 2022). This is a set of processes or initiatives that NHS England is asking different Trusts to implement for 100 days and report on how they have impacted on the hospital discharge process. Viewing these suggested initiatives in the context of findings of my study I note a lack of emphasis on providing holistic care to patients and supporting healthcare professionals to provide this and instead focus on a set of management tasks. Whilst the implementation of these initiatives may in reality incorporate holistic person-centred care, this does not appear to be a priority in the policy documents describing the ‘100 day challenge’. In addition, some of the proposed initiatives are already recommended practice that, despite this recommendation, do not appear to have been experienced by the participants in my study: *1. Identify patients needing complex discharge support early; 2. Ensure multidisciplinary engagement in early discharge plan; 3. Set expected date of discharge (EDD), and discharge within 48 hours of admission*. Thus, the call for personalised care and shared decision making does not appear to be reflected in the guidance surrounding the ‘100-day challenge’ which is purported to support and improve discharging patients from hospital. Nor do these initiatives appear to consider how hospital-based staff will implement and provide appropriate personalised care, what unmet need may exist, and they do not address wider issues in healthcare, such as the workforce crisis.

The 100-day challenge is part of a long list of different approaches that have historically been put together to increase flow through the hospital system, enhance patient discharge, and ultimately have as one of their desired outcomes a reduction in unplanned readmission. These approaches include: having discharge coordinators, shared decision making, discharge checklists, and productive ward. However, these approaches do not fully address or make space for some important factors that patients and families have raised in this study: a need for effective communication, collaboration, and an understanding of processes and decisions, and feeling more in control of the situation. In addition, there is a lack of clarity over how any suggested policies should be implemented. This suggests a need to move away from searching for a "silver bullet" checklist to reduce unplanned readmissions, instead focusing on how we plan, deliver, and assess nursing care. Within this, the misaligned and at times unmet needs of patients and families should be focused on to address the needs of 'embodied beings' as opposed to 'objects who have bodies' (Draper 2014). The issue of misaligned need is not the problem of older people or their families, the problem is the system we are nursing and providing health and care in. As noted by Dahlke et al (2021): "*Healthcare systems are designed for younger people, emphasising efficiency and quick turnover, and do not consider the complexity of older people's health and social concerns*" (p.2). Thus, systems that promote a more holistic approach to the care of older people, such as ambulatory care units, where there is the potential for older people to spend more time with health care professionals and build relationships (Herrler et al. 2022b; Herrler et al. 2022a) could be implemented more widely whilst ensuring healthcare professionals there have appropriate gerontological competencies. This will be further explored in sections below on age friendly and family centred care of older people.

The current NHS system is also in a state of regular change, the most recent of which is the advent of Integrated Care Systems (NHS England 2022d). Their purpose, on paper, is to improve outcomes in population health and healthcare, tackle inequalities in outcomes, experience and access and narrow the gap between the NHS and social care (NHS England 2022). Whilst integration was not specifically mentioned in my study findings relating to communication, a catalyst for change and organisational pressures makes this a topic worthy of a brief mention. A lack of integration has been noted as a cause of readmission (Singotani et al. 2019) so more integration between health and social care is to be welcomed; however, we are yet to see what impact this will have on patients and their families in practice. Furthermore, whilst community-based resources and integrated care are important factors, all the studies included in Singotani et al's systematic review of causes of unplanned readmissions (2019) reported causes related to the organisation of care within hospitals, so it is pertinent to focus on what happens in hospitals, as this PhD study has. Thus, any future planning should incorporate the hospital-based experiences of older people and their families.

7.5 Unplanned readmissions and the ripple effect: Implications

This study provides the chance to view unplanned readmissions from the perspective of patients and their families, moving from problematising these events to exploring their meaning. Ageism drives perceptions that ageing is a problem; however, shifting from problem to opportunity offers advantages for all generations (Kagan, 2022). Thus, exploring unplanned readmissions from the perspective of patient and family experience is a valuable opportunity in the context of healthcare delivery and allows us to consider how we as nurses can make a positive difference to patients and their families by incorporating what is meaningful to them.

7.5.1 Unplanned readmissions as more than a discrete event in time with impacts that ripple out

The findings in this study suggest that multiple elements come together in participants' accounts of their experiences and perceptions of unplanned readmissions. Patients and their families referred to moments before, during and after their unplanned readmission. This suggests that there is much more to unplanned readmissions than the specific event of returning to hospital. This contrasts with how unplanned readmissions have been viewed to date with a focus on counting them as opposed to exploring how patients and others experience them (Taylor and Davidson 2021). A recent concept analysis conceptualised unplanned readmissions among older people as "*an experience, process and event*" (Coatsworth-Puspoky et al. 2021, p.1) which mirrors the findings in this study. My study supports this conceptualisation with empirical data whilst adding to the conceptualisation.

Coatsworth-Puspoky et al.'s (2021) concept analysis was based on published literature and included older people aged 60 and over. The antecedents were a lack of symptom stability, lack of support, lack of knowledge, and a lack of safety. The attributes of an unplanned readmission to hospital include the previous hospitalisation, an urgent or emergent health crisis and a need for acute care. The consequences include recurrent readmissions, longer hospital stay, decreased confidence, unintended consequences, and positive consequences such as decreased caregiving burden and regained control over symptoms. The findings from this concept analysis are welcomed as they reinforce the need to conceptualise readmissions more holistically and value the experiences of older people. This could be done by reinforcing gerontological competencies in education and clinical practice. There is a current dearth of experience and targeted programmes within the NHS are not sufficient to address this (Dahlke and Hunter 2022). Dahlke et al (2022) note that "*By failing* *to recognise gerontological nursing expertise as essential across settings, the importance of nurse-older person interactions in other settings is minimised, including in acute care*" (p.5) and the experiences of older people outlined in this study suggest the need for there to be gerontological competence across care settings, especially in medical and acute areas.

However, Coatsworth-Puspoky et al (2021) conceptualisation of unplanned readmissions does not show the fullness of the experiences reflected in my study. My study adds a more holistic perspective by including the family and points to burdens that ripple out from the individual patient – family unit into the social and professional sphere. Whilst Coatsworth-Puspoky et al (2021) note unplanned readmissions can lead to patients feeling they have regained control over their symptoms, my study goes further by extending this idea and identifying the role unplanned readmissions can play as keys to unlocking further care and support.

The economic impact of unplanned readmissions is well described in terms of their "cost" to health systems (Jencks et al., 2009; Conroy & Dowsing 2012; Mitsutake et al., 2020); however, my study points to the financial burden of unplanned readmissions on patients and families, which forms part of the ripple effect. The financial burden on caregivers has been noted previously; Chou (2000) incorporates financial problems within their concept analysis of 'caregiver burden'. More recently Ufere and colleagues (Ufere et al. 2021) identify financial hardship as an issue for caregivers who have family involved in care transitions, which includes readmissions. However, their USA based study notes financial hardship related to insurance pay outs. A recent report by Carers UK (2022) highlights the precarious situation many caregivers find themselves in citing that 16% of caregivers are in debt because of their role. My study, set within the public NHS system, reflects these findings, highlighting the financial impacts of unplanned readmissions, for instance in relation to lost earnings and paying for hospital parking, that can be experienced by families of patients being readmitted. Initiatives that support families to have free parking, as can currently be the case for those having chemotherapy, could be extended to families in the situations outlined in this thesis. In addition, nurses could use their trusted voices and role as patient advocates to raise these concerns with their organisations and wider society to promote the development of short term, easy to access paid carers leave. Importantly, any potential responses to this issue should be co-developed with older people and their families to ensure they respond effectively and appropriately to their needs.

7.6 Key to unlocking care and support: Implications

The richness and depth of the experiences and perceptions of unplanned readmissions enabled the nuance around these experiences and perceptions to be illuminated, highlighting the fact they can be viewed as a key to unlocking care and support. Constructivist paradigms embrace nuanced accounts and recognises the contribution to knowledge they can afford (van Rhyn et al. 2022). The literature review conducted at the start of the PhD did not capture this nuance. Whilst the notion that hospital could be viewed as the only safe space was recognised, the literature review did not describe any detail around this. This suggests, that for the participants of my study situations were required to reach certain crisis points before further care or support could be 'unlocked', the implications of this will be discussed below.

7.6.1 Unplanned readmissions experienced as a catalyst for change

Within my study unplanned readmissions were ascribed a positive meaning when they acted as a catalyst for change. For instance, when they were viewed as key to unlocking further tests, information, care or support they were viewed as positive or useful despite experiences of them that could be negative or challenging. A recent study on the impact of hospitalisation on older people refers to hospitalisation as having a ‘turning point’ in patients’ lives (van der Kluit and Dijkstra 2022). These could have positive outcomes and prompted the study authors to question hospital avoidance policies (van der Kluit & Dijkstra 2022). As previously noted, the general conceptualisation of unplanned readmissions views them as a problem to be tackled. However, expanding our understanding of them by viewing them from the perspectives of patients and their families enables us to see how they can be suggestive of unmet need that could be addressed via holistic nursing care and asks what it is in the current healthcare system that means it takes an unplanned readmission to prompt this unlocking of further care or support. These experiences are consistent with the Dahlke et al (2021) analysis of health systems who suggest that “*Healthcare systems are designed for younger people, emphasising efficiency and quick turnover, and do not consider the complexity of older people’s health and social concerns*” (p.2). Furthermore, Dahlke et al (2021) note that this leads to the systemic exclusion of older people in healthcare organisations as they are organised to treat people quickly and focus on single, acute episodes as opposed to holistically treating older people who may have chronic as well as acute needs. This suggests that the systems we are nursing in are not conducive to providing the holistic person-centred care older people and their families need. Challenges to providing holistic, person-centred care have been recognised. Barriers include characteristics of nurses at the individual level, such as their personal values and beliefs or their commitment to the role (McCormack and McCance 2016). Furthermore, targeted education and training around gerontological nursing competence can support individual nurses with relevant skills and attributes, this will be described more fully later in the chapter. However, whilst these individual characteristics can be impactful on the provision of person-centred holistic care, it is recognised that the care environment itself needs to be conducive to providing holistic person-centred care (McCormack and McCance 2016). Issues such as skill mix, opportunities for shared decision making, the physical care environment (McCormack and McCance 2016), and a lack of time (Oppert et al. 2018) are all system level factors that impede on the provision of optimum care. Deficits in these systems reduce opportunities for patients and families to engage meaningfully with healthcare systems. However, ensuring staff are equipped with gerontological nursing expertise to facilitate nurse – older people interactions (Dahlke et al. 2022) alongside addressing these system factors can support the provision of appropriate age friendly care. More specific recommendations to deliver this will be outlined throughout the rest of this chapter.

7.6.2 A crisis point in care

As described above, the findings from my study suggest care and support were ‘locked up’ for older people and that a crisis point, an unplanned readmission, was often necessary to receive appropriate care. Knowing that there is propensity for health systems to ‘blame’ older adults for their situation, as seen in the use of the term ‘bed blocker’ (Senger, 2019; Flores-Sandoval & Kinsella, 2020) it is valuable to consider the potential for discrimination to be a barrier to care access for older people. Flores-Sandoval & Kinsella (2020) suggest advanced age is a barrier to quality care and can impact on the interactions older people have with healthcare services, their levels of satisfaction and even bring some older people to avoid accessing healthcare. In addition, Chang et al. (2020) found that health-care providers were more likely to withhold life-sustaining treatments from older adults, in comparison with their younger counterparts. Furthermore, older adults' exclusion from health care research is affected by ageism (Flores-Sandoval and Kinsella 2020). Thus, this research is important in and of itself as it centres the experiences of older people and showcases their needs, these issues and the implications for nursing will be further addressed in the section below.

7.7 The experiences of older age: Implications

The lived experience of old age is a valid form of knowledge of ageing (Carney and Gray 2015) and is an important dimension of experience, as is gender, race, and class, however, "*age has received much less attention from researchers*" (Carney & Gray, 2015, p.124). This study contributes to increasing this attention by illustrating the experiences and perceptions older people had of their unplanned readmissions to hospital. The participants in my study shared their first-hand accounts of being older, accessing healthcare and what this felt like for them which contributes to diversifying the narrative around older age. Carney and Gray (2015) describe a discrepancy between lived experience of ageing and societal expectations, and there are parallels to this around expectations of care provided to older people and what they experienced as illustrated in the theme on misaligned expectation and need. Van Rhyn et al. (2022) asserts that current research does not fully capture the embodied experiences of those aged over 85 years and goes on to note that much of the knowledge on older adults accessing healthcare still remains biomedical in focus. This PhD study, where over half the patients were aged 85 or older, contributes to further capturing and enriching what we know about the experiences of older people in healthcare.

Amplifying the first-hand accounts of older people, as they have been reported in this study, can reduce homogenous perspectives of ageing (van Rhyn et al 2021) which has the benefit of aligning with the person-oriented values of nursing. Homogenous perspectives of ageing can contribute to ageism, which, has far reaching impacts on people's health (WHO 2021b). Thus, there is inherent value in exploring embodiment and disruption in the context of unplanned readmissions to hospital amongst older people and their families. Critical gerontologists assert that this knowledge has value in and of itself, and in addition, by *"making the lives and perspectives of oppressed groups visible, such as older adults affected by ageism, is key for the facilitation of social change*" (Flores-Sandoval & Kinsella, 2020, 227). To think about the implications of this for nursing practice, research, education and policy, it is important to consider ageism, and this will be discussed below.

7.7.1 Ageism and the impact on health

As noted previously the participants in this study were required to reach a certain crisis point, an unplanned readmission, in order to unlock care. Furthermore, as mentioned there is evidence in the wider literature to suggest that older people may experience systemic exclusion in healthcare settings, due to their particular needs not being properly addressed by the way care is often organised in these settings. The focus on speed, on flow, and on individual illnesses or conditions can adversely affect the care provided to older people (Dahlke & Hunter, 2022), thus, it is important to consider whether the experiences of the older people in this study were affected by ageism.

Definitions of ageism

Ageism occurs when age is used as a factor to categorise people and this leads to harm, disadvantage, or injustice (WHO 2021b). In addition, unlike other forms of discrimination, we all have the privilege and potential to become older people, so ageism has also been conceptualised as "*the social discrimination we wage against our future selves as we levy* *it on others*" (Baumbusch et al., 2022, p.A1). Ageism harms both individuals and global health and counters the opportunity for ageing in a positive holistic manner (Baumbusch et al. 2022). Furthermore, when considering the intersection of age with other factors, ageism can compound other forms of discrimination (Baumbusch et al. 2022). Within healthcare, the structural impact of ageism leads to a biomedical approach, that views older people as having a list of problems and what matters to them is missed or overlooked. In addition, this approach is not in alignment with the nursing approach that prioritises holism, care, compassion and views the people in our care in a holistic manner (Baumbusch et al. 2022).

Nurses may well hold ageist views which can impact on the care they provide, this can include 'benevolent ageism' and present as a paternalistic attitude or behaviour (Dahlke and Hunter 2022) and viewed, for example, through 'elderspeak' that is pervasive in healthcare settings (Flores-Sandoval and Kinsella 2020). Elderspeak is defined as *"an inappropriate simplified speech register that sounds like baby talk and is used with older adults, especially in health care settings"* (Shaw & Gordon, 2021, p.2). This can include using a singsong voice or using terms such as 'love' or 'dear'. In some instances, it may be used in an attempt to tailor communication to the needs of older people, however this is misguided, underpinned by ageism, and is perceived as patronising by older people and can in fact hinder communication (Shaw and Gordon 2021). Ageism can impact on nurses' ability to adequately and appropriately assess and manage the care of older people which can have knock on negative effects on the health of older people (Dahlke and Hunter 2022). There is some evidence of this negative effect occurring within the findings of this PhD study with the assertion by participants that they at times felt like a burden. Conversely if nurses have positive perceptions of older people, they are more likely to meet the needs of older people

(Dahlke and Hunter 2022). In their study Dahlke & Hunter (2022) noted that "*Those with positive attitudes towards older persons were also more likely to engage in high-quality interactions with them. Thus, positive intergenerational relations and positive perceptions towards older people might be healthy and beneficial for the whole society as well as our public health*" (Dahlke & Hunter, 2022, p.3). In addition, ageism can be self-directed and internalised by older people themselves (Flores-Sandoval and Kinsella 2020) with conscious or unconscious stereotypes affecting both the cognitive and physical functioning of older people (Dahlke et al. 2021).

Theories of ageing

The findings constructed as part of this PhD study contribute a rich, nuanced understanding of the experiences and perceptions older people and their families had of their unplanned readmission to hospital. The issues raised also complement and add to the findings from the literature review. When considering the implications of these experiences for nursing practice, education, research and policy, the issues of ageism, and different theories of ageing need to be explored as these can reinforce stereotypes of older people and inadvertently be underpinning nursing practice. For instance, this can be seen in the propensity for older people to be held partly responsible for their needs when the issue is insufficient capacity in the healthcare system (Flores-Sandoval and Kinsella 2020).

Different theories of ageing: Deficits vs Strengths

Successful and healthy ageing

The concept of 'successful ageing' is still uncritically accepted in much mainstream culture (Dahlke and Hunter 2022) and is viewed as the normative ideal (Liang & Luo, 2012). This theory of ageing, which is common in the biomedical approach, puts the onus on individuals to take action to avoid what is perceived to be normal ageing decline. Both the World Health Organisation (WHO) and NHS in England refer to ’healthy ageing’ when referring to the care of older people. The WHO definition describes a more holistic approach than described in the concept of successful ageing, defining healthy ageing as “*the process of developing and maintaining the functional ability that enables wellbeing in older age*” (WHO 2021b). This definition does recognise the impact of wider systems and the need for enabling environments to support older people in their functional ability. However, there is a risk with this definition that the interpretation of it and its delivery could continue to focus on specific ‘activities’ or ‘tasks’ as opposed to inherently valuing older people for who they are. For instance, NHS guides on ‘healthy ageing’ (NHS England & Age UK, 2018b) and ‘healthy caring’ (NHS England & Age UK, 2018a) focus on problems to be solved as opposed to celebrating older people’s inherent value. Whilst these guides are useful in their inclusion of practical steps and signposting to specific places for support, the connotation could still appear be that ageing is a problem to be solved.

The concept of successful ageing does not account for other social structural situations such as poverty or trauma, nor does it account for the intersections of gender, race, or class with age. Essentially successful ageing does not recognise the diversity of experiences of older people and does not account for the impact of socio economic and socio demographic factors (Liang and Luo 2012). Additionally, the concept of ‘successful aging’ can perpetuate negative stereotypes and has a very individual focus (Flores-Sandoval and Kinsella 2020). Active ageing is another term that can sometimes be used alongside successful ageing. The definition of active ageing states *“Active ageing is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age”*

(WHO, 2002, p.12). Within this definition the opportunities for health and participation are not limited to being physically active, however, there is a real focus on autonomy and independence. The idea of active ageing has similar connotations and both van Dyk (2014) and Flores-Sandoval & Kinsella (2020) refer to the problematic nature of both these theories of ageing citing them as being ageist and oppressive. These viewpoints essentially view ageing as a series of problems presented by older people who need help, thus ageing is seen as a set of issues or disabilities that lead to loss or a lack of independence, with independence seen as the ideal (Carney & Gray, 2015). Prioritising autonomy and independence in this way can be problematic, not everyone will have the ability or desire for this, furthermore this can appear to devalue social support and those accessing it. Liang & Lui (2012) note that "*Feminist gerontologists challenge the patriarchal nature of successful aging and point out that the implicit code of success is, in fact, based on a White, heterosexual, middle-class, male standard*" (p.328) which underlines how restricted this view of ageing is and how there may be challenges to not fitting into this category. The concept of successful aging can inform how care is planned and organised and what expectations are put on older people, it also overlooks the 'adaptability and ingenuity of older people' (Carney & Gray, 2015) and what their own values and priorities may be. Holism is in keeping with gerontological nursing and should be reinforced (Dahlke and Hunter 2022), thus, instead of advocating for 'agelessness' we need to embrace our disciplinary values in nursing, which includes holism, and embrace ageing. This can be done through viewing ageing in a harmonious manner, as will be outlined below.

Harmonious ageing

The experience and perception of unplanned readmissions outlined in this PhD study point to these experiences having wide ranging impacts that ripple out across time and into wider society. The impacts were experienced individually, through older people as embodied beings, and as families. Thus, these findings resonate with a life course perspective on ageing that recognises that older people are social beings, influenced by the social determinants of health and their environment (Dahlke & Hunter, 2022). Furthermore, the Assertions created about the Quintain were based on the experiences of a range of older people who had different chronic or acute conditions, and in different family set ups, underlining the heterogeneity of older people.

The concept of harmonious ageing allows for such a holistic perspective and reinforces the need for care to person centred. Harmonious aging, as defined by Liang and Lui (2012) is "*inspired by the Yin–Yang philosophy. Harmony refers to the balance based on differences instead of uniformity. This new discourse aims to recognize the challenges and opportunities of old age itself, ease the tension between activity and disengagement theories, heal the integrity of body and mind, and emphasize the interdependent nature of human beings*" (p.327). This supports a move away from ageing needing to be 'successful' to being harmonious where body and mind can have a more harmonious relationship (Liang and Luo 2012), where the challenges are not the focus, rather there is a striving for balance and relationships, and looking towards opportunities, and harmonious ageing captures the diversity of ageing across cultures. Within this theory of ageing, systems that allow for individuals to define their view of ageing, their own needs, and the be part of deciding what health care they desire are prioritised, the older person is situated within the relationships that are important to them and their social contexts (Dahlke and Hunter 2022). Harmonious ageing also appreciates the heterogeneity of older age and the differing experiences older people can have and celebrates both the challenges and opportunities that older age can bring (Liang & Luo 2012). Furthermore, further than just noticing the heterogeneity of older age, harmonious ageing theory incorporates cultural differences to ensure inclusivity and balance. This occurs through an understanding and awareness of how body and mind coexist. Similarly, by recognising and appreciating the multiplicity of family and social relationships that exist it can be inclusive to those from a variety of backgrounds. Liang and Luo (2012) note that "*It is a dialectic and holistic aging discourse that allows for cross-cultural dialogue and application*" (p.333) and thus, can be adapted to societal change. Experiences of unplanned readmissions, as outlined in this PhD study, appear to have been a non-harmonious episode. By highlighting the ripple effect of the impacts of unplanned readmissions, and incorporating family perspectives, this aligns with taking a harmonious ageing perspective which stresses the importance of viewing body and mind as integrated and recognising and appreciating difference.

The implications of different perspectives on ageing are the impact they have on care design and delivery. Currently, a deficits-based approach appears to be prioritised where it takes a crisis point for solutions and care to be unlocked, as illustrated through the findings of this PhD. The current system is not built to incorporate or give space for a harmonious approach to ageing and it appears that older people are disadvantaged when accessing healthcare. Furthermore, there is a gap between how older people experience older age and the societal expectations that people have of older people, referred to as "elderly mystique" (Carney & Gray, 2015, p.124) and social policies are thus contradictory and do not provide the care needed by older people. This PhD study, by centring older people, through highlighting their experiences of unplanned readmissions and the impacts of these experiences on them and their families, as well as noting their misaligned needs, can support a move to age friendly, family centred care. A greater understanding about the diversity of ageing and the contexts influencing older people can support nurses to treat them holistically and with dignity (Dahlke & Hunter, 2022, p.1) and support improving the experiences of older people.

7.7.2 Care of older people

The findings from this study indicate older people and their families experienced misaligned expectations and needs, faced communication challenges throughout their healthcare journey and had expectations around being cured that were not always addressed; elements of this were identified as part of the literature review (Chapter 2). However, my study provides rich, detailed understanding of these experiences, adding nuance and depth to our understanding of older peoples' experiences and perceptions of unplanned readmissions. Furthermore, the family experience is also captured. In addition, insights co-created as part of my study identify that patients and families viewed unplanned readmissions as a key to unlocking further, and much needed, care and support. These findings are indicative of 'care poverty' as described by Kröger (2022) who views care "*as concrete assistance given to older people in order to meet different kinds of care needs*" (p.50) and outlines three domains of care poverty: personal care, practical care, and socio-emotional care. The findings from my PhD study suggest older people and their families experienced care poverty in the domains of practical and socio-emotional care. Practical care includes tasks linked to everyday life, similar to activities of daily living, including taking medication (Kröger, 2022) or being supported to mobilise and move. Socio-emotional care refers to social and emotional aspects of life with loneliness an expression of this care deficit (Kröger, 2022). Kröger (2022) also refers to psychosocial care needs, which includes effective communication and a feeling of belonging for older people.

Age friendly health systems

The findings from my study, alongside the exploration of ageism, theories of ageing and the implications of these for nursing, are an invitation to explore what we mean by care of older people and quality nursing care. Two of the action areas of the UN Decade of Healthy ageing revolve around healthcare (WHO, 2021d) and demonstrate the international strategic focus on care of older people. Similarly, the age friendly movement includes healthcare as a specific area for action and calls for age friendly health systems. It is a reality that older people are at higher risk of injury, however the fault is not the older person's rather the problem lies in the system (Kagan, 2022). Thus, there is a need to explore what systemic approaches can be developed to support high quality care for older people in healthcare settings. This will be examined below through a discussion of Age-friendly health systems (IHI, 2020), Age friendly hospitals (Kuo and Chen 2019), Integrated care for older people (World Health Organisation 2022), and a selection of current NHS based examples of integrated health and care for older people (NHS England 2022b; NHS England 2022a).

Age friendly health systems are intended to address some of the issues faced by older people and support the provision of quality care for older people by using evidence-based practices, causing no harm, and aligning with what matters to the older adult and their family (IHI, 2022). This is implemented using the '4Ms' framework which was developed in the USA. The organisation of care comprises of the 4 'M's' standing for: what **M**atters, **M**edication, **M**entation and **M**obility (IHI, 2020). There are suggested assessments to use to understand the medication, mentation and mobility requirements of the older person receiving care. The intention is that healthcare organisations should organise their resources to deliver care that aligns with this framework. This framework has received support from senior nurses (Cacchione 2020) and policy makers (Mate et al. 2018). However, whilst some detail and evidence surrounding how to complete a 'what matters' assessment exists (Laderman and Jackson 2019) how this 'fits' into the reality of care delivery is less clear. For instance, there is no clarity over who should be having this conversation with older people, and how the outcomes of this conversation should impact on care and any competing priorities. Furthermore, there is little detail over how often these conversations should be occurring. The findings in my PhD study, especially the finding regarding misaligned expectation and need and challenges with communication, suggest understanding what matters to older people is precisely an area that needs development. Asking older people 'what matters to you' is a good focus for care, and there are examples of successful implementation of such strategies within a ward environment which had a positive impact on the delivery of person-centred care (Robertson and Fitzpatrick 2022) however structure and training is required for these conversations to be successful (Rogn Nilsen et al. 2022) and how this can be implemented at scale is yet to be seen. Thus, the 4M framework is welcomed as it centres the needs and experiences of older people, however, its potential in an NHS context would need further research and exploration with the potential for the 'what matters' component to be developed further.

The WHO has suggestions for the provision of quality care to older people in the form of age friendly hospitals, Kuo and Chen (2019) found that certification as an age friendly hospital improved the attitudes of staff towards older people, however the impact on older patients and their families was not captured. More recently, as part of the work towards the UN decade of healthy ageing the WHO has advocated for the development of integrated care for older people (World Health Organisation 2022). They are still in the initial phases of the development of this care model and early feedback on the pilot programme suggests that care integration is welcomed however there are substantial needs for capacity in the system in the form of time, education, and skill development (World Health Organisation 2022). Integration of care is also an approach mirrored in the English NHS. The advent of ICS is further strengthening these approaches. Two recent case studies highlight some of the benefits. A hub approach in Wakefield, West Yorkshire (NHS England 2022b) sees a team of social care and health professionals sit together to coordinate care, they triage referrals and can send out dedicated urgent care teams and community matrons. The idea is to reduce hospital attendance and provide the right care to the right person in the right place. In Birmingham, a coordinated approach from the NHS, social care, local authority and other partners work together to provide an early intervention service to plan and coordinate care and support for older people (NHS England 2022a). This service can be triggered by an admission to hospital or after an ambulance call out. Both approaches involve integration of care with the aim to reduce duplication and confusion and support older people to only need to tell their story once. The move to a more integrated approach where communication between professionals is to be welcomed especially if this improves the communication received by patients and their families. Furthermore, these approaches have the potential to reduce the number of ‘crisis’ points older people may experience thus reducing their need for multiple unplanned readmissions. Thus, they could be a helpful ‘key’ to unlocking care and support that the participants in my study appeared to need and would reduce the need for unplanned readmissions. However, they do not focus on the specific care provided in hospital rather they rely on specific professionals to go in and assess and support older people.

Challenges and enablers of providing age friendly care

The above has outlined some evidence-based approaches to providing age friendly care in hospital settings and in the wider health system. The implementation and delivery of these approaches remains challenging due to a variety of factors, some of which will be addressed in the section below outlining quality nursing care. A recent study from the perspective of clinicians, management and academics on the delivery of age friendly hospital care (Mudge et al. 2021) outlines some challenges to the provision of age friendly care that could explain some of the findings of this PhD study. Mudge et al (2021) found that family could often be invisible to healthcare professionals and require confidence and health literacy to be heard. In addition, the professionals studied by Mudge et al (2021) noted there was often a transactional approach to engagement with family focusing on information exchange as opposed to true shared or partnership decision making. In England, both NICE (2015b, 2015a) and the NHS (2019) promote shared decision making as a component of providing person centred care to older people. However, as is evidenced in the findings of this PhD study this does not appear to be happening in practice. In addition, there do not appear to be any updates or additional guidance from NICE since 2018, highlighting a gap in knowledge around the reality of the implementation and delivery of person-centred care in the NHS. Furthermore, recent studies exploring how older people experience person centred care report that there is still a need for person centred care competence in clinical settings, healthcare administration and health policies (Nilsen et al., 2022). In addition, health care professionals need to be mindful of not oversimplifying individual preferences (Nilsen et al., 2022) and need to ensure the holistic consideration of emotions and life experience are included in sharing decision making (Marriott-Statham et al. 2022). Unfortunately, there appears to be a dearth of evidence surrounding what person-centred care competence should look like (Ekman et al. 2020) which is affected by the multiplicity of definitions of person-centred care. According to the Nursing and Midwifery Council (NMC, 2020) person centred care involves thinking about what makes each person unique and doing everything you can to put their needs first, it involves working with not doing to. In practice, this requires excellent communication skills, making time for people, seeing the whole person as opposed to a condition or illness, and taking the time to think about wider needs (social, psychological, spiritual). Advice for how to deliver person centred care when time is constrained is outlined and includes sharing a quick smile or kind word, explaining why the situation is busy, and apologising if you have made any assumptions. This definition and guidance from the NMC (2020) does not appear to satisfactorily account for or address the current clinical landscape, though it is helpful to have time pressure acknowledged as a barrier.

Thus, despite strategic and clinical understandings of the need for person centred care that addresses the needs of older people, the delivery and implementation of this care is challenging, and is a barrier to the care and support needs of patients and their families being ‘unlocked’ earlier in their healthcare journey.

7.7.3 Quality nursing care

Extending the discussion above exploring the care of older people by examining what constitutes quality nursing care is essential. The patients and families in this study crossed different boundaries during their healthcare journey, being moved between departments or teams during their time in and out of hospital. This is a further prompt to consider a move away from specific pathways or specialities and explore quality nursing care across the system.

Ideally, quality nursing care is provided within environments where workloads are person centred (Nilsson et al 2018), that is, where the skill mix and workload are not stretched, and where professional nursing practice can thrive for the benefit of patients, their families, and the wider system. Within the UK and NHS, to provide quality nursing care, nurses must adhere to our professional code of conduct, and maintain professionalism (NMC, 2018b). Patient experience forms an important element of quality care and therefore responding to these experiences should be central to nurses' professional conduct. Furthermore, nursing work is complex, comprising physical, emotional, cognitive, and organisational components (Jackson et al. 2021), and requires safe and supportive environments to enable nurses to practice to the full extent of their education (WHO, 2021a). To be safe and supportive, clinical environments need to have adequate staffing levels with the appropriate skill mix and resources. Without having these staffing levels there is also a real risk posed to patient safety and care being left undone (Ball et al. 2014; Recio-Saucedo et al. 2018).

Professionalism in nursing supports the provision of person-centred care, however, environmental challenges exist to this delivery, including if there are issues with the skill mix, a lack of resources, reduced opportunities for education and professional development, or an undervaluing of nurses (NMC, 2018a). The work environment and culture can affect nurses understanding of their role and can impact on their work engagement (O'Rourke, 2021). In addition, interpersonal interactions are central to the role of the nurse, and the quality of these interactions are crucial to positive patient experiences (O'Rourke 2021). Currently within the NHS there is a serious and growing workforce crisis. This has not come out of a vacuum and there has been a workforce crisis for many years, though Covid-19, Brexit, and points-based immigration rules have accelerated this issue

(Oliver 2022). The recruitment, retention and wellbeing of nursing staff is severely threatened. Nurses account for over a quarter of the NHS workforce in England (Appleby 2019) and whilst calculating the precise shortfall in nurses is challenging and debated (Appleby 2019) recent figures suggest there will be a shortfall of around 38,000 FTE nurses within the NHS by 2022/23 (Shembavnekar et al. 2022). This workforce crisis is being cited as one of the biggest threats to being able to provide quality care and services to people who need them (Oliver 2022). It also suggests that nurses have long been working in highly pressured and understaffed environments, where providing holistic person-centred care is severely challenged. As described in Chapter 5, some of the contextual factors described here align with the study context. This collective case study occurred during winter pressures where there was considerable stress upon the healthcare system. There was a definite focus within the study site at the time to reduce the amount of time people stayed in hospital beds and a pressure to discharge patients. The study findings need to be appreciated in light of this. Thus, the ability of nurses within this collective case study to provide quality nursing care may have been challenged and explain some of the experiences of patients and families.

Whilst each registered nurse has a duty to uphold the NMC Code (2018b) and provide care in a professional manner (NMC 2018b), challenges to this can also be explained by power relations that exist within healthcare settings. The knowledge of processes and hospital routines is a form of power that nurses have in healthcare settings (Dahlborg et al 2018), and must be acknowledged, however the organisation of work within hospital can be a challenge to nurses providing the care to patients that aligns with nursing values of personhood and holism (Baumbusch et al. 2022). Providing person centred quality focused care to older people can be impeded by the competing demands of throughput which emphasises length of stay, waiting times, and patient discharge (Mudge et al. 2021). Aspinall et al (2021) noted the emphasis on moving patients through a system meant nurses shifted away from a focus on building therapeutic relationships to prioritising tasks and efficiencies. Similarly, Mudge et al (2021) found that care of older people was viewed as complex and disruptive to systems arranged with task-driven pathways. Hospital systems have been conceptualised as harmful to older people (Parke and Hunter 2014). For Parke and Hunter (2014) this is partly due to the orientation hospitals have to resolve acute issues as quickly as possible. The processes nurses work in are confined by this, with cultural habitual practices and task-based approaches becoming the norm over holistic nursing care. For instance, the culture within the hospital system ends up viewing older people as the problem as some may require more time (Parke and Hunter 2014). Griscti et al (2016) posit that the biomedical hospital system is a patriarchal system and that this is what impedes nurses to provide optimum care. Within this system nursing knowledge and expertise is not valued (Aspinall et al. 2021) and the focus remains on disease management and compliance over patient experience and empowerment (Aujoulat et al. 2008). Whether conceptualised as patriarchal, biomedical, or cultural the ideas are complementary: A task based, bureaucratic approach to the organisation of care with an apparent prioritisation on flow, is detrimental to the delivery of high-quality holistic person-centred nursing care to older people. This is reflected within the findings of this PhD study when older people and their families perceived their unplanned readmissions and the care they received as affected by inadequate resources and management priorities. Furthermore, they noted they at times felt like a burden. Thus, the approaches to care outlined above can affect nurses' abilities to provide holistic care and patients and their families can feel the impact of this.

A realist synthesis of evidence explored to support the delivery of dignified care to older people suggests a set of principles that should underpin this care (Dickson et al. 2017). Central to these principles is the requisite for nurses to truly listen to the older people in their care for instance by using appreciative enquiry to build relationships. These conversations need not be lengthy, but they need to be authentic and enable older people to communicate their stories and what is important to them. However, Griscti et al (2016) suggest a major barrier to this occurring is the hospital system itself which does not encourage relationship building. Parke and Hunter (2014) reflect this assertion noting that older people are viewed as a problem that slows down hospital efficiencies. The challenges expressed by the older people and their families in this PhD study with both verbal and written communication and, the misunderstandings they held about their care, suggest they were not able to build relationships with the nurses caring for them and that information was not communicated effectively with them.

Thus, to provide optimum care to older people nurses need to build relationships and listen to those in their care to enhance communication and wellbeing. This requires hospital processes and care pathways to be revisited to value these aspects of nursing care and consider the priority that flow, and efficiency has in its organisation. Suggestions to tackle this include moving away from a focus on specific organs or health systems within the hospital, which can cause silos and barriers to effective communication, to caring for the whole person (Mudge et al. 2021). What the older people and families in this PhD study experienced indicates this was lacking as they noted having misaligned expectations and needs and challenges with communication. Furthermore, they recognised they were receiving care within a system under organisational pressures.

Family centred nursing

Valuing the importance of relationships built between patients, families and nurses, and the full extent of nursing labour is vital for the provision of quality nursing care to older people and their families. That is, the intrinsic nature of care must be valued, as opposed to a focus on its external presentation via check lists or tasks that can be counted (Hoggett 2022). Fundamental care refers to care provided by a nurse to ensure essential patient needs are met (Feo et al. 2018) and often are understood to mean activities linked to everyday survival, such as nutrition, hydration, hygiene, and elimination, and are required by all patients regardless of health condition or clinical setting (Feo and Kitson 2016). In addition, assisting patients in a dignified and respectful manner, alongside incorporating cultural and emotional needs is also included within definition so fundamental care (Feo and Kitson 2016; Mackie et al. 2018). Fundamental care is key to patient recovery (Jangland et al. 2018) and has been found to be optimal for the provision of safe and effective care which is deemed positive by patients (Feo and Kitson 2016). Promoting fundamental nursing care is also a way of emphasising the importance of nursing care that is still invisible or devalued (Feo and Kitson 2016). Fundamental care is foundational to all care processes, and it is important it is articulated and made visible (Kitson et al. 2019). This can be done through highlighting its existence in models of care, advocating for the time to deliver this care, and researching how to effectively teach, deliver and assess fundamental care. For instance, in Jackson et al (Jackson et al. 2021) work, they describe aspects of nursing work that can remain invisible, such as organising and coordinating. Additionally, Hawthorne and Gordon (2020) discuss the invisibility of spiritual care, which they view as part of fundamental care, and advocate specifically assessing patients for their spiritual care needs. Thus, by clearly naming and articulating fundamental aspects of nursing care it becomes possible to identify where it happens and capture it in planning and evaluation of care. Furthermore, how fundamental care is conceptualised by older people and the nurses caring for them warrants further investigation.

Fundamental care is an important component of family centred nursing (Mackie et al. 2018). Models of family centred nursing are current practices that illustrate how holistic care, that incorporates fundamental care, and involving patients and their families can be delivered in current healthcare environments. Outside of paediatrics, they are most often found in critical care or end of life care settings and exploring their potential use in the context of more general acute care settings is valuable The International Family Nursing Association (IFNA 2022) view family nursing as occurring throughout the life course with a variety of models available. Family nursing competencies include understanding that families have inherent competencies, strengths and interactional processes that influence family health beliefs, goals, and actions (IFNA 2015). A recent workshop by the IFNA (2022) underlines the importance of family centred older peoples' care. In addition, work by Esandi et al (2018) expand the meaning of care within families as more than a set of instrumental tasks that bring a stress or burden to the caregiver and highlights how family care can evolve over time and can be reciprocal within family units.

Family nursing models aim to deliver care plans within the context of families and involve collaboration between family and healthcare providers, consider the family context, and provide education for all involved. This leads to better defined and realistic care outcomes, and enhances families' abilities to support patients, with better patient outcomes (Kokorelias et al. 2019). Family centred models were found to be beneficial to patients and their families, for instance, understanding families' needs and priorities contributed to being better outcomes and enhanced families' abilities to support patients (Kokorelias et al. 2019). Thus, these models could support nurses to effectively explore patient and family needs and priorities and communicate appropriately and effectively. Being able to listen to and incorporate a patient's narrative to understand them and their lifeworld (Dahlborg et al 2018) is an important step in providing person centred care, as is creating an environment where patients and their families understand the interactions around them, feel part of them and feel secure (Dahlborg et al 2018 p.343). These elements appeared lacking in the accounts of patients and families in this study. Expanding family centred care models to more general acute care settings could provide nurses with the context to implement and enhance some of the recommendations from health policy makers, whilst moving away from a 'tick box' exercise or task-based approaches to holistic nursing care. Research on providing family focused care to families where a member has Alzheimer's disease (Esandi et al. 2021) co-constructed knowledge that emphasised the family need for balance. Esandi et al (2021) highlight a need to notice interactions within a family, understand the nuances prevalent there and the deliver comprehensive approaches to support and interventions that promote balance. There are interesting parallels here with the idea of harmonious ageing (Liang and Luo 2012), thus, future research should explore the potential for a combined model of harmonious, family centred nursing care.

The experiences and perceptions of unplanned readmissions, along with what we know about delivering quality nursing care, point to a need for a model of family centred care in acute adult settings that enable nurses to use all aspects of their labour (physical, emotional, cognitive, and organisational Jackson et al 2021) to effectively care for patients and families. To address the needs of patients as 'embodied beings' as opposed to 'objects who have bodies' (Draper 2014) alongside supporting their families, I suggest that this model of family centred nursing should explicitly include the understanding of harmonious ageing. Furthermore, the implementation of such a model should be set within an enabling environment that supports professionalism in nursing which can be enabled via strong nursing leadership, advocacy, and education.

7.8 Strengths and limitations of this study

No research is perfect and reflecting on the journey taken during this study there are some limitations that merit discussion. This collective case study is based in one hospital trust in the South of England which has multiple hospital sites. The intention of this study was to develop deep contextual understanding of a phenomenon, in this case, that of the perceptions and experiences of unplanned readmissions faced by older people and their families. Critiques of the approach, for instance that there is an inability to make useful generalisations from such a study, have already been addressed in the methodology (Chapter 3). Furthermore, the strengths associated with this approach have also been previously discussed and include an ability to explore deep, contextually based understanding of a phenomenon, that is grounded in peoples' experiences. In addition, this enables clinically relevant outcomes and recommendations to be developed.

Involving older people at the start of this study, for instance by inviting and acting on feedback of earlier versions of the patient information sheets and, the inclusion of a stakeholder engagement group is consistent with a patient centred approach to research (Locock et al. 2019) and in alignment with the author's personal and professional values and is a strength of this study. However, this study falls short in that it is not fully co-produced and could be perceived as tokenistically involving older people and creating research that is "*about*" as opposed to "*with*" older people (Buffel 2018). Co-producing research is deemed beneficial and important and can be a requirement to secure research funding (NIHR, 2021). Key principles of co-produced research include sharing of power, including all perspectives and skills, respecting, and valuing the knowledge of all those working together, reciprocity, and building and maintaining relationships (NIHR 2021). However, there continues to be a lack of understanding and confusion surrounding the components of co-production and a variety of terms used to describe different levels of engagement interchangeably (Smith et al., 2022). Furthermore, more needs to be done to fully understand the longer-term benefits to patients and communities of co-produced research (Smith et al., 2022). Despite this, the author authentically engaged with stakeholders and believes this has benefits for this research whilst recognising more could have been done to fully co-produce this study.

As noted in both Chapter 3 (Methodology) and Chapter 4 (Methods) the approach to analysis combined Stake's suggestions for collective case study research (1995, 2006) and framework analysis (Ritchie & Spence 1994, Gale 2013). Whilst there were specific steps suggested to be followed, the process was iterative, lengthy and at times complex. The resulting Assertions about the Quintain are presented in the findings chapter (Chapter 6) as a mosaic with the aim of centring, celebrating, and making visible the experiences of the older people and families included in this study. However, the nature of this analytic process may have resulted in certain elements of themes being given less focus compared to specific patient or family experiences. It could be interesting to consider a thematic analysis of this data, following for instance the methods outlined by (Braun and Clarke 2019). Whilst this would be a departure from the collective case study approach, thematic analysis is consistent with a constructivist approach, and it could be interesting to explore whether themes generated as part of this process could offer different insights.

As previously mentioned, to recruit participants for this study specialist nurses working within the study site were invited to identify and approach potential participants as part of their normal working processes. A benefit of this was the ability of these nurses to build connections with potential participants, an important component of ensuring diverse recruitment (Dilworth-Anderson 2011). This resulted in participants who would not normally consider taking part in research stating they felt comfortable to do so in this instance, which is an important strength to acknowledge. The age range of the older people included in this study include people in their 70s, 80s and 90s. The youngest participant was 72 and the oldest 97. A strength is the addition of those classed the 'oldest old', as mentioned previously, they have often been less present in research on older age. However, it could have been interesting to consider the experiences of those aged between 65 – 70. Not every patient wanted to have their family involved, and in some cases if they did follow up did not occur. Considering further multiple avenues to contact family, and agreeing this beforehand with the patient, could have facilitated including more family members within this study. In addition, having an inclusive and broad definition of 'family' was a strength and ensured that patients could chose who they deemed to be family. This contributes to furthering inclusive research and highlights the need for healthcare professionals to have awareness of chosen family when interacting with patients.

Recruitment was relatively slow using the chosen approach which when combined with a period of winter pressures, this was not surprising. Having a selection of recruitment strategies, for instance using social media or involving local older people's organisations, could have sped up this process. More importantly, multiple recruitment strategies optimise participation by diverse groups (Webber-Ritchey et al. 2021) which is essential for quality research today. Linked to this point, the demographic characteristics focused on in this study were age and sex, no consideration was given to race, gender, ethnicity, sexuality, socio-economic background, ability, and all other protected characteristics. This is a key limitation, and whilst the intention was not to be colour blind (Ortiz 2020) or actively anti-diverse, by not considering specific recruitment strategies tailored to diverse populations the outcome has been a study that was not as diverse as it could have been. In effect, this study has perpetuated an uncomfortable truth that should not be repeated in future research.

7.9 Recommendations

The discussion has explored a variety of the implications stemming from this PhD study's findings. The unique contribution to knowledge of this study is revisited below, with corresponding recommendations for nursing practice, research, education, and policy.

1. Unique contribution one: The findings from this study present a deeper and richer understanding of experiences and perceptions of unplanned readmissions to hospital among older people and their families. This study has presented the magnitude of the disruption and illustrated how the impacts of these unplanned readmissions can ripple out across time and wider society.

Practice:

Harmonious ageing emphasises structural forces and individual agency (Liang and Luo 2012) this approach to ageing could be used to help nurses to build effective relationships with older people and support them to self-accept the differences they may feel between their disrupted aging body and their mind. In order to deliver this, implementing the suggested educational interventions outlined in subsequent recommendations below could be considered.

Research:

A further exploration of the ripple effect of unplanned readmissions across a broader range of older people is recommended, prioritising diversity of participants, and using theories of family nursing to underpin this research. This could add understanding of the impact of unplanned readmissions on the whole family, not solely the patient – family member dyad as included in this PhD study. Furthermore, by prioritising diversity of participants elements of the intersection between age, race, gender, class, and ability could be further investigated.

Education:

Rowland and Kuper (2018) suggest that incorporating critical reflexivity into health-care professions education has the potential to help practitioners to deliver more compassionate care as they develop a critical awareness of the power dynamics present in their practice. Engaging in critical reflexivity has the potential to facilitate a deeper understanding of the social structures and powerful discourses that direct the way we think about older individuals, potentially helping to overcome ageism and enhancing the relationship between clinicians and their older patients (McCorquodale & Kinsella, 2015). This can support challenging assumptions, overcome negative stereotypes, and reinforce that the quality of the interaction with older people is also important. The expected benefits of this include an appreciation of the magnitude of the impacts experienced by older people and their families, and enhance the relationships being built between nurses and patients and their families. Flores-Sandoval & Kinsella (2020) suggest the use of observation, narratives and writing to do this work of critical reflexivity, elements that could be delivered as part of educational programmes in the form of written assignments, guided group work or reflections on clinical placements.

Mudge et al., (2021) identified a need for gerontological education and training in core nursing curricula and post graduate study. As such, a recommendation is to encourage nurse educators to review their curricula and identify whether they have incorporated theories of life-course and harmonious ageing into the holistic perspective of nursing (Dahlke and Hunter 2022). If these theories have yet to be included a suggestion is to encourage their inclusion in future iterations of the curricula and in case examples used in educational settings. Furthermore, exploring different ways to work directly with older people in the co-development and co-delivery of nursing curricula is suggested.

Policy:

A recommendation to policy makers and nurses with strategic roles is to support the development of ambulatory healthcare services that can provide holistic care that address the ripple effect of impacts associated with unplanned readmissions as outlined in this study. Harmonious ageing emphasises the need for inclusive community-based models of care that move away from individualist approaches. These ambulatory services would benefit from being specifically age and family friendly and exist within each Integrated Care System (ICS). Where an ICS has successfully implemented this type of ambulatory care service, a suggestion is to evaluate what good looks like to identify the components that could be scaled regionally or nationally. Furthermore, sharing these examples on central NHS websites, or regional equivalents, to facilitate shared learning is encouraged.

Roles and career pathways for nurses educated and trained in gerontological competence should be developed and included within ambulatory care settings and across hospital and social care. This work could align with current ongoing work to identify England's Chief Nursing Officer priorities for the profession.

2. Unique contribution two: Nuance around the experiences and perceptions of unplanned readmissions have captured the fact that as a catalyst for change they can be viewed as key to unlocking care and support. This suggests older people and their families are reaching a type of crisis point before things change for them.

Practice:

This PhD study has highlighted a real need to develop communication strategies when caring for older people and their families. The findings from this study suggest that written information was deemed the most helpful when it was complemented with a verbal conversation that the patient or family member understood and found meaningful. Thus, throughout a patient's hospitalisation, nurses should reinforce written information with verbal conversation. Furthermore, clearly communicating expectations surrounding time frames for clinical improvement should be included within these conversations. Moreover, this conversation should be preceded by a conversation to establish what is important to the older person and further communication and care should be tailored accordingly, using the full range of written, verbal, and digital resources available.

Professional silos in healthcare settings have the potential to reduce effective communication between teams and lead to poorly coordinated interactions with patients (Mudge et al. 2021). The findings in this study align with this, thus, enhancing interprofessional skills and team working is vital. Within clinical practice, this can be addressed during training updates. In addition, corporate and practice development nurses should be encouraged to identify where enhancing interprofessional practice could be reinforced in existing training and education. Where necessary, bespoke sessions on interprofessional skills and team working should be delivered to clinical teams to reduce silo working.

Research:

Future research should explore the different crisis points that older people and their families potentially experience along their healthcare journey to ascertain effective care interventions to address these. In addition, understanding how older people understand fundamental care and how they experience this care could be included. Furthermore, this research should be co-produced throughout.

Education:

A further recommendation is to ensure that gerontological competencies that are appropriate for the education and healthcare systems in England should be identified and developed. Education in these competencies should be included in undergraduate education and in continuous professional development. Furthermore, these competencies should be further developed for nurses working in advanced practice. These competencies should go beyond comprehensive geriatric assessments or frailty assessments and take a holistic approach. Examples of gerontological competence to be explored and assessed for suitability in an English NHS context include the work of Dijkman et al., (2022).

Policy:

A policy recommendation is to identify components of early intervention and coordinated care strategies that are successful at supporting older people and their families. Consideration on basing this work initially on the case studies the NHS has collated on integrated care should be given, for example looking at the work around hubs (NHS England 2022b). The aim would be to develop structures where patients and families do not require reaching a crisis point in order to unlock care they require. Leadership from nurses working within ICS will be crucial for the successful delivery of this work.

3. Unique contribution three: This study's findings involving the experiences and perceptions older people have of their unplanned readmission offer contextually bound first-hand accounts of the lived experience of being older and accessing healthcare, which contributes to diversifying the narrative around older age and supports combatting ageism.

Practice:

The benefits of critical reflection for gerontological practice and to counter ageism have been described. Flores-Sandoval & Kinsella (2020) contend that encouraging all healthcare professionals, whether those who are students, researchers or in clinical practice to reflect critically on their own perceptions of age, where these views come from, and how their views and preconceived ideas may impact on how they provide care for older people. Thus, opportunities for critical reflection on these issues during clinical practice should be prioritised, for example during one of the five reflections required for revalidation with the Nursing and Midwifery Council. In addition, it would be beneficial to invite nurses to identify which colleague in their workplace could support them with this, this could be a colleague adept at working with older people and their families or a colleague whom they trust to engage openly and authentically in critical reflection with.

Research:

Chronological age is used to socially construct old age as a barrier to economic, political, and social participation in much the same way as sexism has served to restrict women (Carney & Gray, 2015, p.126). In order to further diversify the narrative around older age future research on older adults and their health care needs should explicitly incorporate the intersections and interconnections between age, gender, race, class, and ability. Furthermore, this research should consider strengths-based approaches to ageing as their theoretical bases, for instance, by using the theory of harmonious ageing to underpin this work.

Education:

A further recommendation is to ensure that student nurses and qualified professionals are aware of ageist discourses (Flores-Sandoval and Kinsella 2020), and can recognise where these may be impacting on the care they or others around them are providing. Engaging in critical reflexivity can support the identification of any conscious or subconscious ageism, identify if, when and how they may be perpetuating ageist practice and encourage them to speak out about it. Furthermore, use of simulation in nursing education can support healthcare students to develop their communication skills and their work with older people (Busca et al., 2022). Moreover, this could be an ideal opportunity to develop conversation skills to identify what matters to older people. For instance, the advice and tools described by Laderman and Jackson (2019) could be used as a reference point and includes a range of practical advice for conducting these conversations. Furthermore, it would be beneficial to consider adapting this toolkit for the NHS and English contexts.

In Canada they have reviewed gerontological competence in their health education system and have identified a need for greater competencies across the professions (Dahlke et al. 2021). Furthermore, a critical review of nursing education noted that whilst educational establishments incorporated content about older people into curricula, they did not include "*social aspects of learning processes that expose students to ageist perspectives and practices*" (Dahlke et al., 2021, p.3). This further reinforces the need for education interventions to take on a critical lens and use reflexivity.

A further recommendation is to support students to understand the health impact of ageism and the health-related risks of ageism by ensuring this is included in all discussions around equality, diversity, and health inequalities. Furthermore, embedding this understanding through the use of case studies and opportunities for interprofessional learning is advised. One example of an interprofessional course on ageing exists at an educational institution in Israel (Malkin et al. 2022). This course appears to have successfully supported diverse healthcare students to work together to provide care to older people. However, the study protocol for this course refers to successful ageing and the vocabulary used ('elderly') has negative connotations. Accepted terminology amongst gerontological nurses in practice and academia is to use the terms 'older persons' or 'older adult' (Makita et al. 2021). Thus, any module or course component referring to older people should use appropriate vocabulary and be based on a holistic, patient centred, strengths-based approach.

Policy:

A policy recommendation is to create and develop a national network for nurses with gerontological competence and for those who work with older people and are interested in opportunities to develop knowledge, skills, and peer support. Networks are an effective vehicle for quality improvement in healthcare (The Health Foundation 2014). Furthermore, they are an opportunity for people to come together, to raise the profile of their work, develop, spread, and scale what works well and provide peer support for members.

7.10 Chapter conclusion

This chapter has reviewed the findings co-created as part of this PhD study and has highlighted the challenges experienced by patients and their families when going through an unplanned readmission, as well as the positive perceptions afforded them as important catalysts for change. This PhD study has added empirical evidence to a concept analysis on older peoples' experiences of unplanned readmissions (Coatsworth-Puspoky et al. 2021) and added important depth and perspective to this by illustrating the family experience, ripple effect and catalysts for change perceived by patients and their families. Unplanned readmissions are more than a discrete problem to be tackled, they are experienced by patients and families in a myriad of ways and require understanding so that nurses can provide older people and their families with appropriate and high-quality care. The following and final chapter, the conclusion, summarises the main aims and findings of this PhD study and reinforces the implications of this for the nursing profession, highlighting the unique contribution to knowledge co-constructed within this study.

8.0 Chapter 8 - Conclusion

This chapter brings together the whole thesis and is the culmination of the PhD study. This chapter presents the main findings as presented in this thesis and offers a summary overview of each chapter. This chapter will also provide a summary statement of the main novel findings developed as part of this PhD study and reinforce the significance of these unique findings for the field of nursing. This study has emphasised the vital need to explore the experiences of healthcare from the perspective of older people and their families so that quality nursing care can be provided to them and their families. Unplanned readmissions have impacts that ripple out across time and into society, and these must be addressed by nursing and healthcare practice.

8.2 Thesis overview

Chapter one presented the background information on unplanned readmissions to hospital. The multiple definitions of unplanned readmissions were outlined and the rationale for the use of the NHS definition was described. Further definitions for the main terms used within this thesis were also presented ensuring a clear understanding of ‘older people’ and ‘family’. The policy perspectives of unplanned readmissions as understood at the start of the PhD study were discussed pointing to the global and local concerns associated with them. Clinical practice within the English NHS was described with an outline of the clinical practice used to address unplanned readmissions and how it relates to care quality and safety. Patient experience was addressed and the clinical need for further understanding of the patient and family experience of unplanned readmissions was proposed.

Chapter two described the initial qualitative systematic review conducted at the start of the study, the search strategy and quality appraisal used and how the thematic synthesis was conducted. Additional searches were outlined, and themes were discussed in the context of what was known at the time. This chapter outlined the lack of published evidence that existed on returning to hospital in the words of older people and their families and additionally this from an English context.

Chapter three introduced the research aim, research approach, ontology and epistemology adopted and justified the use of a collective case study as informed by Stake (2006). Personal and professional beliefs were also outlined. The interpretivist paradigm and constructivist approach were discussed, and methodological limitations were also addressed. Chapter four outlined the data collection methods used; episodic interviews, documentary analysis, observation, and reflection; and discussed challenges faced during the data collection phase prompting a modification of the data collection. The methodological robustness of this change was explored and justified. Data analysis methods were examined and the rationale for combining the analytic method and ethos of Stake (2006) with the tools of framework analysis were described (Ritchie and Spence 1994). Furthermore, the rationale for and the inclusion of a stakeholder engagement group was described. A discussion of how the different stages of the analytic process contributed to the creation of the analytic framework was offered. Limitations surrounding recruitment, data collection methods and reflexivity were discussed. Additionally, ethical considerations and study rigour were described and examined.

Reporting on a collective case study informed by Stake (2006) requires a descriptive and interpretive element. Chapter five provided the descriptive element and outlined the context of the collective case study, describing the study setting, discharge processes, and study context. A selection of example case summary reports was presented to showcase the variety of patient – family relationships included. A table illustrating a summary of all the included cases along with a table describing demographic characteristic was provided. Chapter six presented the interpretive element, with the study findings or Assertions about the Quintain outlined. Within the context of this collective case study of experiences and perceptions of older people and their families, unplanned readmissions were characterised by a misalignment of expectations and needs between patients, families, and healthcare professionals. They had existential and emotional impacts on patients and families, and an impact on their social lives and social roles. Challenges were experienced with communication and expectations surrounding care – for instance around care processes, timing of discharge and an anticipation one would be cured before discharge. In addition, unplanned readmissions were perceived in some instances as lifesaving and in others as key to unlocking further care and support. Thus, unplanned readmissions produced a ripple effect across the lives of patients and their families with far reaching impacts across time and wider society, which in some instances was welcomed.

The unique contribution of these study findings were conceptualised as:

1. The findings from this study present a deeper and richer understanding of experiences and perceptions of unplanned readmissions to hospital among older people and their families. This study has presented the magnitude of the disruption and illustrated how the impacts of these unplanned readmissions can ripple out across time and wider society.

2. Nuance around the experiences and perceptions of unplanned readmissions have captured the fact that as a catalyst for change they can be viewed as key to unlocking care and support. This suggests older people and their families are reaching a type of crisis point before things change for them.

3. This study's findings involving the experiences and perceptions older people have of their unplanned readmission offer contextually bound first-hand accounts of the lived experience of being older and accessing healthcare, which contributes to diversifying the narrative around older age and supports combatting ageism.

These pose important questions for how we plan, develop, and deliver care to older people and their families. By exploring the experiences and perceptions older people and their families had of unplanned readmissions within an English NHS context, this study emphasises that it took a crisis point for older people to receive the care they needed. Furthermore, the ripple effect of the impacts was found to spread out from the individual patient or family member, across time and into wider society. In the discussion, Chapter 7, the implications of these findings on how we provide care to older people was explored. The influence of ageism and theories of ageing care on nursing care delivery was explored. Quality nursing care and family centre models were discussed, followed by an examination of the challenges and enablers to providing age friendly, family, and person-centred care. These unique findings, in the context of experiences and perceptions of unplanned readmissions in an English NHS context, enable the magnitude of their wide-ranging impacts to be outlined. They provide the impetus to question how we provide care to older people and the opportunity to critically reflect on what more we need to do to truly ensure older people and their families experience the quality care inherent in our nursing values.

In addition, this provides the stimulus to question and change the contexts nurses provide care in, pushing for systems that enable older people and nurses to build positive relationships bult on strong communication and underpinned by gerontological competence. The ripple effect of unplanned readmissions is the momentum we need as a profession to strive to deliver the highest quality care centred on the needs of older people and their families.

8.3 Summary statement

This collective case study exploring the experiences and perceptions of unplanned readmissions to hospital from the perspective of older people and their families in an English NHS context adds vital elements to the concept of an experience of unplanned readmissions. Coatsworth-Puspoky et al's (2021) analysis is welcomed as it provides a holistic view of this phenomenon, however, my PhD study complements their findings by adding the family perspective and enriches, enhances and widens our understanding of the impacts of unplanned readmissions and how they are perceived. We can thus move away from simply problematising them and move to incorporating the understanding provided by this study into nursing care.

This PhD study supports a move away from a focus on reducing the number of unplanned readmissions, which is perhaps a reductive aim and one that does not reflect the reality of health and care today, rather, it is proposed that giving nurses the enabling environments in which to form effective therapeutic relationships with patients and families, as suggested in emancipatory nursing (Dahlborg et al. 2018), patient and family needs could be better met. I suggest that quality nursing care with effective communication, where the negative impacts of ill health and hospitalisation are well mitigated, would enable the 'catalyst for change' moment to take place earlier in people's hospitalisation journey. For some, this may remove or reduce the need for unplanned readmissions.

A nursing model combining family centred care with an age friendly approach is a tool to providing this care. As nurses we must reclaim the structures and processes, we work in, we need to work to the fullest extent of our competence and education, and value providing fundamental care. Building therapeutic relationships can support patients to have "*reflective awareness"* (van Manen 1998 p.17) where knowledge of the self is co-created through the search for significance (Freire 2005, 1974) so patients can move to becoming "autrement le meme" [differently the same] (Bensaid 1978). By using family centred, age friendly approaches we can make the space within our work to support patients to 'come to terms' with their experiences of health and illness (Anjoulat et al. 2008), ultimately providing the high quality, safe, nursing care that addresses and fully responds to the needs of older adults and their families.

The experiences and perceptions of unplanned readmissions are based on experiences that transcend the specific moment of unplanned readmission incorporating instances before, during and after the unplanned readmission. The unplanned readmission has ripple effects with waves that touch on wide personal and professional networks which have deep and varied impacts on peoples' lives. This study confirms the misalignment between how unplanned readmissions are conceptualised by organisations, health care professionals, patients, and families. It is imperative nurses appreciate and understand the experiences and perceptions older people and their families have of unplanned readmission so they can provide responsive, holistic care and support patients and families appropriately.

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Appendices

Appendix 1 - case summaries

Case 01 - Eleanor

Synopsis

Pseudonym: Eleanor (patient); Michael (husband); Age: 77 years old. Interview location: Own home

Readmission within approximately two weeks (according to Michael), this was the first unplanned readmission for a long time according to Eleanor. The readmission to hospital was because of a routine GP visit. During this visit Eleanor noted that her GP asked her to go *“straight to hospital”*. Eleanor was asked to go directly to the teaching hospital and not go to the nearest community hospital. Both the initial admission and subsequent unplanned readmission were triggered by Eleanor’s GP after Eleanor had gone in for a planned visit / check-up.

Eleanor remembers being given a written list of medications after her first hospitalisation and a discharge summary after her readmission, does not recall being given anything else. She has a copy of the discharge summary at home. Eleanor was not given any written information regarding lifestyle or other discharge instructions. Noted her GP had not yet received latest discharge letter.

Situational constraints

- First set of interviews conducted

Uniqueness among other cases

- Spent time in an ambulatory assessment unit

Findings / themes

- Disappointment in self
- Eleanor surprised at readmission, sadness, and thankfulness and gratefulness for health issue being identified, notes a lack of communication between teams (GP + hospital based, and, not new appointment made for her with cardiology), and lack of communication with her as she did not remember any healthcare professional ever telling her explicitly that she had had a heart attack.
- Impact on life (unable to drive)

- Readmission viewed as accepted part of getting older by Eleanor
- Michael shocked at Eleanor’s readmission, but also acceptance that they are living on borrowed time now
- Michael noted the muddle of communication, poor communication, and Eleanor’s assessment being interrupted

Excerpts (quotes)

Eleanor: *“...to be honest I haven’t no I mean I just have accepted it as being part of my senior life”*

Eleanor noted “*disappointment, that it had come up again that I did need another transfusion”*; and later states “*as I said a bit of disappointment of having to stay in”.*

Michael: *“yes it was a shock and uh when these things happen, I sort of go into kind of survival mode and here we go again here we go again right let’s get the bag packed and let’s talk to the people we need to talk to”*

Michael: *“...but it was always where do we go from here and as always when is she coming out and there’s certainly a lack of communication about that or a muddle of communication”* and “*you’re never quite sure who you are going to speak to”*

Michael: *“as far as the hospital is concerned it’s the thing about communication and the communication is still bad because we haven’t had various things which in both cases, both times in hospital Eleanor was told this was going to happen and we still haven’t heard officially so that’s not proper I don’t know where the delay in the process is but it’s not good for anybody”*.

Michael: “*that was the experience which wasn’t a nice one but it came, it came out with the right result anyway, as soon as the infusions and the transfusion had happened Eleanor had got to being practically where she was before”*.

Commentary

The experience of readmission appears mixed - on the one hand there is disappointment and shock, on the other feelings of gratefulness at being well looked after and followed up. The readmission has led to lasting lifestyle changes - no longer being allowed to drive which also has an impact on daily life. However, the experience appears to be taken as normal in light of Eleanor’s age. Eleanor’s husband picked up on different elements - especially around communication and logistics. These are perceived as stressful and caused worry. Michael is affected emotionally by the readmission but he is glad health issues were picked up on and Eleanor received the care she did.

Case 02 - Paul

Synopsis:

Paul, Male, 86 years old (Anne, wife). Interview location: Own home (shares with his wife, they live in a retirement village and Paul wears a pendant alarm). Paul is not sure about the readmission timeframe but he believes the unplanned readmission took place within a few days of being discharged. Paul's starts his account commenting that he cannot remember what happened to him well. However, he goes on to describe his two most recent experiences in hospital. Both of Paul's admission and readmission are linked to falls, and he was also taken to hospital via ambulance both times. The first admission he states was due to a fall after feeling dizzy when he was sat at his computer, the second due to a fall when he was in his bathroom. Both times he activated his pendant alarm and care staff decided to call for ambulances.

After the first visit, no information was received on discharge, nor was paperwork received after his unplanned readmission. Paul notes the most advice he received was from his private neuro physiotherapist. He remembered there was information about needing his GP to conduct a medication review and refer him to the falls clinic. No information was received about his dressing. At the time of the interview, he was waiting for GP medication review and falls clinic. Anne seems to remember receiving some information referring to a copy of the discharge letter their GP received – Paul only recalled this letter after Anne noted she remembered it – they did not have any paperwork to show me. The conversation I had with them after the more formal recorded interview had stopped reiterated the fact they were confused as to who should take control of follow ups and tests after they left hospital. They did not seem clear on this at all.

Situational constraints:

- Both Paul and Anne note issues with recall

Uniqueness among other cases:

- Embarrassment on part of Anne about an ambulance needing to be called.
- Only couple to live in a retirement village in a setting catering to their mobility and care needs.

Findings:

- Paul is living with a chronic condition
- Impact of readmission on daily life, changes made to how Paul walks and socialises.
- Meaning of unplanned readmission on perception of age and feeling older. Anne was more negative than Paul. Paul appeared to break up his sentences with laughs

perhaps to diffuse the tension or make light of the situation. Worry verbalised by family members compounded by multiple readmissions, inevitability.

- Differences in how readmission and impact of is framed between Paul and Anne (Paul frames needing help, for example using the wheelchair, as something he does because his wife wants to do it "*So I can sit in it and she can push me because that is what she wants to do…".* Whereas Anne views this something Paul does because he feels "*wobbly"* and that he says he does want to use the wheelchair.)
- Lack of clarity around health plan after readmission, issues with communication.

Excerpts (quotes):

Paul: (I am) "*probably more careful when doing things um when I sit on the toilet, I sort of remain there for about three minutes or something to let myself settle"* and *"I walk very carefully around the house"*

Paul: "*I suppose they mean that I'm getting on a bit and I have to be .. adjust myself to fit in with them"*

Anne: "*well um I suppose I felt a bit embarrassed with the ambulance coming yet again for him".* However, just as her interview was about to end Anne commented that when she realised Paul would need to be readmitted she felt "*well a bit awful really"* and thought *"here we go again"*.

Anne: "*I wondered if he'd had a mini stroke another stroke again so I was concerned on that…"*

Commentary:

The experience of the specific readmission episode itself is not focused on, however, Paul and Anne did mention feeling their age, and like a burden. There are also hints of worries about the future reflecting the impact of the unplanned readmission. During the interview itself the focus appears more on how Paul has adapted his life considering his recent falls. The experience in terms of how Paul and Anne were cared for is not a focus but the lack of information (written and verbal) does seem to have had an impact on them.

Case 03 - Barry

Synopsis

Barry, Male, 72 years old. Interview location: Rehabilitation ward, community hospital. Barry describes waking up one morning and not being able to walk, this then led to a fall. His wife called for an ambulance. Then, he was admitted to hospital for a few days and then discharged home. A few hours after arriving home, he walked in his garden and had another fall and his wife called for an ambulance again.

Barry states he did not ever receive any written information or any verbal explanation about what was going on or any information on the plans for his care or what to expect.

Situational constraints:

- In a ward so staff coming and going (though Barry was in his own room)

Uniqueness among other cases:

- Barry has been in a rehab hospital for two weeks and not been outside since arriving which is having a detrimental affect on his health and wellbeing
- Barry partly ascribes the poor communication and care he experienced as due to his socioeconomic status
- This interview really had an impact on me, I felt for Barry and felt frustrated and sad at the lack of quality nursing care he described. I stayed after the interview to take Barry outside for a walk
- Rich interview, Barry was very open about his feelings and emotions

Findings:

- Barry has experienced poor communication, his GP also has not received information
- Feeling discharged too soon, not feeling cured
- Not feeling cared for properly, not feeling listened to, feeling confused
- Impact of readmission on his own mental health (feeling low, depressed) and on his family, partly due to setting he is currently in (rehab ward in community hospital & not being able to go outside)
- Unplanned readmission made Barry feel like a yo-yo, feeling of uncertainty and not understanding any plans for care, frustrations and feeling despondent, not knowing plans or what is going to happen. As a result, does not view rehab hospital as optimum location to recuperate, would prefer to be at home.

Excerpts (quotes):

Barry: *"but you see these people won't tell you anything um I thought I was hoping I would be going home today but they say I still got some problem with me water so don't look as if I'm going yet"*

Barry: *"nobody give me any answers"*

Barry: "*I mean I understand these girls [healthcare assistants] they don't know anything but the three that sit down in the kiosk [staff nurses] they should do cos they are senior staff. But they won't tell me hardly anything. Nobody wants you to know because you might know one sentence more than they do. It's as simple as that"*

Barry: "*but they never bothered to focus on anything, they did their usual checks. Put him over there he'll be alright. They kept me in there for two or three days then said well you can go home...but they hadn't done nothing to put anything right"*

Barry: *"but you see these people don't want to know about that they don't want to know how you feel…nobody wants to listen to you"*

Barry: "*um they don't want to listen to you cos you don't know anything. But the trouble is you know there's something wrong.. Ahhh I've given up on all of them now"*

Barry: "*that's why I want to go home to recuperate...take my little dog for a walk with my missus"*

Barry: *“alright, I was only a working fella but all the same I’m surely due something over this it’s like now I don’t really know what was up with me”*.

Barry: “*as I’ve said before we would like to be kept in the loop...we’re not kept in the loop if there ever was a loop”*

Barry: “*I mean it was worrying my wife to death and I couldn’t see what was going on with me if you see what I mean”* (re: multiple hospitalisations)

Commentary:

Overall, the experience and perception of readmission appeared to be a negative one for Barry. The communication and care received did not appear acceptable or appropriate to him, nor did they seem holistic or person-centred. These experiences appeared characterised by uncertainty, not knowing what is going on, feeling lost, low, and down. Hospital did not seem to be bringing him what he wanted which was to feel better. He also missed his family and being outside and active.

Case 05 - Toby

Synopsis

Toby, Male, 79 (and wife Phyllis). Interview location: Own home. The latest unplanned readmission was within two weeks. Toby outlined a history of multiple admissions and readmissions. He made the decision to begin his story at the point of a GP visit that he perceived to be the starting point for a chain of events. Toby had a heart attack and was admitted. Two weeks later an ambulance was called due to him having difficulties breathing so he was readmitted, medication changes were made. He went home after two days in the hospital. Then, he experienced chest pain so he was readmitted and again sent home. After a few days at home, he experienced pain in his left side and was again readmitted.

Toby received written information. He had it organised in a folder and it had been organised in chronological order (I believe by his wife Phylis). This written information appeared to be perceived as both useful and well understood by Toby and Phylis. Furthermore, Toby noted that in one of the letters (combined with an interaction with a doctor) it was made clear what expectations he should have of his own recovery - this then had a positive impact on his experience of his own health and recovery.

Situational constraints:

Uniqueness among other cases:

- Verbalised how he was not given opportunity to manage his own long-term condition whilst in hospital
- Positive experience of safety netting before latest discharge and Toby understands expectations, he can have of himself and his recovery though still unsure of some practicalities around what he can and can't do (this safety netting and communication did not occur during previous hospitalisations and discharges)
- Their rural setting, at the intersection of two hospital Trusts and reliance on public transport add complexity to their situation

Findings:

- Toby lives with long term condition, expertly managed by himself
- Uncertainty during hospital stay and on previous discharges about what he could and could not do, frustration
- Communication issues, plan and situation not made clear, GP unclear on plan, too many specialists involved, uncertainty and worry experienced by Phyllis when Toby in hospital

- Positive feedback on specific instances of care that he had received from doctors, porters, nurses.
- Community based care not perceived adequate or responsive, acknowledgement of limited resources in hospital (beds for instance)
- Impact of unplanned readmission on life lack of transport made readmission an issue as Phyllis could not visit easily for instance
- Discharged too soon
- Readmission lifesaving, part of life now, but hospitalisations also a worry for both

Excerpts (quotes):

Toby: "*in the dark you can't see what the time is because the light I had wasn't working um and you think um is it time for my injection is that going to come round is the breakfast going to come round before"*

Toby: *"Um in fact I've got a letter somewhere and the doctor says that um I realise that I can't do the walking suddenly and I got to be patient and they said four weeks didn't they [to Phyllis]?".*

Toby: "*they don't tell you much you know, maybe in their language they do but um apart from that." … "well you wonder why when you see everyone else walking by and um well, shuffling by, but um why is it me that can't get out and everyone else can"*

Toby: "*The one thing that does stick in my mind is the fact that if they didn't take me in when I had that heart attack I might not be here now"*

Toby: "*What I would object to um and strongly for a lot of reasons um the treatment you get once you leave the hospital is non-existent" … "And when I left the last time after the heart attack I was told there would be a nurse getting in touch with me and un to tell what I could do and couldn't do and also look after me after leaving hospital….I phoned her and talked to her and said that she'd have to come to see me [due to access/transport issues Toby finds it hard to get to the nearest town] and she didn't like that much at all um she's made one appearance"… "But she's supposed to be looking after me"*

Toby: "*um one instance we had to wait and wait and of course we had to get a taxi home and at night-time that's £40 - £45ish pounds to get a taxi and if we'd got the tablets earlier we probably would have had a cheaper taxi"*

Toby: Unplanned readmission = "*another ride in an ambulance"* and "*I was a bit frustrated then because I thought 'oh no I'm not going back there'".*

Toby: Hospital simultaneously a place where "*something's wrong so you're going in there to get it put right"* and *"nothing appears to happen"* (re his medication & polypharmacy)

Phyllis: "*But I can understand why they were sending him home because of the bed situation but he would have been..if he could have stayed in for longer it might have helped whether...but it seemed to me that he was coming home too soon" … "he was shuffling about and his breathing wasn't right...once he was here I thought well I don't know perhaps he's not as well as he should be to come home. That was my only um sort of thing that I felt he wasn't quite right".*

Commentary:

The experience of readmission (and there were multiple readmissions) was worrying, unsettling and not an easy one. The positive experience they had of interactions with individual healthcare staff was very apparent. It was the systems at play they found frustrating and difficult to navigate and understand. The final letter along with a corresponding conversation with a consultant was the most helpful as it was clear, they could make sense of it, and had clear expectations of how long Toby should wait before expecting to feel better and walk more easily.

Case 06 - John

Synopsis

John, Male, 89 years old. Interview location: Hospital ward, bedside (Acute hospital). Readmission within four days (approximately). This readmission is the second unplanned readmission within a six-week period. Over the course of approximately six weeks John had been admitted multiple times via the District Nursing team or GP due to cardiac issues. He is not clear as to exactly what these issues are and regularly comments that he did not feel unwell or consider he was having any difficulties. Currently in hospital, he describes his most recent admission preceding the most recent unreadmission as being due to heart issues to do with his heart rate. This was identified by carers who contacted John's GP who made the decision to admit John. Once discharged John stayed at home for approximately four days before being readmitted on his GP's advice, John describes the reason as being due to the results of some blood tests he'd had.

John appears not to have received any written documentation and noted in the interview that he did not remember receiving any advice even verbally on what to do when home.

Situational constraints:

- Interview conducted in a four bedded ward; curtains pulled around the bed space.
- John happy to go ahead in these conditions but it was busy, noisy and I was interviewing after having done a full nursing shift.
- Declined for me to contact his family about being interviewed

Uniqueness among other cases:

- States he did not feel unwell
- Nursing staff that were caring for John referred to him as a "failed discharge" when I first met them to find out where John was on the ward

Findings:

- Accepting of unplanned readmissions as part of life, not something he can control, healthcare professionals prompted all hospitalisations and readmissions
- Unplanned readmissions part of getting older, stoical acceptance of restrictions and health deteriorating
- Hospital a place where experts work to get you better, you are back in hospital for your own good, accepting of staying in hospital until what is wrong with him is sorted out (expectation of cure)
- Hospitalisation has had a negative impact on John's mobility and independence.

Excerpts (quotes):

John: "*Well, I just take it, I just accept it as life, you know, I've got to the stage where I take a sort of philosophical .. attitude to life, accept what comes and if I have to go to hospital, I accept that"*

John: "*Well, I just accept that it is part of life. If I survive until the end of August, I shall be 90, yes I shall be 90 at the end of August. So, I have to accept life is going to be restricted*" … *"I can't cope with the jigsaw puzzles now but that doesn't bother me I just accept alright I can no longer do what I used to do".*

John: "*...next thing I knew I was pulled back into hospital again".* Further in the interview John mentions this again commenting that "*..I felt perfectly alright, I didn't feel there was anything wrong...so I was quite surprised when I was asked to go back into hospital"*

John: "*I don't feel like doing anything. I feel a general lassitude...I would normally read when I was at home and so on but um since I've been in hospital I don't feel like doing anything"…* "*If I'm restricted to bed or sitting down all the time life is going to be uh more difficult"*

Commentary:

In John's case it appears he frames the unplanned readmission as part of life, part of getting old. Whilst the care he has received at home and in hospital is described briefly and in positive terms, the fact that he is having to go back to hospital is viewed as something he does not have any control over. This does not necessarily make it easy and there are hints within this interview that it is not an altogether pleasant experience despite John's regular protestations that it is something he is accepting of.

Case 07 - Betty

Synopsis

Betty, Female, 88 (and son Stew). Interview location: Hospital room (private room) for Betty (Stew not present), home for Stew (Betty present). Betty mentions in the interview that the time between the admission and unplanned readmission was not very long, it appears the readmission took place within approximately 24 hours of being discharged home. Betty discusses having had chest pains and telling her son who called a doctor, this led to her admission to hospital. It appears the unplanned readmission was also for symptoms relating to heart failure (chest pain).

Betty was in hospital during the interview (after her unplanned readmission) but she said that she did not receive any written information after her first admission to hospital. When I asked her son, Stew, during his interview he noted he did not understand the paperwork, he also noted he did not know where it was, I think he had lost it.

Situational constraints:

Uniqueness among other cases:

- Contrast between Betty's positive accounts of care received with Stew's negative perception and how they both conceptualise the unplanned readmission. (example: Stew reported his mother was stressed in contrast to her account)

Findings:

- Perception of Stew: unplanned readmission due to Betty not being 'cured' the first time, not being in an appropriate setting and being discharged too soon. Betty more stoical, accepting, downplays her symptoms. Perception that unplanned readmissions are to be expected at her age, grateful to be around, being on borrowed time.
- Impact of the unplanned readmission on wider family, rippling out. Financial implications (more parking to pay etc). Stew playing link role between hospital and wider family causes stress (and communication issues).
- Communication issues, lack of clear messages, information changing quickly/at last minute, uncertainty and mixed messages from different staff.
- Feelings of stress and uncertainty for Stew, he felt forgotten
- Written information not meaningful or used.
- Being in hospital brings back memories of other hospitalisations, of family being hospitalised, or being ill, dying.
- Hospital a positive place, you are looked after, don't have to make an effort, wider family visit.

Excerpts (quotes):

Betty: "*Um, but of course I haven't been terribly ill have I. These pains soon disappeared and I've had several tests. Doctors coming round and listening saying I think you can go home today, tomorrow, so nothing serious just a bleep really. It's certainly nothing to complain about" … "I had chest pain but they were very very minor so that didn't interfere with my way of life" …"I wasn't lying at home fighting for breath or anything like that, I don't know how I came to be back in here but there you are. I feel a lot better now. Ready to start again, ready for the next time I think!"*.

Betty: "*they usually make you very welcome which they did do um you know and offer you a cup of tea and settle in the bed and asking if there's anything you wanted and then you.. From then on there wasn't much to report you just lived normally as though you were in a hotel or something" …"Good...I think everybody would rather be at home than stuck in a hospital. Although as I said nothing to complain about"*

Betty (re: the unplanned readmission): "*it's just coming into hospital, um there's not much more I can say about that….it's just a break you know"*

Betty: "*I'm 88 so I've had my three score years and ten haven't I so I'm now on borrowed time so I'm fortunate with the extra time that's the way I look at it but that's something you can't do anything about you just have to accept your lot and that's it"*

Betty: "*What has been nice I've found is all the visitors I've had. People in the family that I haven't seen for a long time have turned up and sat for a couple of hours here so that's been a benefit" ... "So that's a benefit to me it's been that I've had a few more visitors but* *um nice to see the youngsters all grown up telling me what they're up to and that sort of thing".*

Stew: "*Yeah, we got a load of paper and all that but you don't tend to look at that do you, I mean it's better if you can sort of talk through*"

Stew: "Well stressful because you know that it's going to end up with her going back into hospital and obviously it's the upset it causes her um you know…but um yeah as I say obviously you know from yourself whether someone is ill or not and as soon as she got here and started coughing and spluttering again it was obvious it weren't right um it turned out she hadn't even been treated for the virus she went in for…".

Stew: "*Stressful cos I suffer with stress anyway um I had a bit of an episode so a few years ago and I'm still on citalopram now and it was something I could have done without um but you know you just have to get on with it I suppose it was just the fact that I couldn't get information"*

Stew: "*Yeah it's just the stress and not knowing what's going on and you try and deal with your family outside and and trying to give them information and you can't you, you don't know what's going on .."*

Commentary:

For Betty, it appears the actual experiences of care have been positive. When talking about the time at home between readmissions and the readmission itself she appears to minimise her symptoms and place the responsibility on her son to decide about calling the GP or ambulance. However, there are some moments when Betty does communicate that she is a worrier and that the experience has not been altogether positive. She does seem to be stoical and is preparing herself for further readmissions in the future due to her age and condition. For Stew his mother was distressed by being in hospital, this is not reflected in the same way in her account. Stew also describes in detail the emotional turmoil and impact of his mother's readmission on him. Issues around communication were particularly stressful for him. Having the role of mother's caregiver and being a link for the family appear to be stressors. Furthermore, his expectation is that his mother should be 'cured' before discharge. There were moments when Stew outlined the kind of communication and care he would like to see indicating he is a thoughtful and reflective person and he was able to put his mother's care into a wider context throughout. In terms of paperwork both Betty and Stew appeared to have a lack of understanding and paperwork did not appear to be important as they had lost it and Stew even noted he did not understand it.

Case 08 - Neil

Synopsis

Neil, Male, 86. Interview location: Hospital ward (at the bedside). Readmission within a few hours (readmitted same day as discharge home). Neil had a fall and had been admitted after the first fall. Then, after being discharged home, he fell at home again and so was readmitted that same day. Both times he was taken to hospital via ambulance.

I interviewed him approximately three weeks after the unplanned readmission, he had been in hospital ever since his unplanned readmission. Neil did not want me to contact his daughter to see if she wanted to take part in the research.

Neil did not have any written information from the first admission and as he was still in hospital after his unplanned readmission, he had yet to be given any written information regarding that stay.

Situational constraints:

- Neil was in a busy bay of four patients
- Neil felt unwell during the interview, we stopped interviewing quickly though Neil continued to talk to me about his life after we stopped recording.
- Interview conducted after I had been on a clinical shift, in the early evening, perhaps this contributed to the interview outcome.

Uniqueness among other cases:

- The most unwell person interviewed

Findings:

- Feeling frustrated at being in hospital so long because of the unplanned readmission, would prefer to be at home.
- Treats each day as a bonus
- Appears stoical about health conditions and having falls
- Unsure about what is going on, doesn't know why he has the symptoms he does

Excerpts (quotes):

Neil: "*on the Saturday night I was getting my tea out of the oven and I had another bad fall which cut me head and um made me nose and arm bleed and hurt me back and here I am today*"

Neil: *"they're not sure….I've had XRays on me back and the only thing they can see was a couple of the little uh vertebrae aren't they? They had closed up, compressed where I fell… But other than that they couldn't find nothing else but I'm still getting a lot of terrible back pain".*

From my research journal: I wondered whether Neil was tired from his day and whether this contributed to his difficulties breathing and the length of the interview. However, Neil had been very happy to speak with me and when I explained the previous day (during my lunch break) that I could come after my shift the next day he welcomed that. In my reflective notes I also commented on the fact that he kept talking after we stopped recording, and after a few moments he said 'ok get home safe' which I took as my cue to leave. Neil also said, 'I hope you've found that useful' and I assured him that I had. Despite his experiences of being unwell he still wanted to make sure he could help. I thanked him and wanted to make it clear how much I appreciated him taking part and telling his story. I thought to myself that despite some moments when his demeanour was 'grumpy' he was very kind. He also noted that he really wanted to be at home and that despite the pain he would be 'walking out' if they didn't let him leave which suggests he may be feeling frustrated.

Commentary:

Initially, Neil appears to take the experience of readmission in a stoical, or matter of fact way. He knows he is not feeling well and that the healthcare team are trying different types of medication to help. However, the readmission has also caused Neil frustration and perhaps even anger - he would prefer to be at home and is frustrated by the pain. So, whilst I got the impression Neil understood why he needed to be readmitted he was frustrated and how long the process was taking and missed being at home.

Case 11 - Evelyn

Synopsis

Evelyn, Female, 97. Interview location own home. Unplanned readmission within two days (approximately). Initial admission to hospital due to possible heart attack and stayed for six days. Then, readmission to ward via the emergency department and stayed for two days. First admission prompted by Evelyn calling daughter who came round and then called GP who then called an ambulance. After this admission home care was arranged for Evelyn (two nights later she was back in hospital, Evelyn had a total of two weeks' worth of home care planned). Readmission prompted by healthcare professional providing a check-up (not sure what team or what type of healthcare professional) and then calling for an ambulance. Did not want me to call daughter but happy for me to leave information pack for her daughter. I got no response.

There was a pile of written information on a coffee table in the living room where we were sitting for the interview. On this pile was: A discharge letter from the first admission and discharge letter from the readmission, copies of medicine information leaflets (copies of what would be found inside medication boxes), a hospital at home leaflet, an Age UK leaflet and a signed purple DNACPR form.

Situational constraints:

- Communication challenges as Evelyn has hearing and speech issues.

Uniqueness among other cases:

Findings:

- Written information received but not meaningful or useful. Not aware of content or significance of it. Not aware of requirement for a GP review post unplanned readmission.
- No recall of written information being explained verbally or of any discharge advice after unplanned readmission.
- Experience of care during hospitalisation
- Downplaying symptoms
- Unplanned readmission a surprise but reassuring, hospitalisation expected due to age

Excerpts (quotes):

Evelyn: "*When I came out of hospital on Monday and I was told they'd be someone to come and check my blood pressure and heart which they did, I don't know who they are."*

Evelyn: "*slight heart attack*" and "*it wasn't a bad heart attack".*

Evelyn: "*It's just sitting there. If you're ill, when I first went in it didn't worry me but when I started getting better just sitting in that chair. I can't see to read or write which is worse in my case...but tis boring especially when everybody is asleep it's so quiet…but there's nothing I don't think they could do to alter that but that's my only complaint really of the whole experience".*

Evelyn: "*I had wonderful treatment I've got no faults at all with anything, the treatment I had couldn't have been better if I'd been private it was excellent, it didn't matter what you asked, as it happened you didn't have to ask for much but they're so friendly".*

Evelyn: "*I didn't really need any looking after I felt, I felt a bit weak, I'm still not quite got the energy I had before I had this but I'm doing very well".*

Evelyn: "*Nobody will be in for a day or two *laughs* no one's that interested anymore *laughs*"*

Evelyn: *"you are very friendly and you're interested in the work you're doing and I was pleased to help you because you appreciated what I said"*

Evelyn: "*I think it was all done so quickly to be quite honest it really surprised me"*

Evelyn: "*Well, I was very satisfied, it give me great satisfaction when I came out the second time to say that it was exactly the same my medication and everything I felt quite happy yeah"*

Evelyn: "*I'm not terribly worried about hospitals at my age because how can I expect any different *laughs* I love hospitals I worked at the Hospital for 18 years…".*

Evelyn: *"no I don't I just don't feel I've got quite the energy as I had before I went in but I just put that down to age, I can't expect to keep going *laughs*".*

Commentary:

It seems Evelyn was reassured to have gone back to the hospital, despite verbally underplaying her symptoms her behaviours perhaps show she was worried which again support Evelyn being reassured about going back in. Evelyn does appear to have an expectation that she will be in and out of hospital due to her age. This readmission appears to signify to her that she is getting older. There seems to be a discrepancy between what was said in the written information (discharge letters saying medications need GP review) vs. what Evelyn understood in hospital on discharge from the readmission (all same, medically OK, medications same). The role of the nurse was touched on, Evelyn however was not always sure who she was being cared for by. Evelyn was very positive about being involved in the interview and being listened to.

Case 12 - Joan

Synopsis:

Joan, Female, 78. Interview location in Hospital Cafe (on request of Joan). Readmission return period not clear, but according to Joan it was quick. First admission was for having exacerbation of COPD, query pneumonia and a fall. As a result of the fall sustained a knock to the head and is also now using a walker. Readmitted due to diarrhoea (this is Joan's explanation) and daughter instigated by calling a healthcare professional. Initially Joan was resistant for me to leave a pack for her daughter, she did not want me to get in touch. Then by the end of the interview she said I could leave a pack with her but when I tried to call to follow up there was no reply so I was unable to get in touch with Joan's daughter for an interview.

Joan noted she did not remember receiving any verbal information, but she did have some written information. These were discharge letters and were crumpled in her bag. She was able to show me them. When referring to them she noted she understood them. Joan verbally noted how frustrated she was with the letters, hospitalisation, and appointments. She commented on the cost of taxis to get to and from hospital.

Situational constraints:

- Interview location public and noisy though efforts made to choose a table furthest away from other people to ensure privacy

Uniqueness among other cases:

Findings:

- Written information available, does not appear to be referred to or used as a source of information. Frustration linked to paperwork and hospital in general. Lack of recall of verbal information or advice.
- Unplanned readmission within a short timeframe
- Unplanned readmission not conveyed as significant, stoical acceptance, but there was a sense of relief associated to it
- Communication issues during hospitalisation
- Experience during hospitalisation, impact of it (exhaustion)

Excerpts (quotes):

Joan: "*um no it* [discharge letter] *didn't tell me anything I didn't know...it would do to a non-lay person but not to me. I worked in hospitals"*

Joan: "*I haven't really got much to say about it because I was pretty bed bound, I think I was still suffering from my either my knock on my head and the pneumonia and so I was very weak and I really can't remember much about it I mean it was in out in out"*

Joan: "*I was going back in because I'd got this awful diarrhoea um what else is it meant to mean? I worked in a hospital I know what they're like like you do um sorry um, no it didn't mean anything to me".*

Joan: "*I just let things go by I took things as they came and I'm not a big worrier um so it was OK, no worries about that.''*

Joan: "*uh well I suppose relief that DAUGHTER wasn't going to have to look after me and I don't know why I was having the diarrhoea I mean my tummy was all obviously upset from what I don't know and what pills I was on you know um, no nothing else. OK, I'm just going back in"*

Joan: *"...I do like to see the same person each time because otherwise, I mean they have swarms of them and how things don't get passed on or do get passed on that was the only thing that worried me"... "I didn't want to repeat everything"*

Joan: "*I did get my bed moved up in both cases to be right next to the window um so I had a lovely view, on the top floor"*

Joan: "*The only thing I got was that I was exhausted when I came out...well they wake you at a quarter past five in the morning"*

Commentary:

For Joan her readmission is a relief - because then her daughter will no longer have to care for her and she will be able to get help with her diarrhoea. There appears to be some bravado or an attitude that she is OK with the readmission and with hospital admissions in general, however, there are also comments made that suggest Joan did not always understand what was going on. This attitude is further discussed in the reflective diary, Joan comes across as "spiky" and is very clear to the staff at the outpatient appointment that she is independent and will not require her daughter. Joan mentions that she was in and out and back in again in a quick period of time and appears to be matter of fact mentioning this has no meaning for her apart from perhaps relief and that she was very happy with the care she received. She is in a hurry to get back to her home when the taxi arrives.

Appendix 2 – Patient and Family Information Sheets

Readmission to hospital
Exploring the perception and experiences of people aged 65 years and over (and their families or caregivers) of readmission to an acute hospital Trust within 30 days of discharge.

Participant Information Sheet

I would like to invite you to take part in this research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. The researcher would go through the information sheet with you and answer any questions you have.

Talk to others about the study if you wish and ask me if there is anything that is not clear.

What's involved?
I am proposing to interview patients about their experience of returning to hospital within 30 days of being discharged from hospital. This could be a return to a ward or clinical area that is different to the area you were initially discharged from. I am particularly interested in hearing your story of what happened that meant you came back to hospital. I am interested in anything that you think is important not necessarily only things to do with your health.

I think that by listening to a range of people there is the potential to make improvements to how people are looked after in hospital and how they are supported when they leave. I am also hoping this would mean nurses are more aware of issues that may affect people when they are in hospital. At the moment most of the information about readmissions to hospital is based on statistics and not on the perspectives of patients or friends and family.

Why have I been invited?
You have returned to hospital within 30 days of being discharged from hospital and are aged 65 years or over. The specialist nurses who work at the hospital have identified you as someone who may be suitable to take part in the study which is why you are receiving this information.

Do I have to take part?

It is completely up to you whether you would like to take part or not. You are free to leave the study at any time without giving a reason. Your decision to take part, not take part, or leave the study would have no effect on the standard of care you receive in hospital or at home. If you do decide to take part anything you say and the information you provide would be kept confidential.

What would taking part involve?

If you agree to take part I would contact you to arrange a time and place to meet that is convenient to you, this could be in your own home or in hospital if you are still there. I would explain the study further to you and would be able to answer any questions or queries you have. At this point I would also go through the consent form with you and obtain written informed consent from you before starting an interview.

At the interview I would like to know your thoughts, perceptions, and experiences of returning to hospital. I would be interested in your views on what happened that meant you returned within 30 days. I would also be interested to find out how this has affected you and those around you. As part of the interview I would also ask you whether you received any written information from healthcare professionals during your initial hospital visit or during your discharge, and, if you did I would be interested to see what you were given. I would also ask you whether you received a paper copy of your discharge letter.

I would also ask you whether there was someone significant to you, perhaps a family member, friend or neighbour, who was around during the time of your hospital stay and readmission to hospital. If there is such a person I would ask whether you would be happy for me to have a discussion with them about your return to hospital. I would not give them any information about you or what you say in the interview, I would just be interested in their perspective on your return to hospital. If there is such a person I would provide you with an information pack and ask you to give it to that person. If they return the reply slip to me I would then contact them about interviewing them. After our interview I would contact you once about two weeks later to find out whether you had been able to give the information pack to your significant other. That would be the only time I would contact you again.

The interview would take approximately 60 minutes to complete and would be audio recorded (with your consent) and transcribed later.

What are the possible benefits of taking part?

Some people have found that having the time and space to tell their story about a situation to someone who is removed from it is therapeutic and they have found it helpful to be able to talk. This may or may not happen for you.

The benefits of taking part could also be to other people in the future as this research could help improve the care and support other people receive when they are in hospital or being discharged from hospital. What you share with us would hopefully help others in the future.

It would also hopefully help nurses understand what is important to people when they are in and just home from hospital.

What are the possible disadvantages and risks of taking part?

You may feel uncomfortable or distressed when remembering your return to hospital or your period of ill health. If you do become upset I would pause the interview and be sensitive to your needs. I would ask you whether you wish to continue with the interview and you would be able to decide whether you would like to continue or end the interview. I can also provide you with information on local and national support services.

It is a possibility that people's stories may reveal situations where they or someone close to them are at risk of physical, emotional, sexual or financial abuse. Stories may also highlight issues of poor professional practice by healthcare workers.

As a registered nurse, I am on the Nursing and Midwifery Council (NMC) Register and must adhere to a Code of practice. As part of this Code I must ensure the safety and care of patients and the public. For safeguarding issues, I would talk through your experiences, make sure you are safe, and explain the next steps. I would discuss the concerns with the Trust Safeguarding Adult Lead Practitioner, who would provide advice and guidance. This would be done to ensure your safety and would be managed sensitively and appropriately. This follows both NMC and Trust guidelines.

For issues around professional practice, we would discuss the situation and I would support you to contact the Patient Advice and Liaison Service (PALS) who offer guidance and support. I would also speak to the Trust Freedom to Speak Up Guardian for advice. If this situation were to take place I would make sure you felt safe, were included in decision making and that your confidentiality was protected. However, if I felt you or someone you know were at risk of harm I would need to share this information with other professionals as a duty of care. I would always discuss what information I need to share and with whom prior to doing so.

As part of the monitoring processes for this research, I will have regular debriefing meetings with my supervisor to discuss any possible issues of concern and seek their advice. These will be confidential and your personal details would not be disclosed. My supervisor's input is intended to help decide the best course of action and to ensure I am following the appropriate research governance and professional practice guidelines. Before talking with my supervisor I would discuss the situation with you and identify what support or information you would find helpful.

Would my taking part in this study be kept confidential?

Yes, I would follow ethical and legal practice and all information about you would be handled in confidence.

Would there be any payments or expenses?

There would be no payments for participating in this study.

What would happen if I don’t want to carry on with this study?
If you withdraw from the study, I would destroy all your identifiable information. If your decision to withdraw takes place after I have started analysing information I may not be able to destroy my analysis. If you want to withdraw at any time please contact me or a member of my PhD supervisory team.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to me or my PhD supervisor (Dr Helen Aveyard) who would do their best to answer your questions. You can contact me on 01865 488214 and Dr Aveyard on 01865 484848.

If you have any concerns about how the research is being conducted, you can contact Mrs Hazel Abbott, Ethics Lead, Faculty of Health and Life Sciences at Oxford Brookes University on email: heabbott@brookes.ac.uk or phone: 01865 482639.

Involvement of the General Practitioner/Family Doctor (GP)
We would not inform your GP or other healthcare professional if you participate in this study but you are free to tell them yourself if you would like them to know.

What would happen to the results of this research study?
This research will involve me listening to stories of people who are aged 65 years or over and who have been readmitted to hospital within 30 days of discharge. This research will combine the experiences of a number of people so that nurses and other healthcare professionals can have a good understanding of patients’ experiences and plan improvements based on this information. Findings from this project may be used for staff training purposes. There would probably be articles and conference presentations that result from this project. This project would also be written up into a thesis towards my PhD. In these documents no participants who shared their stories would be identifiable.

If you are interested in receiving an update on this research, please let me know. If you decide to take part I would ask you at the end of the interview whether you wanted to receive any updates. Then, I would take a note of your contact information and ask for your permission to keep it securely until I send you the update. This may take a few months and would be available towards the end of 2018. Once I had sent you the update I would safely destroy your contact information. I would be the only person who has access to your personal contact details.

Who is organising and funding this research?
This research is being carried out as part of my PhD studies. I have a scholarship to undertake this research from Oxford Brookes University.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee (REC) to protect your interests. This study has been reviewed by the Oxford Brookes University Faculty Research Ethics Committee (FREC Study Number 2016/32).

Sources of support

If you would like to report any concerns, make suggestions or a complaint about your experience at OUH you can do so confidentially through the Patient Advice and Liaison Service (PALS). You can contact them on the phone, via email or in person. Their leaflet with information about the service and their contact details is included in this pack.

Other places that can offer support include:

- Age UK run a free national advice line open 8am – 7pm 365 days a year. To talk to someone call 0800 678 1174.
- The Silver Line is a helpline for older people and runs a free confidential helpline providing information, friendship and advice to older people. Call 0800 470 80 90.
- The Royal Voluntary Service has volunteers that can assist older people looking to get help to become more independent. They can be contacted online at: www.royalvoluntaryservice.org.uk via the telephone (standard rate) 0845 608 0122 or by post: Royal Voluntary Service, Beck Court, Cardiff Gate Business Park, CARDIFF CF23 8RP.
- If you are a care giver Carers UK has information and support online at www.carersuk.org or you can call them on 0808 808 7777.
- Citizens Advice offer advice on benefits, work, debt and money, family, housing, law and immigration. You can access advice online www.citizensadvice.org.uk or by calling 03444 111 444.
- You can contact your GP or practice nurse if you have any health issues or would like health advice. You can visit www.nhs.uk for information on GP services and how to find a GP.

Further information:

If you require any further information please contact:

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The supervisory team for the PhD consist of:

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Dr Helen Walthall – *Programme Lead Nursing Department of Nursing Faculty of Health and Life Sciences Oxford Brookes University.*
Professor Debra Jackson – *Director, Oxford Institute of Nursing, Midwifery & Allied Health Research (OxINMAHR); Professor of Nursing, Faculty of Health & Life Sciences, Oxford Brookes University; Associate Chief Nurse (Research), Oxford University Hospitals NHS Foundation Trust.*

A copy of this information sheet and the signed consent form would be given to you to keep.

Thank you for taking the time to read this information sheet.

OXFORD BROOKES UNIVERSITY Oxford University Hospitals NHS Foundation Trust Oxford Institute of Nursing, Midwifery & Allied Health Research research • patient care • education

Readmission to hospital
Exploring the perception and experiences of people aged 65 years and over (and their families or caregivers) of readmission to an acute hospital Trust within 30 days of discharge.

Participant Information Sheet

I would like to invite you to take part in this research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. The researcher would go through the information sheet with you and answer any questions you have.

Talk to others about the study if you wish and ask me if there is anything that is not clear.

What's involved?

I am proposing to interview patients and their friends or family about their experience of returning to hospital within 30 days of being discharged from hospital. This could be a return to a ward or clinical area that is different to the area they were initially discharged from. I am particularly interested in hearing your story of what happened that meant your friend or family member returned to hospital. I am interested in anything that you think is important not necessarily only things to do with health.

I think that by listening to a range of people there is the potential to make improvements to how people are looked after in hospital and how they are supported when they leave. I am also hoping this would mean nurses are more aware of issues that may affect people when they are in hospital. At the moment most of the information about readmissions to hospital is based on statistics and not on the perspectives of patients or friends and family.

Why have I been invited?

You have a friend or family member, who is aged 65 years or over and who has returned to hospital within 30 days of being discharged. They have been interviewed about this experience and have given your name as someone who is significant to them and knows about their readmission experience. They have identified you as someone who may be suitable to take part in this study which is why you are receiving this information.

Do I have to take part?

It is completely up to you whether you would like to take part or not. You are free to leave the study at any time without giving a reason. Your decision to take part, not take part, or leave the study would have no effect on the standard of care your friend or family member

receives in hospital or at home. If you do decide to take part anything you say and the information you provide would be kept confidential.

What would taking part involve?

If you agree to take part I would contact you to arrange a time and place, such as your home, that is convenient to you. I would explain the study further to you and would be able to answer any questions or queries you have. At this point I would also go through the consent form with you and obtain written informed consent from you before starting an interview.

At the interview I would like to know your thoughts, perceptions, and experiences of your friend or family members' return to hospital. I would be interested in your views on what happened that meant your friend or family member returned within 30 days. I would also be interested to find out how this has affected you and those around you.

The interview would take approximately 60 minutes to complete and would be audio recorded (with your consent) and transcribed later.

What are the possible benefits of taking part?

Some people have found that having the time and space to tell their story about a situation to someone who is removed from it is therapeutic and they have found it helpful to be able to talk. This may or may not happen for you.

The benefits of taking part could also be to other people in the future as this research could help improve the care and support other people receive when they are in hospital or being discharged from hospital. What you share with us would hopefully help others in the future. It would also hopefully help nurses understand what is important to people when they are in and just home from hospital.

What are the possible disadvantages and risks of taking part?

You may feel uncomfortable or distressed when remembering your friend or family members return to hospital or their period of ill health. If you do become upset I would pause the interview and be sensitive to your needs. I would ask you whether you wish to continue with the interview and you would be able to decide whether you would like to continue or end the interview. I can also provide you with information on local and national support services.

It is a possibility that people's stories may reveal situations where they or someone close to them are at risk of physical, emotional, sexual or financial abuse. Stories may also highlight issues of poor professional practice by healthcare workers.
As a registered nurse, I am on the Nursing and Midwifery Council (NMC) Register and must adhere to a Code of practice. As part of this Code I must ensure the safety and care of patients and the public. For safeguarding issues, I would talk through your experiences, make sure you are safe, and explain the next steps. I would discuss the concerns with the Trust Safeguarding Adult Lead Practitioner, who would provide advice and guidance. This would be done to ensure your safety and would be managed sensitively and appropriately. This follows both NMC and Trust guidelines.

For issues around professional practice, we would discuss the situation and I would support you to contact the Patient Advice and Liaison Service (PALS) who offer guidance and support. I would also speak to the Trust Freedom to Speak Up Guardian for advice. If this situation were to take place I would make sure you felt safe, were included in decision making and that your confidentiality was protected. However, if I felt you or someone you know were at risk of harm I would need to share this information with other professionals as a duty of care. I would always discuss what information I need to share and with whom prior to doing so.

As part of the monitoring processes for this research, I will have regular debriefing meetings with my supervisor to discuss any possible issues of concern and seek their advice. These will be confidential and your personal details would not be disclosed. My supervisor's input is intended to help decide the best course of action and to ensure I am following the appropriate research governance and professional practice guidelines. Before talking with my supervisor I would discuss the situation with you and identify what support or information you would find helpful.

Would my taking part in this study be kept confidential?
Yes, I would follow ethical and legal practice and all information about you would be handled in confidence.

Would there be any payments or expenses?
There would be no payments for participating in this study.

What would happen if I don't want to carry on with this study?
If you withdraw from the study, I would destroy all your identifiable information. If your decision to withdraw takes place after I have started analysing information I may not be able to destroy my analysis. If you want to withdraw at any time please contact me or a member of my PhD supervisory team.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to me or my PhD supervisor (Dr Helen Aveyard) who would do their best to answer your questions. You can contact me on 01865 488214 and Dr Aveyard on 01865 484848.

If you have any concerns about how the research is being conducted, you can contact Mrs Hazel Abbott, Ethics Lead, Faculty of Health and Life Sciences at Oxford Brookes University on email: heabbott@brookes.ac.uk or phone: 01865 482639.

What would happen to the results of this research study?
This research will involve me listening to stories of people who are aged 65 years or over and who have been readmitted to hospital within 30 days of discharge. This research will combine the experiences of a number of people so that nurses and other healthcare professionals can have a good understanding of patients' experiences and plan improvements based on this information. Findings from this project may be used for staff training purposes. There would probably be articles and conference presentations that result from this project. This project would also be written up into a thesis towards my PhD. In these documents no participants who shared their stories would be identifiable.

If you are interested in receiving an update on this research, please let me know. If you decide to take part I would ask you at the end of the interview whether you wanted to receive any updates. Then, I would take a note of your contact information and ask for your permission to keep it securely until I send you the update. This may take a few months and would be available towards the end of 2018. Once I had sent you the update I would safely destroy your contact information. I would be the only person who has access to your personal contact details.

Who is organising and funding this research?
This research is being carried out as part of my PhD studies. I have a scholarship to undertake this research from Oxford Brookes University.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee (REC) to protect your interests. This study has been reviewed by the Oxford Brookes University Faculty Research Ethics Committee (FREC Study Number 2016/32).

Sources of support
If you would like to report any concerns, make suggestions or a complaint about your experience at OUH you can do so confidentially through the Patient Advice and Liaison Service (PALS). You can contact them on the phone, via email or in person. Their leaflet with information about the service and their contact details is included in this pack.

Other places that can offer support include:

- Age UK run a free national advice line open 8am – 7pm 365 days a year. To talk to someone call 0800 678 1174.
- The Silver Line is a helpline for older people and runs a free confidential helpline providing information, friendship and advice to older people. Call 0800 470 80 90.
- The Royal Voluntary Service has volunteers that can assist older people looking to get help to become more independent. They can be contacted online at: www.royalvoluntaryservice.org.uk via the telephone (standard rate) 0845 608 0122 or by post: Royal Voluntary Service, Beck Court, Cardiff Gate Business Park, CARDIFF CF23 8RP.

- If you are a care giver Carers UK has information and support online at www.carersuk.org or you can call them on 0808 808 7777.
- Citizens Advice offer advice on benefits, work, debt and money, family, housing, law and immigration. You can access advice online www.citizensadvice.org.uk or by calling 03444 111 444.
- You can contact your GP or practice nurse if you have any health issues or would like health advice. You can visit www.nhs.uk for information on GP services and how to find a GP.

Further information:
If you require any further information please contact:

Emma Pascale Blakey:
Doctoral Researcher
Oxford Institute of Nursing, Midwifery & Allied Health Research (OxINMAHR)
Faculty of Health and Life Sciences
Level 2 Colonnades
Headington
Oxford
OX3 0BP
Tel: 01865 488214
Email: 15128144@brookes.ac.uk

The supervisory team for the PhD consist of:

Dr Helen Aveyard – *Senior Lecturer Department of Nursing Faculty of Health and Life Sciences Oxford Brookes University.*
Dr Helen Walthall – *Programme Lead Nursing Department of Nursing Faculty of Health and Life Sciences Oxford Brookes University.*
Professor Debra Jackson – *Director, Oxford Institute of Nursing, Midwifery & Allied Health Research (OxINMAHR); Professor of Nursing, Faculty of Health & Life Sciences, Oxford Brookes University; Associate Chief Nurse (Research), Oxford University Hospitals NHS Foundation Trust.*

A copy of this information sheet and the signed consent form would be given to you to keep.

Thank you for taking the time to read this information sheet.

Appendix 3 – Consent form

CONSENT FORM

Code……………………..

Project: *Readmission to hospital - Exploring the perception and experiences of people aged 65 years and over (and their families or caregivers) of readmission to an acute hospital Trust within 30 days of discharge.*

Name of researcher: Emma Pascale Blakey – PhD candidate and staff nurse
OxINMAHR, Oxford Brookes University, The Colonnade, Headington Campus, Oxford, OX3 0BP.

Please initial box

1. I confirm that I have read and understand the information sheet version ….. dated ….. for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving reason and without my medical care or legal rights being affected. ☐
3. I understand and agree that I will be interviewed about my experience of returning to hospital / my friend or family member's experience of returning to hospital by a PhD candidate and this interview will be audio-recorded and transcribed for the purpose of this study. ☐
4. I understand that the record of the interview may be looked at by individuals from Oxford Brookes University who are members of the supervisory team or by regulatory authorities from OUH NHS Foundation Trust, where it is relevant to my participation in this research. ☐
5. I agree to the use of anonymised direct quotations in the reporting of findings. ☐
6. I understand that the researcher may access my medical notes in order to file a copy of this consent form and information sheet within my notes. I give permission for these individuals to have access to my records for this purpose. ☐
7. I agree to take part in the above study YES/NO

…………………………………………………………………..	……………………………….	……………………………………
Name of Participant	Date	Signature
…………………………………………………………………..	……………………………….	……………………………………
Name of Person taking consent	Date	Signature
…………………………………………………………………..	……………………………….	……………………………………
Name of witness (if requested by participant)	Date	Signature

One copy of the signed consent form and information sheet will be retained by the research participant. One signed copy of the consent form will be stored securely by the research team.

Appendix 4 – Invitation to take part in a research study

Emma Pascale Blakey
PhD Candidate
Oxford Institute of Nursing, Midwifery and Allied Health Research
Oxford Brookes University
The Colonnade
Headington Campus
Oxford
OX3 0BP

Invitation to take part in a research study

Readmission to hospital – Exploring the perception and experiences of people aged 65 years and over (and their families or caregivers) of readmission to an acute hospital Trust within 30 days of discharge.

Hello my name is Emma and I am a staff nurse at the John Radcliffe Hospital (Oxford University Hospitals NHS Foundation Trust) and a PhD candidate at the Oxford Institute of Nursing, Midwifery and Allied Health Research (OxINMAHR) based at Oxford Brookes University. As part of my PhD studies I have been looking at why and how people aged 65 and over return to hospital within 30 days of having been discharged from hospital.

At the moment very little is known about how patients experience returning to hospital or what perspective they have on this. We also do not know much about how patients' friends or loved ones experience this either. Knowing how you feel about your return to hospital and what your thoughts are on this are vital. By listening to peoples' experiences of coming back to hospital we can help to improve future care provided by the hospital.

This letter is to invite you to take part in a research project for patients who have returned to hospital within 30 days of being discharged and who returned to an Oxford University Hospitals NHS Foundation Trust hospital.

Alongside this letter is an information sheet telling you more about the research, what we are aiming to do and what it would mean to you if you agreed to take part. You are under no obligation to take part and are free to withdraw at any point throughout the process.

Although a nurse has given you this letter, the care you receive will not be affected by whether you take part or not and is not linked to any care you receive from your clinical team. The purpose of this research is to improve future patient care by understanding more about patients' experiences of readmission to hospital.

If you are interested in taking part, please complete the reply slip below and return in the pre-paid envelope enclosed in this letter which is addressed to me. Alternatively you can call the project office on 01865 484158.

Thank you for taking the time to read this letter and information sheet.

Emma

I would be interested in taking part in the research on readmissions to hospital.

Please contact me on:

Address:

Telephone:

Email:

Appendix 5 – Interview schedule

Readmission to hospital
Exploring the perception and experiences of people aged 65 years and over (and their families or caregivers) of readmission to an acute hospital Trust within 30 days of discharge.

Episodic interview Sheet

Introduction:
Thank you for agreeing to take part in this interview.

In this interview I will ask you to recount your return to hospital / your friend or family member's return to hospital. I will then ask you further questions about this or probe where necessary for clarification.

It should take about 45 – 60 minutes to complete. If at any time, you wish to stop or have a break, please let me know. If you want any questions repeated or clarified, please ask. If there are any questions you would rather not answer please let me know.

Code………………………. (Researcher to complete)

The following interview prompts will be used to guide the interviews:

- First of all, could you tell how old you are? Who do you live with?
- Can you talk to me about your return to hospital? / Can you talk to me about your friend or family member's return to hospital?
- What did this return to hospital mean to you?
- What was the most significant aspect of your return to hospital? / What was the most significant aspect of your friend or family member's return to hospital?
- If you look back is there anything you think might have made a difference to your / friend or family member's readmission?
- Is there a family member/friend/caregiver I could talk to about your readmission?
- Is there anything else you would like to talk about?
- Do you have any questions?
- Would you like me to send you an update on this research when it is available? If so, please let me know the best way to contact you.

Appendix 6 – Ethical approval letters

Emma Blakey
PhD Research Student
OxINMAHR
Colonnade Building
Oxford Brookes University
Gipsy Lane Campus

11 April 2017

Dear Emma

Re. The perception and experiences of people aged 65 years and over (and their families and caregivers where appropriate) of readmission to an acute hospital trust within 30 days of discharge

Thank you for your recent correspondence, further to the review of your application by the Faculty Research Ethics Committee.

I can confirm that all the points raised in my letter dated 22 February 2017 have been satisfactorily addressed. I am therefore pleased to approve the research by Chair's Action, on behalf of the Faculty Research Ethics Committee.

I enclose hard copies of the necessary information for forwarding with your application to the NRES for ethics review and to the HRA in order to negotiate access to the research site. When you are ready to submit, please transfer to me the IRAS form for electronic authorisation on behalf of OBU, the Research Sponsor. Also, when submitting your application to the HRA, you will need to complete a Statement of Activities and a Schedule of Events (see http://www.hra.nhs.uk/resources/hra-approval-applicant-guidance/statement-activities-hra-approval/).

If you have any further queries, please do not hesitate to contact me.

Yours sincerely

Hazel Abbott
Chair, Faculty of Health and Life Sciences Research Ethics Committee

Cc. Dr Helen Aveyard, PhD Supervisor

NHS
Health Research Authority

Ms Emma Pascale Blakey
Oxford Brookes University
The Colonnade,
Headington Campus
OX3 0BP

Email: hra.approval@nhs.net

10 July 2017

Dear Ms Blakey

Letter of HRA Approval

Study title:	**The perception and experiences of people aged 65 years and over (and their families or caregivers where appropriate) of readmission to an acute hospital trust within 30 days of discharge**
IRAS project ID:	**221137**
REC reference:	**17/LO/1073**
Sponsor	**Oxford Brookes University**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also

provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.

- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **221137**. Please quote this on all correspondence.

Yours sincerely

Kelly Rowe

Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Hazel Abbott, Oxford Brookes University, Sponsor Representative*
Heather House, Oxford University Hospitals NHS Foundation Trust, Lead NHS R&D Contact
Dr Helen Aveyard, Oxford Brookes University, Academic Supervisor

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Covering letter on headed paper [Cover Letter]	1.0	11 April 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Indemnity]	1.0	18 July 2016
Interview schedules or topic guides for participants [Interview Schedule]	5.0	21 June 2017
IRAS Application Form [IRAS_Form_08062017]		08 June 2017
Letter from sponsor [Sponsor Letter]	1.0	11 March 2017
Letters of invitation to participant [Invitation letter (patient)]	4.0	21 June 2017
Letters of invitation to participant [Invitation letter (friends and family)]	3.0	21 June 2017
Other [Statement of Activities]	1.0	10 July 2017
Other [Schedule of Events]	1.0	10 July 2017
Other [Email from Hazel Abbott]	1.0	24 May 2017
Other [Response to Validation Queries]		08 June 2017
Participant consent form [Consent Form]	4.0	21 June 2017
Participant information sheet (PIS) [Participant Information Sheet (PIS)]	4.0	21 June 2017
Participant information sheet (PIS) [Friends and Family Information Sheet]	4.0	21 June 2017
Referee's report or other scientific critique report [Scientific Peer Review Form]	1.0	11 April 2017
Research protocol or project proposal [Study Protocol]	4.0	21 June 2017
Summary CV for Chief Investigator (CI) [CV]	1.0	11 April 2017
Summary CV for student [CV]	1.0	11 April 2017
Summary CV for supervisor (student research) [CV Dr Helen Aveyard]	1.0	11 April 2017
Summary CV for supervisor (student research) [CV Dr Helen Walthall]		11 April 2017
Summary CV for supervisor (student research) [CV Professor Debra Jackson]		11 April 2017

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in

England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Ms Hazel Abbott

Tel: 01865 482639

Email: heabbott@brookes.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The statement of activities and schedule of events will act as agreement of an NHS organisation to participate.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this
Section	**HRA Assessment Criteria**	**Compliant with Standards**	**Comments**
			research study

4.3	Financial arrangements assessed	Yes	No application for external funding has been made. The statement of activities confirms that no funding will be available to participating sites from the sponsor.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type in this study; participating NHS organisation will be a recruiting site. Interviews with participants may take place at site or at participants home.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The CI will also act as PI at site.

The Chief investigator will provide training to the specialist nurses who are helping with recruitment. This will take the form of a teaching session. It will involve a Power Point presentation outlining the purpose of the research and eligibility criteria. There will also be an interactive component where the trainer will go through all the relevant documents with the team and use role play to highlight how recruitment can be conducted. This has already been agreed to by the manager of the team of specialist nurses

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

The Chief Investigator (interviewer) has confirmed that they are employed by the participating NHS organisation. No further HR Good practice checks required.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 7 – Hospital Information Leaflet

“Planning your discharge – Making preparations for your return home”

A patient information leaflet from Oxford University Hospitals NHS Foundation Trust

Access: https://www.ouh.nhs.uk/patient-guide/leaflets/files/13187planning.pdf

Appendix 8 – Recruitment Information and processes

Recruitment – steps followed:

1. Potential specialist nursing teams identified and contacted to arrange a conversation
2. Present study to the team / point of contact in the team, answer any questions
3. If team agrees to support by recruiting potential participants, give recruitment packs and ensure team understand contents of pack and who they can approach about it, including eligibility criteria, why I am doing this research, and share my contact information with them.
4. Create a plan with each team of nurses helping with recruitment: How many packs do they want, identify the best method of communication between us, how do they want any nudges from me (email, phone call, in person visit)?
5. Leave the team with recruitment information packs – make sure there is a Patient Advice Liaison Service (PALS) leaflet in the pack.
6. Follow up with team as agreed / as required. Ask the teams if there are any other teams that may be interested or who they could recommend.
7. Specialist nurses hand out recruitment information packs to potential participants

Aide memoire created for when I received a reply slip:

1. If I receive a completed reply slip, I contact the potential participant using the means they have chosen (phone, email, and letter) to see if they are interested.
2. If they are interested I check eligibility criteria.
3. If they want to get involved and are eligible, we set up a time and place for the interview.
4. Check whether they have any queries or concerns

Aide mémoire created to use before interviews:

1. If the interview is in a person’s home I follow lone working policy and let supervisors know date and time of interview.
2. If the interview is in a person’s home, greet them and follow where they would like to be for the interview.
3. If the interview is in hospital or a clinical setting, we find a family room/area of the participants choosing to conduct the interview in and ensure they feel comfortable.
4. Equipment I will need for the interview: Dictaphone (plus one backup), interview notebook/pad, reflective journal, study master file, copies of all study paperwork, three copies of the consent form, interview guide, pens, and bring the recruitment information pack for friends/family to possibly give at end of interview.
5. Procedure during interview:
    - Begin by introducing myself and the study
    - Ask if they have any questions
    - Go through consent form, receive consent, sign forms

- Put a code on the consent form and interview guide (i.e. C01 if in the community, H01 if in hospital, and identify whether this person is a patient or family member)
- Put Dictaphone on
- Begin interviewing making notes as appropriate.
- At the end, check whether the interviewee has anything to add or if there is anything further they would like to cover. Ask them if they would like to receive any updates on the study. Also ask them if they would like to pick their own pseudonym. If they were a patient who was readmitted take the opportunity to ask them if there is a family member who was close to them during this time and see if I can give them a pack to give to that person?
- Thank them

11. If I am following lone working policy message supervisors as soon as I have left.

12. Once I have left – make notes of everything that comes into my mind about the interview, any reflections and thoughts or comments.

Date	**Team**	**Number of packs given**	**Any feedback?**
24/08/2017	Discharge Liaison (HOSPITAL TOWN)	20	The team have not given any packs out in September as not identified any appropriate patients but they are still interested in supporting this research and will continue helping
01/09/2017	Heart Failure Specialists (HOSPITAL A CITY + HOSPITAL TOWN)	40 (20 for each hospital)	The team have managed to give 2 packs to potential participants The team are motivated to support this research and have asked for follow up meetings
07/09/2017	Discharge Liaison (HOSPITAL A + B CITY)	20	The team have given out 5 packs to potential participants
07/09/2017	Ambulatory Assessment team (HOSPITAL A CITY)	5	The team requested further packs, 10 given in December 2017
23/10/2017	Ambulatory Assessment Team (HOSPITAL A CITY)	3	Nursing and medical staff are interested in this research
23/10/2017	Emergency Department + Critical Care team (HOSPITAL A CITY)	7	Request for further packs, 5 given on 31/10/2017
08/11/2017	Tissue Viability Team (HOSPITAL A CITY)	20	This team cross all medical specialities
21/11/2017	Stroke team (HOSPITAL A CITY)	10	They had heard about the study and already identified a potential participant
29/11/2017	Renal specialist team (HOSPITAL B CITY)	5	
10/01/2018	Cardiology specialists (HOSPITAL A + B CITY)	6	
07/02/2018	Nurse Consultant (Across hospital sites)	5	
Further packs given to these teams throughout Spring 2018 and sent to teams as requested			

Table 3: Recruitment packs and distribution

Table 4: Reply slips, outcomes and comments

Reply slip	**Outcome** (P = patient + interview number) (F = family + interview number)	**Comments**
1	Interview P01 and F01	Interviews conducted at home
2	Interview P02 and P02	Interviews conducted at home
3	No Interview	Person readmitted again. When I called on receipt of reply slip family member emotional. Patient in last few days of life, interview declined.
4	Interview P03	Person wanted information again so re-sent pack to their address. Called back and they wanted me to call back again on 4/12 to confirm an interview on 5/12/17
5	No interview	Relative would like me to call back as the potential participant took sleeping tablet too late and is currently “away with the fairies”. Spoke to potential participant on the phone and does not want to be interviewed as feels like life is hard since they have been back from hospital and they are finding things difficult.
6	No interview	Daughter said they are back in hospital. Patient is too unwell - end of life and deteriorating relatively fast
7	Interview P04	Called 12/12/17 they would like me to call back 14/12 in the evening. Still a possible interview. Called back and set up interview.
8	No interview	Called on 10/01/18 - no answer so called back. Tried repeatedly over several weeks, never any answer.
9	No interview	Interested but has been readmitted again and for ?malignancy so does not feel they are in the right frame of mind to take part (have left conversation open and they will get in touch if they are wanting to be interviewed as they were interested to take part)
10	Interview P05	Called, they are happy to be interviewed, scheduled for 26/01/18. Interview carried out at home.
11	No interview	Called on 5/03/18, spoke to relative who said potential participant had passed away in the night. I apologised and gave my condolences.
12	Interview P06	Interview conducted in hospital environment
13	Interview P07 + FF07	Interview conducted in hospital environment & plan to interview FF07 on 02/05/18 Interview with FF07 conducted.
14	Interview P08	Interview carried out in hospital on 26/04/18
15	Interview P09 & FF09	Interviews carried out 03/05/18 in outpatient department.
16	P10	Interview scheduled for 11am on Monday 14/05/18
17	No interview	Called on 9th May, asked me to call back on 16th May as

		participant due back from hospital on Monday 14th May Called back 20th June participant back at home. Interview scheduled for Monday 25/06/18. Arrived to speak with possible participant, not eligible for participation despite having discussed criteria on the phone.
18	P11	Called 09/05/18, no answer, called back interview conducted on 23/05/18
19	P12	Called and set up interview, interview conducted 01/06/18.
20	P13 + FF13	Called and set up interviews, conducted on 12/06/18
21	P14 + FF14	Called and set up interviews, conducted on 13/06/18

Table 5: Codes and categorical aggregation

Excerpt from interview transcript	**Codes**	**Categorical aggregation (used to create matrix)**
"And quite honestly I had no wish to come home until I felt a bit better so as far as I was concerned, I wasn't glad to be back in hospital from the point of view of having something wrong with me but I was glad to be back where they could do the required treatment… OK?" (Catherine, Case 13)	Emotions Feelings Hospital is the place to go	Emotional impact on patient Meaning of hospital
Excerpt from interviews and notes	**Codes**	**Categorical aggregation (used to create matrix)**
"One of the things is that in the letter from the hospital to the doctor they said they would review his medication but to me that hasn't been done" (Anne, Case 2) Notes: No written document available to show me	Lack of communication Unclear written information Expectations	Understanding of written information Expectations of care

Table 6: Data analysis and steps taken

Framework Steps (Ritchie & Spence 1994; Gale et al. 2013)	Steps suggested by Stake (2006)	What I have done:
Transcription Other data can be included, in written format, or other documents as required	Interviews transcribed, but other data can be included in written format and other documents	I transcribed all my interviews and wrote up reflective notes and notes on people's relationship to written documents and my thoughts on the written information they did or did not receive
Familiarisation stage, re-reading transcribed data and reviewing documents	Writing up case reports to describe each case in detail and including all data Can be called 'within case analysis'	I familiarised myself with transcribed interviews, with reflective notes and notes regarding written information by reading and reviewing all this data I wrote a descriptive case report for each case following the headings suggested by Stake: Synopsis, situational constraints, uniqueness among other cases, findings, excerpts (as quotes) and commentary I also coded the interview transcripts and notes to support identifying 'clusters' and 'merged findings' or 'categorical aggregation'.
Coding the data – classifying the data by describing how the data were interpreted and applying codes to the data		
Developing a working analytical framework (use key concepts, themes etc from the familiarisation stage to create a tentative framework)	Short sentences to describe findings from each case, find 'clusters' of findings across the cases, Bring together into 'merged findings Can be called categorical aggregation Stake suggests three different types of matrices that can be used depending on the number and nature of the cases Merged findings used as the basis of the creation of the inductive framework	For this step I followed Ritchie & Spence (1994) so created the matrix in the two-step process. The initial analytical framework was modified and updated during the indexing stage in order to capture the fullness of the merged findings and data and to clarify them to reduce repetition Due to the number of cases in my collective case study this enabled me to keep clear what information came from what case and I created a large Matrix according to the merged findings identified in the within case analysis. These findings from the case reports are equivalent to Stake's case 'findings'
Indexing / Applying the framework to the data	Add detail into the matrix from each case and how they contribute to each merged finding	During the 'charting' phase I mapped summary details from each case into the matrix that had been inductively created using merged findings
Charting (synthesise data and plot in the framework. Enables each case to be viewed individually by going across the framework but also each tentative theme/issue/concept to be viewed across all cases by going down the framework in that relevant column)		
Mapping and interpretation (This process has as an end point to create themes that run across the cases. There are a variety of suggestions to help enable this process, for example, looking at contrasting cases, defining concepts, mapping the range and nature of phenomena...)	Consider 'what does this case tell us about the phenomenon we are interested in?' Then bring together to create assertions Write cross-case assertions. These assertions help us to understand the collective case study. They are situated in the experience of each case but enable us to describe and understand the whole	Generated Assertions about the Quintain using Stake's suggested rhetorical dialectical questions and through reflection and revisiting the matrix on multiple occasions. This was an iterative process that took time and thought Insights gleaned from the stakeholder engagement group were used to shape the direction of these Assertions about the Quintain

Appendix 9 – Literature review search strategy

Search strategy:

EXPERIENCE	READMISSION	Over 65
Life experiences (CINAHL heading)	Readmi*	Aged (CINAHL heading, Medline & Embase thesaurus term)
Narratives (CINAHL heading)	Re-admi*	Aged
Experienc*	Readmission (CINAHL heading)	Aged, 80 and over (CINAHL heading and Medline thesaurus term)
Feel*	Rehospitali*	“older adult*”
Qualitative studies (CINAHL heading)	Re-hospitali*	“old* age”
Perspective*	Patient readmission (Medline thesaurus term)	Geriatrics (CINAHL heading, Embase and Medline thesaurus term)
Patient attitudes (CINAHL heading)	Reattend*	Geriatric*
Attitude*	Re-attend*	Frail elderly (CINAHL heading, Medline & Embase thesaurus term)
	Hospital readmission (Embase thesaurus term)	Elder*
		Senior*
		“old* person*”
		“old* people”
		“65 year*”
		“80 year*”
		“over 65”
		“over 80”
		Aged hospital patient (Embase thesaurus term)
		Very elderly (Embase thesaurus term)
		“oldest old”

Inclusion Criteria:
English language.
Qualitative studies focused on experiences of unplanned readmission to hospital of older people aged 65 years and over.
Exclusion criteria:
Age under 65.
Readmission to mental health or oncology services or for planned follow up.
Study of discharge processes or other hospital transitions.