An evaluation of healthcare professionals' decision-making in the care of frail older people at end of life.

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Content of the thesis

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List of abbreviations

ACP	Advance care planning
AHP	Allied Health Professional
BGA	British Geriatric Society
CFS	Clinical Frailty Scale
CGA	Comprehensive Geriatric Assessment
CQUIN	Commissioning for Quality and Innovation
DNAR	Do Not Attempt Resuscitation
DoH	Department of Health
EoLC	End-of-life care
5YFV	Five Years Forward View
GMC	General Medical Council
ICT	Intermediate Care Team
LACDP	Leadership Alliance for Care of the Dying Person
LCP	Liverpool Care Pathway
NHS	National Health Service
NS5YFV	Next Steps Five Year Forward View
NICE	National Institute for Clinical Excellence
ONS	Office of National Statistics
PHE	Public Health England
R&D	Research and Development
SDM	Shared Decision-Making
S4H	Skills for Health
UK	United Kingdom
UTI	Urinary Tract Infection
WHO	World Health Organisation

Glossary of key terms

CQUIN	CQUIN stands for commissioning for quality and innovation. The system was introduced in 2009 to make a proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of patient care.
End-of-life	End-of-life care it is not solely concerned with imminent death, palliative or terminal care but is an inclusive term that encompasses a range of dying trajectories and is usually focused on the anticipated last year of life. The remit of end-of-life care within the UK has largely been defined by the GMC (2010 p8) as "people are approaching the end-of-life when they are likely to die within the next 12 months."
Frailty	Frailty is a multi-dimensional syndrome that can be described as the presence of functional limitations, co-morbidities and need for supportive care - Related to ageing process - Heterogenic in nature - Expressed as limited resilience to adverse events - Influenced by bio-pathological reserves, socio-economic status, environmental structures and resources as well as psychological well-being
ICT	Within primary care the role of intermediate care teams (ICT) to support older people at home is well established. Introduced in the early 2000's in response to NHS policy imperatives to keep older people well and at home by managing acute episodes of ill health, preventing admission to hospital and promoting independence (Melis et al 2004). ICT sit as a bridge between acute (hospital care) and primary (community based) care providing specialist support predominately to older people.
Professional reasoning	Professional reasoning includes the process used by practitioners to plan, direct, perform and reflect on client care. By broadening the concept beyond clinical care professional reasoning encompasses supervisory, managerial and educational perspectives related to service delivery.
Shared decision - making	Shared decision-making is a process in which health and social care practitioners and patients work together to determine choices in intervention, support and care that considers the patient's preferences

Abstract

There is a global demographic shift toward an ageing population, and in the UK the proportion those aged 65 and over continues to rise (ONS 2017). As people age, they are progressively more likely to live with complex co-morbidities, disability and frailty (Kings Fund 2014). Frailty has been acknowledged as a key priority NHS England with the need to provide timely, proactive support for older people as they continue to age (NHS England 2014;2017). Therefore this evaluation aims to evaluate the influence of policy and practice on the decision-making of professionals to inform service delivery.

This evaluation utilised a case narrative approach to explore professional decision-making that underpinned the care of three deceased frail older people. Data was collected in two phases, a comparative review of the clinical documentation followed by narrative interviews of professionals. Ten professionals from nursing, occupational therapy and physiotherapy participated across 3 cases. Data analysis was iterative, informed by the narrative reality conceptual framework (Connelly and Clandinin 2000). Two grand narratives emerged, these were the clinical story of care of a frail older person reaching end-of-life and professional's stories of decision-making.

Grand narrative one set out the clinical story of care, providing a contextual account of frailty and end-of-life from a professional perspective. Grand narrative two explored the professional's stories in supporting a frail older person reaching end-of-life. The practice implications centred on the process of care for frail older people and how medicalisation of ageing and death resulted in protocol-driven, asynchronous technical care. The aim of care being to diagnose and treat illness and functional decline within a deficit-based decision-making approach, whereby independence and risk management were the foci of decision-making. The paradigm of active ageing has been incorporated into professional decision-making leading to an absence of end-of-life care needs being considered within practice. The theoretical implications indicate that a transitional understanding of frailty may offer a critical lens through which to recognises the individual needs of older people.

The evaluation recommendations focus on developing the competencies of professional decision-making by utilising recognised tools to support the identification and management of frailty, guiding professionals to consider the holistic needs of the older person within the context of everyday life including end-of-life-care. To achieve this, there needs to be investment in developing the leadership of all professional groups especially AHP in contributing to Frailty pathways, thus ensuring care is targeted at the three core transitional phases of rehabilitation, habilitation and palliation. In doing so the divergence between policy and practice can be challenged, thus incorporating end-of-life care explicitly into NHS organisational goals for older people.

Prologue

Where do I start, how do I start? What are my assumptions and how do I recognise them? How will my story unfold, entwine with that of the participants stories in the research process? What is the essence of me that started this journey into death and dying, questioning the fragility of growing old today? It began nearly twenty years ago in 2000. My grandfather suddenly went "off legs", a common phrase I had seen on many referrals in my practice as an occupational therapist; a sudden deterioration, no apparent cause other than old age. My Grandpa was 74 years old, a chest infection underlying the deterioration and ravaged his body quickly turning into cor pulmonale and heart failure, not recognised by the GP or family as significant. I however was hesitant, unsure, a niggling doubt that something was not right and to this day I live with this shadow. I travelled with Grandpa in the ambulance and held onto his fragile hand the entire journey, whilst we were offered reassurance by the paramedics that they would get him sorted in the hospital. The close family were summoned and met the ambulance at the hospital. We were five children and one grandchild (me) entrusted to make it right, to be in control, to navigate the system, to get answers. The hospital was hectic, to them he was another old man with an over bearing but caring family. He died three days later. We were never told this might happen, although I suspected he would not be leaving the hospital with us. My aunt (the youngest child once a nurse) and I had hushed conversations in corridors, read care plans, nursing records and sneaked a look in medical notes when no one was looking. We were desperate for the real story, hoping to put together the real picture of what was happening to my Grandpa, not the edited versions we were being given by the healthcare professionals. My Grandma watched unaware, trusting the system, unquestioning the medical team, hoping for the best. It was left to us my aunt and I to start laying down the pathway of what might be and was, preparing our family for the death of Grandpa. Doctors came and went, tweaking medication, giving us reassurance of getting him back on his feet in no time, whilst nursing teams set up fluid balance charts, pressure care monitoring and changed his mattress. Basic care often forgotten. I still see him in my minds-eye a lasting memory of his final days in a hospital bed. Every morning we arrived as early as we were allowed, to be faced with seeing my grandpa with his mouth caked dry, unshaven, bed wet, no drink accessible and the call bell out of reach on the wall behind his bed. Ringing in my ears staff comments about my grandpa, *"He's a lovely old gent your grandpa, no trouble at all, never a bother"* and deafening is the silence of all the conversation that never happened about his impending death. Choices over place of death were never spoken about or given by any of the healthcare professionals even when his deterioration was obvious. Instead a phone-call at 7pm on Thursday night to tell us he had passed away with my Grandma and aunt at his bedside.

Chapter one:

Introduction

As an occupational therapist I hold my professional ethos and values as central to my practice and have often felt out of step with colleagues, viewing the wholeness of a person critical to my work with them and frustrated at a system that does not always see the whole picture of everyday life. Thibeault (2011) captures the essence I feel as a therapist

> *"we have opted for wholeness nearly a century ago and have been at odds with the system ever since. We don't fix people, you see: with them we simply try to find a way to meaning, balance and justice. I chose occupational therapy because it blends science and humanism, intellectual rigor and compassion."*

Much of my career since 2000 has been shaped by the death of my grandfather; from that point on I have predominately practiced in end-of-life care both in hospitals and hospices. Currently I work in academia and at a local hospice. Throughout my career the importance of narratives, story-telling has been consistent thread of my practice. By using narratives, I have developed therapeutic relationships with the people I work with at end-of-life, to understand who they were, are and wish to be, despite facing death- with the aim of reaching shared-decision over the focus care, which is deeply rooted my personalised approach to practice. Exploring a person's narrative therefore forms part of my clinical landscape, shaping my reasoning and as such is familiar territory to me. Brody (1998 p3) eloquently draws our attention to the importance of narratives in clinical practice and resonates with my values as a therapist.

> *"To deal with the part of medicine which treats everyone as the same, we must extract the narrative from the patient and recast it…"*

going on to assert that if we fail to do so

> *"we dehumanise the patient, fail to address him or her as an individual, and ultimately may very well increase the patient's suffering".*

Hurwitz *et al* (2004) explore the contribution that objective (medical- scientific) and subjective (phenomena – narrative) perspectives provide in shaping clinical practice when working with people. Importantly, the idea that objective and subjective inquiry within clinical practice are divorced from one another is being challenged and with that there is a growing urgency in calling for the humanisation of practice (Marcum 2008).

In developing this synergy of practice, practitioners are drawing on reasoning to support decision-making as a tool to understand the whole context of a person's life. Mattingly and Flemming (2000) describe reasoning as encompassing the narrative form, contributing to a wholeness of knowing a patient as a person thereby bringing together an objective and subjective view of our patients within our clinical encounters. Mattingly (2004 p73) asserts that the role of narratives is to humanise clinical practice, to reach into society by looking beyond illness and disability or confined structures of clinical cases and see patients as people- calling for narratives to be used as a vehicle for social and clinical change; transforming practice, policy and societal views on illness, disability and death.

In my work as a hospice occupational therapist, I often encounter clinical situations that draw on me professionally and personally, to analyse and interpret our patients' personal stories; to help them to make sense of their own narratives at end-of-life. Often this contrasts with a dominant biomedical culture that seeks to diagnose by dissecting the underlying pathology of dying, rather than considering the impact of illness on living one's remaining life. Mattingly (2004) considers that therapists reluctantly speak of drawing in the patients and seeing the whole within clinical encounters, often defending themselves against criticism of lacking scientific or objectivity in professional practice. Yet, it is these encounters that can offer healing moments even when curation is no longer possible. Mattingly proposes that when there is no biomedical cure to illness, human vulnerability is exposed in raw form and that one common act in the face of this vulnerability is to tell one' life-story.

End-of-life is an intensely private story of experience situated in much wider public discourses. The last decade has seen countless inquiries into the care of older people at end-of-life with accounts of indignity, compassionless care, discrimination and failures in basic standards in caring for older people recounted in policy, practice and the media (DoH 2008; DoH 2010b; Abraham 2011; Healthwatch 2015). These accounts are set against an equally challenging context of an ageing population and austerity measures that continue to influence the public and political landscape of healthcare. In my everyday practice I am intensely aware of the need to consider how we respond to the challenges of an ageing population through policy and practice. Clinical encounters often reside in the need to balance promotion of independence in old age whilst also enabling supportive approaches to care that recognise end-of-life as a natural part of ageing. It is from this position that Frank's (2004) accounts of the rhythm of life at end-of-life resonate greatly. Drawing on the metaphor of *"tick"* and *"tock"* taken from Kermode (2000) he uses the metaphor to explore what he claims is an embedded cycle of expectation and resolution at end-of-life. The "tick" creates an expectation that the "tock" resolves. He proposes that we live our lives as narratives, and the tick refers to the kind of life and events (chapters of our story) that are and have been lived. The "tock" is the ending to the chapter and what is expected as the right resolution to our storied life. Throughout our lives the "tock" that culminates one chapter of our life often starts the next "tick". In this sense death is the final "Big Tock". Death in many ways is filled with human uncertainty and my clinical practice in end-of-life care echoes this.

Witnessing the rhythm of old age and end-of-life, my clinical practice is littered with questions of “what if” and “what will happen to me at the end?” in the search to make the final “Big Tock” matter for patients, families, colleagues; informing my thinking and therefore decision-making as an occupational therapist.

Frank (2004) proposes that clinical practice at end-of-life centres on an alignment between what kind of life *(the tick)* has been lived as a representation of a fitting end (death- *the big tock*) for that person; to live and die well. The challenge in practice however is to recognise the narratives of the professionals and patients in shaping the context of dying. It is therefore timely to consider the reasoning process of professionals in determining care of frail older people. To understand what forms of resolution fitting at end-to-life, especially if they do not align between professions or professionals, patients and their families. Thereby providing a critical lens to evaluate the influence of policy and practice contexts on the decision-making of health professionals who daily work with frail older people as they approach end-of-life.

1.1 Aims and objectives

To promote a personalised responsive approach to end-of-life care for older people as urged by the inquiries of care, it is critical to evaluate current practice (DoH 2008; DoH 2010b; Abraham 2011; Healthwatch 2015)- to offer an understanding of ageing, frailty, death and dying. This evaluation will thus contribute to a broader understanding of the interplay between policy and practice underpinning the decision-making of professionals in supporting frail older people at end-of-life, and by doing so add to the knowledge base in designing personalised care across professional boundaries and policy agendas.

1.1.1 Aim of evaluation

- To evaluate the influence of policy and practice on decision-making of professionals supporting frail older people approaching end-of-life to inform service contexts.

1.1.2 Objectives of the evaluation

- Critically evaluate the process of end-of-life care for specific frail older patients’ cases drawing out policy, practice and professional perspectives.
- Review the care of specific deceased frail older patients’ cases through reviewing of medical notes and interviews to benchmark clinical practice against national policy and guidance.
- Explore decision-making around end-of-life care of frail older people as retold through the narratives of healthcare professionals to inform service contexts.

1.2 Thesis structure

To provide clarity within the evaluation an overview of the thesis structure is provided.

Chapter Two: Critical review of policy and practice within the context of frailty and end-of-life care

This chapter will present a critical analysis of key policy development that has influenced concepts of end-of-life care and frailty within the NHS to provide a contextual basis for the evaluation. The operationalisation of these policy directives on professional practice will then be debated culminating in a critical consideration of policy and practice within decision-making for health professionals further justifying the evaluation.

Chapter Three: Evaluation methods

The methods chapter sets out the underpinning theoretical position of the evaluation, followed by detailed examination of the evaluation process including justification of the processes utilised. An outline of the narrative approach to evaluation data collection through interviewing healthcare professional and reviewing clinical documentation is provided. The theoretical basis of analysis is justified culminating in a description of the two final grand narratives.

Chapter Four: Grand narrative one – The clinical story of frailty at end-of-life

Three themes are presented within the grand narrative to describe the context of care and professional decision-making at end-of-life for frail older people. The themes are the retold experience of frailty at end-of-life; the importance of place and space in the experience of care at end-of-life for frail older people and finally the passage of care for the frail older person as they approach death.

Chapter Five: Grand narrative two - The professionals' stories of decision-making

Three themes are presented within the grand narrative focusing on the professional's story of decision-making and influences upon this. The professional's stories were analysed within and across the professional groups of nursing and therapists. The three themes are the tensions arising from changing the culture of care within the service context influencing decision-making and organisation of care. The medicalisation of professional identity and finally colliding personal and professional lives within practice influencing decision-making.

Chapter Six: Discussion - Developing a broader theoretical understanding of frailty and implications for practice

The discussion chapter sets out the underpinning theoretical and practice-based contribution of the evaluation in examining the influence of policy and practice on professional decision-making when supporting frail older people as they approach end-of-life.

Chapter Seven: Conclusion, recommendations and limitations

The final chapter draws together the evaluation to present final conclusions, reflecting on the limitations of the evaluation and provides a summary of the key recommendations for future practice.

Chapter Two:

Critical review of policy and practice within the context of frailty and end-of-life care

This chapter presents a critical review of policy and practice that underpins professional decision-making; drawing on local and national perspectives as influencing factors in the care of frail older people at end-of-life. There are five key sections:

- Ageing well - setting out current demographic trends in ageing within the UK focusing on the old and oldest portions of the population. Key policy context is reviewed and considered in relation to health and social care.
- Living well - considers the increasing prevalence of frailty, drawing on research, practice and policy reviewing current care approaches.
- Dying well – defining the context of end-of-life care through an analysis of policy and practice considering key challenges supporting frail older people.
- Decision-making - The final section considers the role of professional decision-making in health and social care and the influence of policy, research and practice in shaping this.

2.1 Ageing well

The United Kingdom (UK) has an ageing population (Collard *et al* 2012). As people age, they are progressively more likely to live with complex co-morbidities, disability and frailty (Kings Fund 2014). In response to the growing political and global recognition of demographic shifts in ageing the focus of research and policy were realigned to identify the risk factors of ageing and establish interventions to ameliorate decline in function during ageing through empowered populations (Liang and Luo 2012; Bulow and Soderqvist 2014; van Dyk 2014; Lloyd *et al* 2014 and Timonen 2016). The focus of policy and practice therefore resides within a paradigm of ageing well across a person’s lifespan in response to an ageing population.

2.1.1 Demographic ageing profile

The ONS (2017) mid-year report from 2016 (presented in figure 2:1 below) summarises statistical population trends within the UK highlighting a decreasing mortality rate resulting in longer life expectancies in the UK. With a narrowing of the gap between male and female in term of life longevity, surmising that changes in male high-risk occupational hazards and a fall in smoking rates have contributed to this narrowing of the gap.

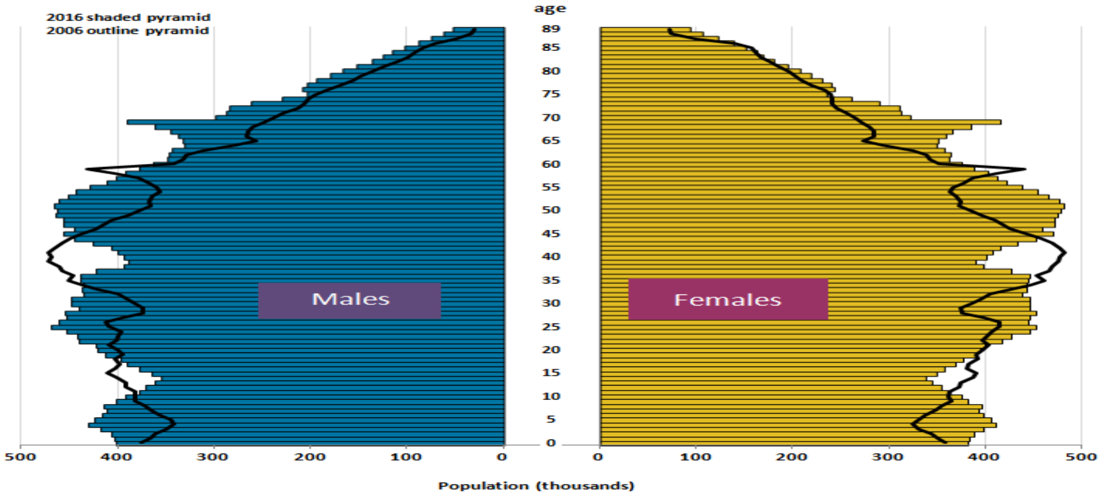


Figure 2.1: ONS comparative demographic pyramid between 2006-2016

The demographic profile of the population aged 65 and over is set out by the ONS (2017) and is presented in figure 2:2 below, this shows that in the preceding years from 2002 the number of people aged 65 and above has increased and will continue to rise. The oldest old are not represented within this report and therefore skew the overall demographic picture slightly.

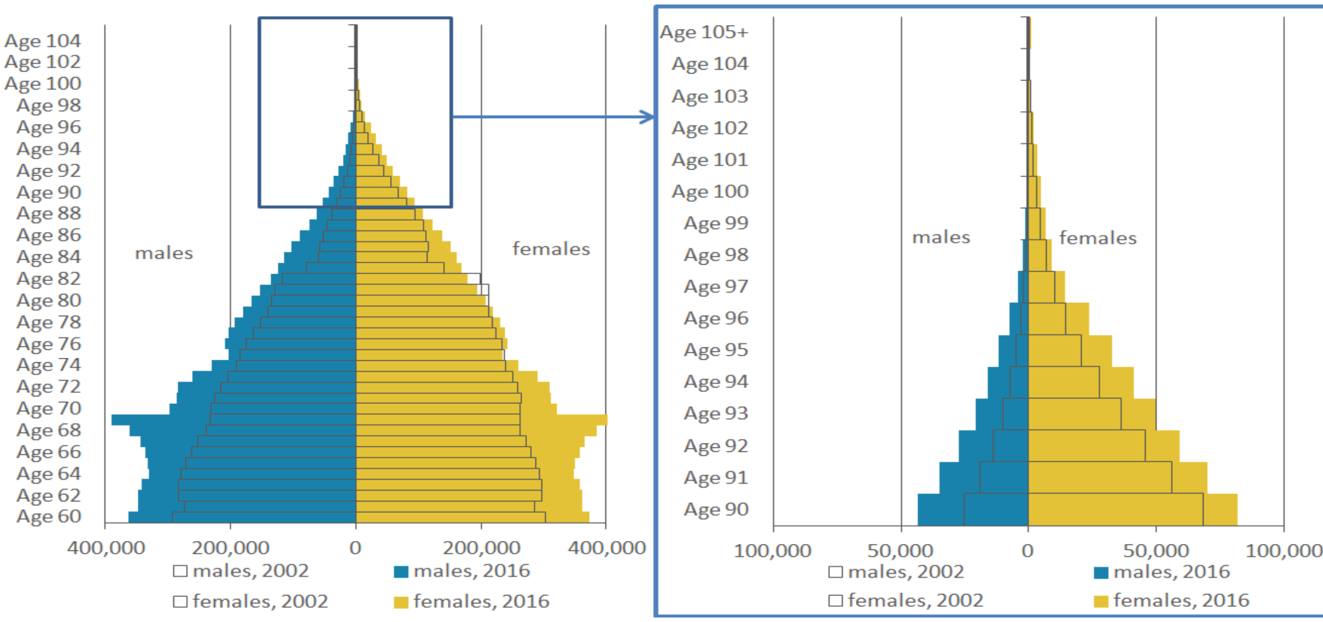


Figure 2.2: ONS demographic trend in ageing population and gender (2002-2016)

The ONS (2017) estimates of the very old report that the population aged 90+ have grown rapidly from the post-World War I baby boom and overall the account for under 1% of the population, again seeing the proportion of men in this age range increasing over time. As presented in figure 3 below, just under 150 000 people were estimated to be aged 100 and over (centenarians) in the UK in 2016- showing a rise from 2015 of nearly 400 people. The ONS suggest that centenarians account for 2 people in every 10,000 within the UK indicating a rise in this population from previous years.

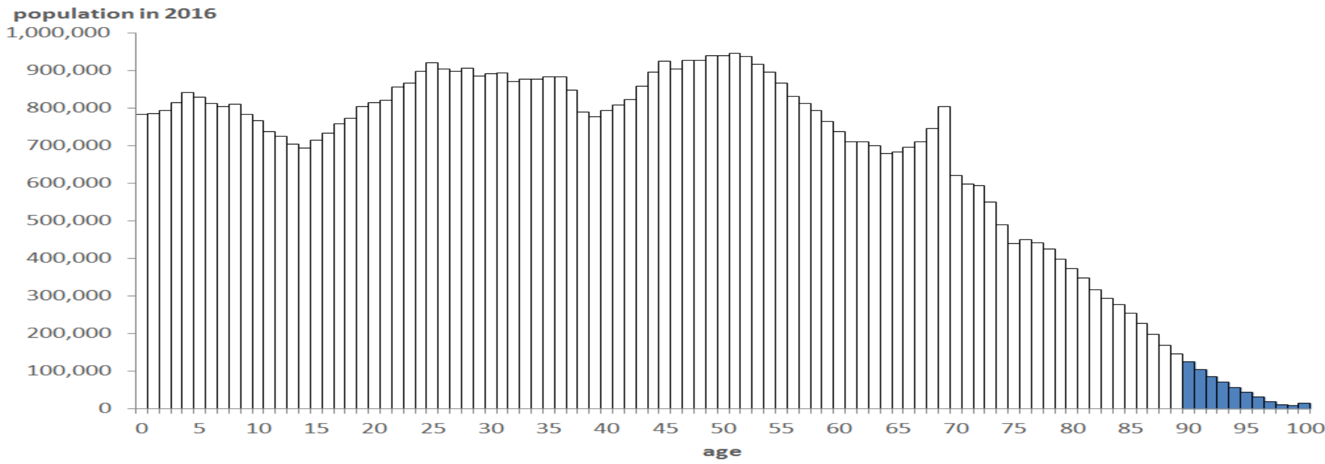


Figure 2.3: ONS (2016) Proportion of the oldest old

The ONS analysis provides contextual insight into the demographic shift within the UK and is therefore of significance in planning for current and future health and social care needs especially crucial at a time of political and financial uncertainty.

2.1.2 Impact of ageing on health and social care

The major user of the NHS is the older person; with the average age of a hospital patient being over 80 years old (Tadd *et al* 2011) and are more likely to have longer periods of stay (Cornwell *et al* 2012). NHS digital (2016) healthcare utilisation reports for emergency care evidence that approximately 13% of all emergency department attendees were aged 75+ in 2015-16, equating to over 2.5million contacts. Furthermore, nearly 20% of all patients supported following discharge through re-enablement or intermediate care programmes were re-admitted to hospital within 91 days.

Coupled with greater utilisation of healthcare, as people age they tend to rely on formal and informal care. 453 000 people receive formal home care from statutory services with 84% of these aged 75+. In addition, 2.5 million people aged 75+ receive some level of informal support from friends, family or neighbours and a quarter of these informal carers are aged 65+ (The Health and Social Care Information Centre 2010). The Health and Social Care Information Centre (2013) report that people aged over 65 account for 51% of the gross adult social care spending within local authorities and approximately two thirds of primary care prescribing budgets; overall 70% of the total health and social care spend is supporting people living with long-term conditions of which a significant proportion are likely to be aged (DoH 2013b). Age UK (2017) reports that in real terms there has been a £160 million cut in total spending on older people’s social care over the past five years to 2016-17. This is despite an increased demand on health and social care due to the increasingly complex needs of older people as they live longer with long-term health needs, disability and/or frailty. It is therefore unsurprising that global policy has shifted towards health promotion and the importance of ageing well (Timonen 2016)

2.1.3 Ideological shift towards ageing well and resulting policy context of care

Diverse fields of study have arisen seeking to unravel the complexity of ageing from social, physical and ecological perspectives, aiming to understand ageing to improve the experience of growing old (Stuart-Hamilton 2011). Active ageing and ageing well theories have dominated conceptualisation of ageing within society, policy and practice (Gilleard and Higgs 2010; Liang and Luo 2012; Nicholson *et al* 2012; Lloyd *et al* 2014) often characterised as the 'Third Age'. The conceptualisation of active ageing is based on the idea that ageing populations are a societal resource, with individual responsibility for health, continued economic and social productivity extending into old age (van Dyk 2014).

Active ageing as a conceptual idea underpins national and global policy. Over the last two decades the WHO and EU have set out active ageing policy frameworks to address the challenge of an ageing population. Claiming that "measures to help older people remain healthy and active are a necessity, not a luxury" WHO (2002 p6) and the EU commission (2013 p16) highlighting more recently that

> *"the challenge is to find ways to contain the growth in demand for long term care while improving the capacity to provide more, better care with fewer human resources and less funding, enabling elderly people to manage without care, or with far less today, despite functional limitations"*

This paradigm shift from older people being passive recipients of care instead places responsibility on them to actively age well and therefore manage their own functional limitations without the need for care. The policy frameworks of WHO and the EU outline global intentions of population health measures that promote continued active participation in personal, social and economic affairs across the life-course. This has been embedded into national policy in the UK, whereby the maintenance of personal autonomy and independence in healthy ageing are viewed as central to NHS and social care reform, thus reinforcing the third age and importance of living well (Timonen 2016).

2.2 Living well

The focus on ageing well has influenced care of the older person, increasingly older people are being encouraged to live well, and in the last 12 months there has been heightened importance placed on those older people who experience frailty to support them to live well (Vernon 2016; NHS England 2017; Vernon 2017; DoH 2018a; DoH 2018b). Frailty is a multi-dimensional syndrome that can be described as the presence of functional limitations, co-morbidities and need for supportive care (NHS England 2014). It is recognised within the integrated pathway guidance (DoH 2014) that the identification and impact of frailty is complex and challenging. Clegg *et al* (2013) reports that frailty is the most challenging consequences of an ageing population. Surmising that there is a need for clear clinical indicators to assess the stages of frailty, to aid clinical decision-making with the aim of providing appropriate goal determined care to promote living well.

2.2.1 Definition of frailty

Frailty is commonly referred to as a multifaceted syndrome, characterised by a loss of reserves (energy, physical abilities, cognition and health) that precipitate vulnerability and disability (Storey *et al* 2004; Rockwood *et al* 2005; de Vries *et al* 2011; Clegg *et al* 2013). There however, remains a lack consensus on a unified definition or conceptualisation of frailty (Markle-Reid and Browne 2003; Clegg *et al* 2013). Rockwood *et al* (2005) propose that frailty has three operational definitions that are typically rule based and medically orientated (Markle-Reid and Browne 2003). They serve to predict, diagnose, and plan strategies of care with a common goal of stratifying risk and adverse outcomes (such as institutionalisation or death) ultimately to reverse the trajectory of decline and promote healthy ageing. de Vries *et al* (2010) suggest that the exact causes of frailty are not fully understood, although there are close associations with ageing and socio-environmental factors which influence changes in health status of older adults. Commonly, a deficit-based approach to identifying, assessing and managing frailty is utilised within the NHS to stratify risk of frailty and outcomes of care (Clegg *et al* 2013; Vernon 2016) and are based on modified versions of the Frailty Index proposed by Rockwood and Mitiniski (2011).

The Frailty Index (Rockwood and Mitiniski 2011) and the simplified Clinical Frailty Scale (CFS) (Rockwood *et al* 2005) include a wide scope of clinical, pathological and physiological deficits assisting in identifying factors that may enhance or mitigate the risk of vulnerability. These are based on a deficit accumulation model as reported in table 2:1 over-page.

The Clinical Frailty Scale
1. Very fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.
2. Well – People who have no active disease symptoms but are less fit than Category 1. Often, they exercise or are very active occasionally, eg, seasonally.
3. Managing well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.
4. Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being 'slowed up' and/or being tired during the day.
5. Mildly frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.
6. Moderately frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.
7. Severely frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).
8. Very severely frail – Completely dependent, approaching the end-of-life. Typically, they could not recover even from a minor illness.
9. Terminally ill – Approaching the end-of-life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Table 2.1: Clinical Frailty scale (Rockwood *at al* 2005)

At present Rockwood and Mitinski's (2011) deficit accumulation model has the greatest sphere of influence within practice and is the nominated NHS clinical tool for assessing frailty in the latest primary care NHS CQUIN (NHS England 2017a).

2.2.2 Clinical assessment and management of frailty

Clegg *et al* (2013) report that older people's clinical presentation is often non-specific, with extreme fatigue, unexplained weight loss and frequent infections. Physical changes in mobility, poor balance and gait impairment indicate a high risk of falls. Cognitive decline and delirium are reported with a rapid onset of fluctuating confusion and impaired awareness. It is estimated that 30% of older people admitted to hospital may develop delirium and is independently associated with adverse outcomes. Fluctuating levels of disability result in day-to-day instability, with older people reporting 'good', independent days and 'bad' days on which formal and informal care is often needed.

The CFS provides an indicator of the range of frailty that can present in older people and often is used to guide clinical decision-making in identifying health and social care needs. Often leading to onward referrals for more detailed assessment and care planning (Kings Fund 2013). However, utilising the CFS in isolation does not lead to improved outcomes of care (Puts and Alibhai 2018). The CFS does not provide a detailed assessment of the older person's needs to support a comprehensive understanding of complexity of care informing professional decision-making and therefore Rockwood and Mitiniski (2011) closely associate the CFS with the comprehensive geriatric assessment (CGA). The CGA is a multidisciplinary diagnostic tool to capture a detailed assessment of the medical, psychological and functional capabilities of a frail older person and emerged over three decades ago (Rubenstein 2004). According to Stuck *et al* (2002;2011) it enables a co-ordinated, integrated plan for the long-term treatment and follow-up of frail older people. Clegg *et al* (2013) note that the comprehensive geriatric assessment has strong predictive validity in assessing degrees of frailty and should be considered as gold standard in geriatric care, supporting evidence based clinical decision-making within a person-centred approach.

The CGA commonly includes the following domains:

Medical	• Co-morbidities and disease severity • Medication review • Nutritional status • Cognitive status
Mental Health	• Emotional status • Motivation • Mood/anxiety • Fears
Communication	• Speech • Hearing
Functional Capacity	• Mobility

	● Balance ● Elimination ● Activities of Daily Living ● Instrumental Activities of Daily Living ● Sleep
Social circumstances	● Marital status ● Social engagement and network ● Informal support/care
Environment	● Home environment and accessibility ● Transport and community resources

Table 2.2: Comprehensive Geriatric Assessment domains (Rockwood and Mitiniski 2011)

Commonly the five conditions often associated with frailty also known as the frailty syndrome are delirium, recurrent falls, sudden deterioration in mobility, new or worsening incontinence and medication side-effects (DoH 2018b). The use of the CGA therefore should support professionals in developing a robust awareness and recognition of frailty syndrome. In addition to this, Rockwood and Mitiniski (2011) urge that many frail older people have complex needs and the impact on the persons total care should be the focus not merely diagnostic indicators. The importance of co-ordinated and integrated care for frail older people is reiterated across NHS policy and research (NHS 2014; Kings Fund 2014; National Voices 2013; Ellins *et al* 2013) Older people and their families place high value on continuity of care delivered by familiar clinicians and in contrast poorly co-ordinated and disjointed care is associated with poor quality and reduced satisfaction in care (Rolland 2013; Haggerty 2012; Health Foundations 2011a). This has been further emphasised in the recent Skills for Health (S4H) NHS core capabilities frailty framework (DoH 2018b), recognising that the current and future workforce need to be upskilled to meet the needs of frail older people. In doing so the workforce need to challenge historical siloed working practices between different professions and service sectors that are evident in the care of older people (Picker Institute 2018). Reinforcing the importance of a personalised approach called for previously by Rockwood and Mitiniski (2011 p24)

> *"Acknowledging and accepting each person's "big picture" that includes a multitude of social and medical needs allow clinicians to provide more comprehensive treatment that prevents inappropriate efforts to dissect each issue and deal with it separately."*

2.2.3 Influence of ageing theories in understanding frailty

During the preceding decades global and national policies have sought to apply the growing body of knowledge around ageing to shape institutional practices in designing and delivering healthy ageing programmes across societies. Theories of ageing and policy frameworks present a positive paradigm known as the third age however this has led to a lack of recognition of transitions towards end-of-life for the ageing population despite this being the final reality for every human being. The main tenet of research centring on frailty seeks to understand, define and diagnose syndromes to rationalise evidence-based intervention to reverse frailty trajectories prolonging the third age of ageing well, to assist in the management of the burden of care within society (Nicholson *et al* 2012; Clegg *et al* 2013, Turner and Clegg 2015). Policy relating to the care of older people therefore draws influences from active ageing and bio-medical perspectives adding to the invisibility of death and dying for the older person (Timonen 2016). The legacy of the third age theories in defining and characterising current conceptual and societal foundation of ageing has created what Gilleard and Higgs (2010 p122) refer to as the "shadows" of generations who hope to die before they get old. As such ageing, frailty and death are depicted as the fourth age, a final location stripped bare of social and cultural values of independence, autonomy and pleasure in later life.

Whilst there have been attempts to draw together a coherent understanding of the experiences of ageing, there remains a tension in examining the division between the third and fourth ages both in practice and academia. Frequently in the media, political and medical discourses are posited over the rising demand and cost of health and social care for the very old. Lloyd *et al* (2014) assert that this has resulted in a tightening of eligibility criteria for support, shifting the ideological framework underpinning healthcare priorities and expectations towards ageing well and living well thereby reinforcing a moral precedent on older people to remain self-reliant further prolonging the third age. Gilleard and Higgs (2010) argue that this presents a contradiction and tension for practitioners in managing "unsuccessful ageing"; neither ageing nor living well. Nicholson *et al* (2012) and Coleman and O'Hanlan (2004) argue that positive meanings within the fourth stage of life are needed to redress the balance in how frail older people are valued both broadly within society but also in healthcare. The predominance of a medically-orientated deficit approach to managing frailty fails to recognise the differing way in which people living and approach an aged death can contribute to the fabric of society. By focusing on deficit, it presents a view of frailty as a problem to be solved so that ageing well can be extended without loss. Therefore, this fails to consider how to support older people as they approach a normal aged death but, more broadly, to overcome the current societal failure to engage with the experiences of decline and loss for older people at end-of-life in dying well.

2.3 Dying well

End-of-life care as a term is often a source of confusion both in policy, research, practice and the wider society (PHE 2015, EoLC Programme Board 2014, Hui *et al* 2014, Gysels 2013, Izumi *et al* 2012) with little consensus on its definition or scope of practice. In the UK there are multiple definitions of end-of-life care stemming from policy, professional bodies, research and practice, however there are common elements. The goal is to promote quality of life, prevent and relieve suffering, follow a holistic multi-professional approach and is focused on the care of people who have life-threatening advanced, progressive illnesses (Hui *et al* 2014, Gysels 2013, Izumi *et al* 2012). The essence of end-of-life care is to enable the person to experience a good death. To die well. The UK remit of end-of-life care has largely been defined by the GMC (2010) as people who are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days). It also extends to people with advanced, progressive, incurable conditions, general frailty and coexisting conditions that mean they are expected to die within 12 months and those with existing conditions if they are at risk of dying from a sudden acute crisis in their condition or life-threatening acute conditions caused by sudden catastrophic events. The GMC recognise that end-of-life care needs may not present in isolation and are often accompanied by other health and social care needs. Therefore, consideration of the person's individual context is paramount as it may be influenced by other factors such as religion, culture and social circumstances. It is thus evident that the scope of practice in end-of-life care should not therefore be universally defined but is culturally bound and locally determined.

2.3.1 Contextual analysis of policy of end-of-life care drawing out key issues for care of older people

The main policies that surround end-of-life care are set out below in the timeline (see diagram 1) generic relating to NHS and Social care reform but also specific to end-of-life care practices within the UK and more latterly NHS England following the devolution of power to Wales, Northern Ireland and Scotland (PHE 2015).

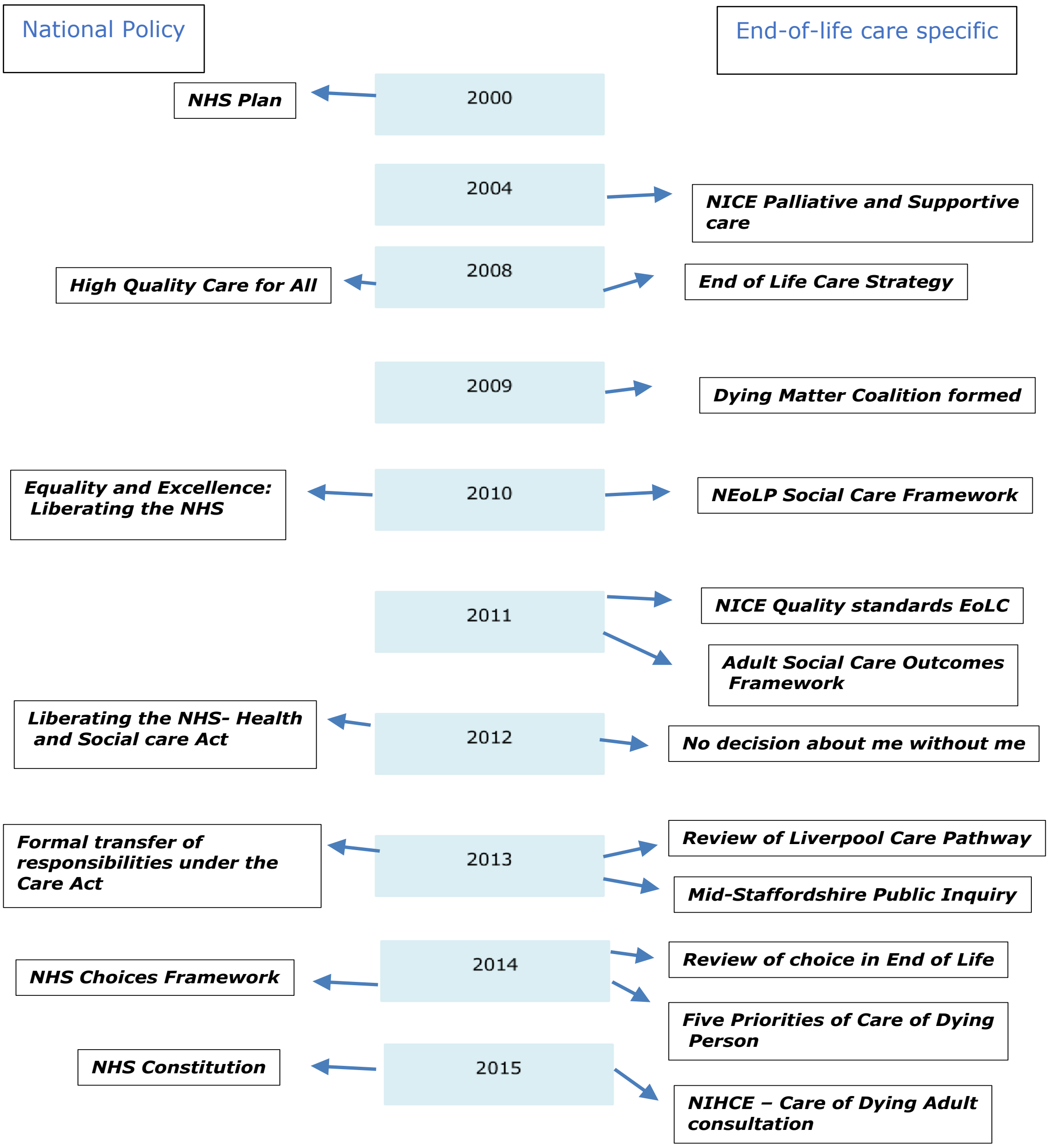


Diagram 2.1: Key policy informing end-of-life care

The period between 2000 - 2009 set out the governments' vision for modernising the NHS. The DoH- NHS Plan (2000) began a decade of investment and expansion with a focus on quality, evidence-based practice and robust governance and as such took a mechanistic approach to care. The resulting policy formation centring on end-of-life care set out process driven care underpinned by tools and protocols to deliver a personalised care planning approach formalised under the End-of-life Care strategy (DoH 2008). The key concept of the strategy was to define a care pathway that enabled a co-ordinated, seamless and responsive approach meeting the needs of the patient and their carers following a process driven approach. Importantly this placed end-of-life care as core to all health and social care with an expectation that all professionals should be skilled in supporting anyone approaching end-of-life. This saw a departure from end-of-life being viewed within the realms of specialist intervention through palliative care and into the scope of everyday practice across all professions and services.

In 2010 there came a change in government, the previous years of expansion and growth curtailed with an urgent need to reduce national deficit. The white paper Equity and excellence: Liberating the NHS (DoH 2010a) signalled a shift to embed end-of-life care policy development within public health rather than as a specific thread of NHS policy or workstream. The resultant NHS Constitution (DoH 2012a) aimed at unifying Heath and Social Care, becoming formalised in the Health and Social Care Act (DoH 2012b, 2015) to pool resources and target needs on a local level. This placed responsibility for commissioning of health services within the local community, responsive to local needs rather than centrally determined. Therefore, end-of-life care provision was to be organised and delivered according to local needs and coincided with the influential GMC (2010) policy statement defining end-of-life as individually determined and not diagnosis led, reinforcing commitment to a public health focus of care. Since 2015 and the supposed embedding of end-of-life care as implicit within health and social care policy it has become increasingly invisible with wide variations in service provision (Collins 2018; Bleakley *et al* 2019). In fact, the recently published NHS Long Term Plan (DoH 2018) setting out the next decades workstream of care fails to acknowledge end-of-life provision and focuses primarily on preventative medicine to tackle an *ageing population crisis*.

2.3.3 Care of old person at end-of-life

During the same period of major health and social care reform from 2012-2018 the NHS has been subject to increased public scrutiny. A series of critical concerns were widely reported over the treatment and care of people, particularly older people at end-of-life. The documented failings of care led to a public inquiry into the quality of care at Mid Staffordshire Foundation Hospital (DoH 2010b & 2013a). The accounts presented revealed a culture of dispassionate care that was process driven, where indignity and de-personalised care was commonplace, and concerns raised often centred on the care of some of the most vulnerable groups of patients, frail older people (DoH 2010b). The public inquiry commonly referred to as the Francis Report (DoH 2013a) found an underlying culture that failed to put patients at the centre of care, coupled with a defensive, closed leadership that faced inwards. This resulted in widely condoned poor practice and behaviours that fell far below the threshold of acceptable standards set out by professional regulations and Health and Social Care systems. The Francis report (DoH 2013a) recommended that common values enshrined in the NHS Constitution (DoH 2012a) should be communicated and owned by all working within the NHS. A committed, caring, compassionate workforce working to a common culture that places patients at the centre of its business.

During the same period a key protocol of end-of-life care, the Liverpool Care Pathway was subject to national review following high level of complaints and increasing mortality rates in care of older person (LACDP 2014 p9). The review concluded

> *"Evidence from relatives and carers strongly suggested that care of the dying elderly is of the greatest concern. Caring with compassion for people at the end of their lives should be the aim of all doctors, nurses and healthcare staff. Good care for the dying is as important as good care at any other time of life… Generic protocols are not the right approach to caring for dying people: care should be individualised and reflect the needs and preferences of the dying person and those who are important to them."*

As a response the Leadership Alliance for the Care of Dying People (LACDP) proposed universally adoption of the five priorities of care across NHS England from commissioning to frontline care. Commonly termed as the Five Priorities of Care for the Dying person (2014) person-centred care is central. Fundamentally that individual care must be provided according to the needs and wishes of the dying person. This change in terminology from *patient* to *person* centred care signalled a significant shift in attitude in how the NHS in England should function and resonated with the NHS constitution (DoH 2012a) and Francis Report (DoH 2013a) findings. The findings reiterated that the underpinning values of dignity, respect, care and compassion should be the hallmark of all service provision, rather than protocol-driven care.

2.3.4 Policy and practice at end-of-life for older people

Policy development across the past two decades has seen a shift from national guidance to local implementation. National guidance as set out in the End-of-life Care Strategy (DoH 2008) placed end-of-life care within the mindset of all professions across all specialities thereby promoting the use of protocols to support all professionals' decision-making in identifying and proactively planning end-of-life care as a mechanism to drive quality improvement within the NHS. Latterly, this explicit emphasis on protocol driven decision-making of care has been criticised particularly in respect of older people at end-of-life as it fails to recognise the individual preferences and needs leading to poor quality care (DoH 2012a, 2013a). The implications for this are significant since within the UK and globally we are facing an increasingly ageing population who have complex needs as they approach end-of-life and are currently supported in a segmented manner across health and social care (Kings Fund 2012, 2013). In caring for older people as they approach end-of-life it is widely acknowledged that the hallmarks of high-quality care are that care is personalised, delivered by familiar professionals with a proactive open approach to care planning thereby promoting their sense of autonomy through shared decision-making with professionals (Kings Fund 2013; Age UK 2013, 2017). The explicit focus in the preceding reforms are to meet the demands in the NHS of an ageing population by promote ageing well. In contrast end-of-life care does not feature a specific workstream and requires further evaluation. The lack of specificity therefore has the potential for end-of-life care to unwittingly become invisible within professional decision-making and therefore an evaluation of the extent to which policy has influenced the organisation of care within the NHS for frail older people and enacted through the decision making of professionals in practice is warranted.

2.4 Decision-making in health and social care

Health and social care professionals operate in increasingly complex circumstances, Jasper *et al* (2013) proposes that professionals must be aware of processes, protocols and guidelines drawn upon in making decisions and judgements about clinical care- recognising that decisions are both informed and influenced by the policy and practice contexts within which they are made. Equally Jasper *et al* (2013) reminds professionals that decisions can be influenced by governmental, societal, patient and family agendas that provide a context to healthcare delivery. Bannigan and Moores (2009) highlight in negotiating these complex circumstances high-level thinking skills are required as a tool for effective decision-making.

2.4.1 Defining professional decision making in the context of health and social care

Decision-making is known by many terms including clinical reasoning, professional reasoning, professional thinking and clinical decision making but all share commonality in attempting to make sense of the complex process that underpin decision-making in health and social care (Higgs *et al* 2018). Unsworth (2016) argues that in developing sound reasoning process to underpin decision-making expert healthcare professionals create new knowledge in practice. This is then shared within the culture of healthcare in an iterative and interactive exchange between and across professions in a context-rich process of care. Then through reflecting on practice professionals can collectively build knowledge in clinical practice. Unsworth (2016) further proposes that this is vital in developing shared understanding of the divergent value base of knowledge in practice that can simultaneously accommodate policy, research and practice evidence. Chaitow and De Lany (2011), Benner *et al* (2008) and Jensen and Shephard (2007) concur that professional skills to orchestrate high-quality, evidence-based care are dependent on the ability to reason think and judge. Sullivan (2004) notes that there are three core components that underpin professional decision-making, firstly analytical reasoning of a detached scientist using logic, evidence and knowledge objectively. Secondly the application of professional inquiry through experience and practice in applying knowledge in specific contexts. Finally, consideration of the relationship between the patient and the professional as integral to the process of care. Benner *et al* (2012) concurs stating that application of knowledge and practice expertise is required to identify patient problems and propose interventions that aim to result in positive outcomes of care. Therefore, decision-making requires professionals to balance evidence-based practice drawn from research and policy with practice experience alongside clinical encounters with patients.

2.4.2 Complexity of decision-making at end-of-life

Decision-making at end-of-life is inherently complex and filled with uncertainty often coupled with both practical and existential concerns and therefore requires a level of evaluation to contribute to building a greater appreciation of underpinning influences and tensions in practice to extend our knowledge. Romo *et al* (2017) and Gramling *et al* (2015) propose an integral component of the care of the older person is the importance of understanding their preference for end-of-life care, especially when death is imminent. It is evident that older people focus on the outcome of care rather than specific interventions often deferring decisions to others (Romo *et al* 2017; Williams *et al* 2007 and Gott *et al* 2004). Romo *et al* (2017) findings make a significant distinction in the expression of control in decision making for older people at end-of-life. The active control of patient's decision-making is often held in high regard by healthcare professional and central in adhering to ethical and legal parameters of practice. In contrast Romo *et al* (2017) propose that older patients do not need to be "actively" in control but instead feel that their care is "under" control by delegating decision-making to others as an expression of autonomy at end-of-life. Proposing that older people prefer to do so through indirect communication of their priorities, values and preferences thereby balancing the demands of decision-making within their personal and social resources. This undoubtedly requires an ideological shift for professionals and reinforces the importance of personalised approaches to care- to understand and appreciate older people's personal goals, choices and perspective of control at end-of-life.

Ageing brings an expectation and familiarity of death and whilst not necessarily welcomed it is anticipated but not feared. Fear instead stems from the processes leading towards death; increasing frailty signalling vulnerability and incapacity. Lloyd-Williams *et al* (2007) Nicholson *et al* (2013) and van Wijngaarden *et al* (2015) emphasise how older people's perception of dependency are shaped by experiences of the death of others and their own ideas of independence, suggesting that feelings of fear resonate as the indignity of a life where simple functions of everyday are beyond the control of them.

The challenge of an aged death is unpredictability. An aged death does not follow a predictable or measured decline. Instead everyday life is experienced as fluctuating periods of stability and erratic decline in personal capacities. Therefore, open discussions around death and dying are difficult to time, often emotive for both the older person and their family. Older people's narratives within research elude to the importance of a good death being one that is dignified. Exemplifying the right to choose how one's ending will be; asserting ownership over the final act of self-determination of a life well lived (Lloyd-Williams *et al* 2007 and van Wijngaarden *et al* 2015). Exercising autonomy through planning one's personal, financial affairs and funeral arrangement offer some aspect of control that is otherwise elusive in facing end-of-life (Grenier 2006, 2008; Lloyd-Williams *et al* 2007; Hurd-Clarke *et al* 2012; Hewitt *et al* 2013; Nicholson et al 2012 and van Wijngaarden *et al* 2015).

In contrast anticipated features of a bad death were related to social connectedness and contexts of care exposing older people's concerns of isolation, dependency and becoming a burden to family and society at end-of-life (Grenier 2006, 2008; Lloyd- Williams *et al* 2007; Hurd-Clarke *et al* 2012; Hewitt *et al* 2013; Nicholson et al 2012 and van Wijngaarden *et al* 2015). In anticipating death this is evidenced as expressions of the fear of dying alone at home or within institutional care surrounded by paid carers (Lloyd-Williams *et al* 2007; Hurd-Clarke *et al* 2012; Nicholson et al 2012 and van Wijngaarden *et al* 2015). The context of care at end-of-life often viewed by older people as shaping their anticipated experience of death. The importance of home as a place of death for the older person often mitigated by perceived levels of dependency and need for formal care. Often the older people expressed concerns of being "forced" to live and ultimately die within formal care institutions. Associating this with a worsening quality of life, impersonal care and diminished autonomy and control over end-of-life wishes (Grenier 2006; Bravell *et al* 2010; Hurd-Clarke *et al* 2012 and van Wijngaarden *et al* 2015). The importance of listening to and recognising the older person's choice at end of life are therefore paramount in ensuring high quality personalised care.

Shared decision-making (SDM) in healthcare is emerging as a central component of personalised care (Bunn *et al* 2017) and is one of the hallmarks of high quality of care from an older person perspective, as reflected in the Frailty Core Capabilities Framework (DoH 2018b). SDM reflects the shifting ideologies of health and social care toward collaborative approaches of care and is increasingly evident in policy and practice (Bunn *et al* 2017; Coulter and Collins 2011). SDM is a process in which health and social care practitioners and patients work together to determine choices in intervention, support and care that consider patient preferences and is a common feature in specialist end-of-life care settings. The challenge however in supporting frail older people at end-of-life where care is often provided outside of specialist end-of-life care services is balancing the differing professional, patient and family perspectives, often at the interface of health and social care organisation where the focus is promoting living well rather than dying well. Karsoho *et al* (2016) discusses that there co-exist two dominant logics at end-of-life; "dying well" promoted predominantly through palliative care professionals and "lifesaving" mainstream medicine whereby interventions are directed at curing disease with the central goal of preserving life and comfort care a secondary consideration. These dominant logics influence decision-making at end-of-life with Howarth (2007) and Broom (2015) asserting that development in health care has led to the medicalisation of dying. Where over the course of the twentieth century dying has been transformed from an *existential* moment to a *medical* challenge to be addressed by expertise and skill. To dissect the process of death, to manage it within a controlled environment and predict the outcomes.

The underpinning policy and practice of supporting frail older people is undoubtedly viewed as a *medical* challenge and greatly influenced by "lifesaving" logic as reported by Karsoho *et al* (2016). As evidenced by a Lancet (2014) editorial report, that medical instincts to preserve life may actually go against patient's wishes at end-of-life. The lifesaving logic approach focuses on assessing and curing the component parts of the body to sustain life but in doing so fails to acknowledge the broader context of the frail older person's life inhabiting an aged body and proximity to death. In addition, the striking findings of Reid *et al* (2015) report that medical staff described uncertainty in diagnosis impending death as it challenged their ability in decision-making in an objective evidenced manner. They also expressed fear that they would be criticised by peers for not continuing to provide active life sustaining intervention. Fear also resided in being viewed by others as fatalistic and not going above and beyond to sustain life despite recognising that death was a part of the professional landscape of medical practice. Indeed, within the study nursing staff often recognised deterioration and end-of-life care needs of the same patient group but did not feel equipped to challenge medical opinion therefore, they continued to provide intervention despite this. Reid *et al* (2015) discuss the culture of care around death and dying as being nihilistic. Whereby recognising and diagnosis dying in moving towards *dying-well* logic to providing comfort and care was viewed as "giving-up" or "allowing" a patient to die. The culture and dominant medical ideological perspective was evident across the study as influencing across professional boundaries and therefore directly shaping decision-making of patient care in many other professional groups.

The protocol and process driven care set out in the NHS end-of-life care has been subsumed by guidance that are less specific and rely on professionals establishing the priorities of care of the dying person. However, it is evident that in doing so this places identification of end-of-life care trajectories within the decision-making process of all professionals. In the case of frail older people where end-of-life care trajectories are unpredictable, and care is often managed at the interface between primary and secondary care by generalists it is critical to evaluate how care is orchestrated. Current policy and practice guidance promotes healthy ageing. Whist it is undoubtedly important to prevent illness, age well and live well, we are all going to die. The consequence of enabling people to live healthy longer lives is that they will die at a much older age with more long-term conditions and therefore complexity of needs that require professional to make increasingly challenging decisions.

This chapter has explored the context of care for frail older people at end-of-life highlighting the importance of advance planning and shared decision-making as strategy to ensure people live and die well. The recognition that access to timely and appropriate medical and social support are considered as hallmarks of high-quality end-of-life care is well evidenced and equally reflects findings of the national review of Choices at End-of-life (2013). However, older people often experience a lack of advance-planning, are frequently admitted to hospital in crisis situations and have limited access to palliative care (Age UK 2013). Therefore, there is a growing urgency to recognise the vulnerability of frail older people at end-of-life and reorganise our approaches to care through personalised, tailored interventions that promote autonomy at end-of-life through supportive mechanisms (Kings Fund 2013, 2017; Müller-Mundt *et al* 2013; Kotter & Rockwood 2013; Lancet 2014). Critical to this is evaluating the decision-making process utilised by professionals in determining the organisation of care provided to frail older people as they approach end-of-life, therefore the thesis aim, and objectives presented in chapter one is cognisant with this. The following chapter sets out the methodological approaches utilised to achieve this.

Chapter Three:

Evaluation method

The methods chapter sets out the underpinning theoretical position of the evaluation, documenting the operationalisation of the evaluation process and is organised in the following manner:

- The opening sections justify the scope of the evaluation outlining the methodological approach of narrative inquiry.
- The next section sets out the design of the evaluation identifying the two phases, data collection, the ethical issues and strategies adopted within the evaluation.
- The final sections centre on the analytical process drawing together the forms of data collection into the grand narrative.

3.1 Evaluation principles and practice

Evaluations seek to generate knowledge that allow for judgements to be made around the impact and effectiveness of programmes, interventions or services (Froggatt and Hockley 2011). Whilst there is no single universal definition or approach to evaluations, commonly they are participatory, systematic, goal orientated approaches providing judgement of the effectiveness of a service to show evidence of meaningful societal benefit (Patton 1986; Weiss 1990; Scriven 1991; Rossi and Freeman 1993; Clarke 2012 and Henry *et al* 2013).

3.1.1 Evaluation methods

Evaluations are a form of applied social research whereby the primary purpose is not the pursuit of truth but instead is concerned with the effectiveness by which existing knowledge is used to inform and guide practice (Clarke 2012 and Davidson 2005). There is broad consensus that the major goal of evaluation should be to influence decision-making or policy formulation by providing feedback, to generate the assessment of overall quality or value and to find areas for improvement (Davidson 2005).

Shavelson & Towne (2002) described three fundamental questions that drive evaluation. Descriptive – "what is happening?", causal – "what the cause of what is happening?" and mechanism – "how or why is it happening?" Traditionally evaluations are considered summative or formative in nature (Brown and Gerhardt 2002 and Boland *et al* 2014). Summative evaluations target audiences are predominately policy-makers, commissioners and public sector organisations and are usually led through independent inquiries with an emphasis on quantitative data collection- with a focus on standardised implementation and/or outcomes by generating an assessment of the overall value of services (Clarke 2102; Herman *et al* 1987; Scriven 1967). Formative evaluations tend to be qualitative and contextualised; providing feedback to support the process of improvement by identifying strengths and weaknesses- emphasising the participatory experiences of stakeholders to ascertain if changes are needed to drive forward service improvement (Boland *et al* 2014; Clarke 2102; Beyer 1995; Herman *et al* 1987; Scriven 1967). The traditional demarcation between these forms of evaluation is however increasingly being questioned. As Shavelson (2018 p12) argues fundamentally the route of evaluation should not be determined as either formative or summative but by the collection of rigorous evidence to addresses the policy and/or practice *questions* driving the evaluation. Adding *"questions that gave rise to the evaluation should drive the design and conduct of the evaluation".* Significantly whatever the goal of evaluation, it is essential to consider the multiple contexts within which is it embedded. National large-scale policy such as those set within health or education and their underlying politics shape the context of evaluation therefore, any evaluation must be sensitive to these (Shavelson 2108). The exact evaluation design is therefore informed by Shavelson (2018) critical questions rather than traditional definitions of formative or summative and is outlined later in the chapter.

3.1.2 Critical appreciation of evaluation and its contribution to knowledge in health and social care.

The drive for evidence-based practice has brought forward the challenge of implementing robust research outcomes and policy in what are complex health and social care organisations (Stetler *et al* 2006). Increasingly evaluations are being used to inform organisational understanding of existing and new approaches to drive forward high-quality care (Boland *et al* 2014; Stetler *et al* 2006). Siriwardena (2009) proposes that evaluations in healthcare are often undertaken for two common goals. Firstly, to determine the quality of care. However, following the Darzi report on standards of care, "quality of care" is now understood to encompass effectiveness, efficiency and safety as well as patient experiences (Darzi 2008). Secondly to explore whether the aims of care are being met and to provide feedback to inform future improvements. Inherent within these goals of evaluation is the importance of recognising human factors as influencing change (DoH 2016). Ownership of change is essential for quality improvement in healthcare. Professionals such as medical staff, nurses and therapists have a collective influence over the successful leadership of change within health services and therefore integrated, participation in evaluations are essential hallmarks of quality improvement (Kings Fund 2018).

Expert reviewers such as health professionals within evaluation are increasingly being drawn upon to provide valuable expertise in understanding and exploring the context of the issue and offer insight into potential areas for development. Boland *et al* (2014) suggests that by drawing on stakeholders of care in the form of expert review at differing stages of the evaluation process, authentic relationships can be developed. Siriwardena (2009) proposes that within evaluations in healthcare narrative techniques for quality improvement include story gathering as a tool for collective-sense making. The use of participative approaches such as this contribute to developing shared understanding between evaluator, participants and the wider audience. This is a vital component in health contexts as the aim is to drive forward improvements in patient care leading change from within (Greenhalgh *et al* 2005; Siriwardena 2009; Clarke 2012; Boland *et al* 2014). This therefore situates evaluation as a key approach in healthcare to drive improvement and consequentially an appropriate approach to develop further knowledge underpinning decision-making within the context of clinical care of older people.

3.1.3 Justification for an evaluation in exploring professional decision-making at end-of-life for frail older people.

As highlighted evaluation is becoming an increasingly common feature in quality improvements within health and social care. Froggatt and Hockley (2011) suggest that evaluations in end-of-life care contexts are valuable in evidencing complex and developmental interventions. They further propose a reliance on summative data alone can lead to incompleteness in understanding the whole picture of care concluding that broader interpretations of the interplay between summative and formative are required to enhance quality improvement. Therefore, this evaluation draws on expertise of healthcare professional in a participatory approach to provide insight into the contextual basis of decision-making in determining the approach to caring for frail older people at end-of-life.

3.2 Evaluation design

Evaluators should be aware of the underpinning philosophical assumptions pertaining to the scope of the evaluation and methodological approaches considering their implications, thus ensuring a rigorous evaluation (Patton 1987, Clarke 2012). To be effective evaluators must be equipped with a deep appreciation of the application of research methods and methodologies alongside necessary technical skills of investigation (Suchman 1967, Shadish *et al* 1991 Clarke 2012).

3.2.1 Evaluation questions

Fundamentally the question driving the evaluation should inform the evaluation design, with the scope of evaluation determined by the methodological principles on which it is based (Shavelson & Towne 2002). Patton (1987) one of the founding proponents of evaluation methods argues that the key in designing an effective evaluation is to ensure that the information gathering process is appropriate to the specific situation and policy context to address the goal. This evaluation has two underlying questions informed by Shavelson & Towne (2002) fundamental approach. Firstly, the evaluation is descriptive seeking to explore "what is happening" in the context of decision-making for frail older people -to illicit an understanding of how professional knowledge is applied in decision-making and to define the scope of practice in supporting frail older people at end-of-life. Secondly the evaluation is mechanistic exploring "how or why is it happening?"- seeking to examine the underpinning influence on decision-making from policy and practice to inform future care provision. In doing so qualitative methods using narratives as proposed by Siriwardena (2009) are appropriate to illicit an understanding of how knowledge is both influenced and applied within a service context and across various professional viewpoints.

3.2.1 Narrative inquiry within the evaluation

In order to evaluate decision-making, narratives enable professionals' to tell their story of care and as Williams (2004 p279) describes narratives are *"small windows opening on to the gritty realities of social structure and social change",* with the use in health-based research focusing on individual stories, drawing out the accounts of health, illness and care providing broader representation of experiences; telling us truths about the lives lived. Clandinin *et al* (2007) propose that narratives have three commonplaces that serve as a conceptual framework for the narrative inquirer; temporality, sociality and place should focus the inquirers attention as checkpoints to explore the fullness of experience. They assert within narrative inquiry there should be simultaneous exploration of all these commonplaces and in healthcare, Charon (2004) recognises that within clinical encounters these commonplaces all happen at once. Temporality refers to temporal transition, the notion that narratives are shaped by connections to the past, present and future. People, events and experiences are in process, transitioning and that narratives form part of a much larger sequence of time (Bold 2012) and are often entwined in change. Sociality is concerned with personal and social conditions; the personal dimension refers to the feelings, characteristics, attributes, moral disposition of the narrator and inquirer as a way of exploring thoughts and feelings of experience. The social conditions are viewed as existential; the environment and how surrounding factors and forces, people or resources form that individual’s context (Connelly and Clandinin 2006). In narrative inquiry it is important to consider both dimensions of experience exploring both the personal meaning and wider expression of social structure and process. The final aspect is place; this refers to the specific, concrete physical and topographical boundaries of the experience or event. This commonplace is fluid, changing as the narrative unfolds and each place offers differing levels of influence on both the temporal and social dimensions. Clandinin et al (2007) inform that it is essential to locate the narrative as events occupy multiple locations and shape our experiences.

According to Connelly and Clandinin (2000) narrative accounts have four directional dimensions and through these the telling of events is articulated. The dimensions are inwards (internal feelings, emotions, morals and aesthetic reactions), outwards (existential conditions, environment, contexts), backwards (the past and present experiences that shape the present) and forwards (the present experiences and imagining the future) and are expressed in the telling of experience. This evaluation of end-of-life care is informed by both the structural and contextual basis of care such as national policy and guidance surrounding end-of-life care and frailty as they are enacted within the scope of professional practice. These were considered alongside the narrative accounts of healthcare professionals themselves in providing end-of-life care to frail older people to view the way in which practice is formed and shaped thus forming the commonplaces and directional dimensions proposed by Clandinin and Connelly (2000).

3.3 Positionality within the evaluation

Traditionally healthcare has been dominated by a positivist paradigm and this has influenced healthcare research, policy and practice on a macro and micro level often operationalised through evidenced based practice models (Sackett *et al* 1996). As such knowledge stems from deductive methods of knowing, of experimentation, repetition and direct observation of patterns to identify cause and effect and that through this human science can accurately reflect reality (Cruickshank 2012).

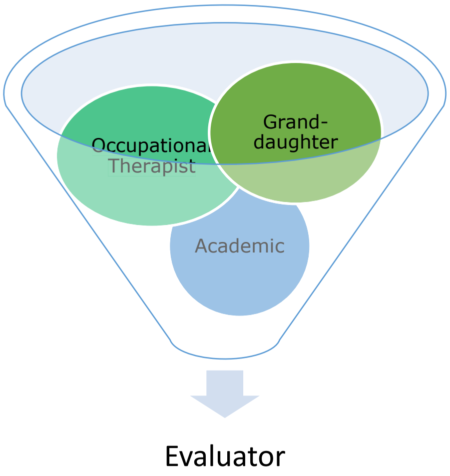
In response to the criticisms of the dominance of positivism in healthcare increasingly interpretative paradigms such as social constructionism is drawn upon to humanise medicine (Alexander 1985; Danermark *et al* 2002). The tenets of social constructionism’s are largely unreconcilable with positivist, taking as Cruickshank (2012) and Easton (2010) propose a binary opposition. Whereby positivism is considered a ‘single flawed entity’ with sceptical rejection of any proposition of a single unified notion of truth and reality. Social constructionism generally considers knowledge as constructed rather than created and therefore reality is socially defined (Andrews 2012). Instead reality is referred to as the subjective experience of every-day life. This has the potential to undermine professional knowledge in being able to develop theoretical underpinnings that can accommodate differing perspectives, observations, conformability and complexity of concepts examined (Cruickshank 2012; Walsh and Evans 2014). This creates a tension in research and practice for healthcare professionals where clinical practice requires both objectivity and subjectivity. To adopt social constructionism position within the evaluation therefore would fail to acknowledge the differing perspectives that healthcare professionals accommodate in their practice. Unlike social constructionism, critical realism does not dismiss entirely the positivist position- adhering instead to the possibility that knowledge may be positively applied to assist development of technology and medicine. Critical realism instead recognises that positivism stems from applying knowledge that is created by fallible theories rather than by certainties (Cruickshank 2012; Zacharidis *et al* 2013 and Walsh and Evans 2014). By taking a critical realist approach the differing epistemological positions are considered in synergy and therefore influences my positionality as neither inside (value laden interpretative account of knowledge) or outside (objective independent account of knowledge) but instead holds a critical appreciation of both- thus providing a platform to view the differing ideological perspectives that influence professional decision-making.

Critical realism provides a lens for considering frailty and death that occupies a space between positivism and interpretivism drawing on intra and interdisciplinary views. In terms of criticality appreciating that the unifying reality of death exists independently of our knowledge or perception of it and is therefore both subjective and objective with much unknown. Just as critical realism operates in a space between positivist and interpretative so my place within this evaluation occupies a similar space. I am neither inside or outside the place of enquiry in the evaluation. I cannot divorce myself from my operational lenses as a practitioner or academic as they shape my experiences within the *empirical* and *actual* level of ontology (Walsh and Evans 2012 and Dyson and Brown 2005). However, by adopting a critical realist approach these positions enable me to criticality examine the *real* level of ontology, exploring the knowledge through which I view the phenomena contributing to the formation of ideas.

3.3.1 Reflexivity within the evaluation

Critical realism provides a lens for considering frailty and death that occupies a space on the continuum between positivism and interpretivism drawing on intra and interdisciplinary views, that the unifying reality of death exists independently of our knowledge or perception of it. Whilst human endeavour generates knowledge it is relative and fallible to the process of its production, located in place, time and context and whilst much has been done to understand the ageing process and hold back the final "big tock", death is one true unifying reality. There is increasing public and private dissatisfaction in how we care for the vulnerable in society, driving forward an ethical imperative to open-up debate around frailty, loss and death as a spectrum of everyday life that has located old people as marginalised, silenced and invisible unable to fully assert citizenship and agency as the antonym to successful ageing (West and Glynos 2016; Timonen 2014; Nicholson *et al* 2012). By offering an understanding of ageing, frailty, death and dying my aims was to expose a holistic view of the phenomena to contribute to a broader understanding of the interplay between theory, research, policy, experience and practice in supporting frail older people at end of life. In doing so, one of the greatest challenges was ensuring transparent accountability of the rigour within which the evaluation was conducted and presented; sensitively capturing and representing the multiple levels of knowledge uncovered during the evaluation process (Finlay 2012; Riach 2009 and Crowe and Luty 2005).

The term reflexivity is a complex umbrella concept that can be used to describe different levels of introspection with the aim of uncovering an individual's self- consciousness, self-referentiality and reality (Riach 2009, Crowe and Luty 2005, Mauthner and Doucet 2003). Often application of reflexivity within the evaluation process is assigned to the dynamics of the data collection, evaluation context or to signify positionality; but to do so this places the evaluator at the epicentre of any discussion and therefore fails to address the challenge of presenting the fullness of possible truths (Gemignani 2017; Finlay 2012; Riach 2009; Alvesson 2003).



In considering my positionality it was essential that I consider the roles that I held recognising the important lenses that this brought to the process of the evaluation. From a critical realist stance, these aspects according to Gemignani (2017) exist as priori of the research process and are therefore ever present irrespective of the investigators ability to be aware of them. The practical action of reflexivity is to make explicit what is implicit with the aim of mediating their effect but in doing so be aware that they cannot be excluded or eliminated. Finlay (2012) proposes that there are 5 lenses of reflexivity, of central concern in this evaluation were contextual-discursive and ethical reflexivity.

Contextual-discursive considers the social perspective and shared meaning and is aligned to the narrative approach of Connelly and Clandinin (2000) used in this evaluation. During the evaluation process I was increasingly immersed in the world of frailty both in hearing the stories of the professionals, collating the clinical records and personally through the experiences of my grandmother as she navigates life with frailty. Although this was not envisioned at the outset of the thesis it has resonated with poignancy the experiences that have been laid out in literature, policy and stories of the healthcare professionals. As Finlay (2012 p6) also an occupational therapist discusses "scrutinizing the complex political/ ideological agendas that exist around our participants and within the broader research context" and as such is embedded in the reflexive process of this evaluation through a discursive appreciation of place, sociality and temporality.

The ethical dimensions of reflexivity were inherently complex given the nature of the evaluation and whilst procedural processes were put in place it was also critical to consider further relational challenges in navigating my role as the evaluator. My relationship with the participant, their stories and myself was important to contemplate to monitor the ethical integrity of the evaluation. The complexity of these issues is fully discussed in section 3.5 and highlight the importance of power, relationships and emotional labour for both the evaluator and participant.

3.4 Evaluation data collection

The evaluation utilised a novel approach integrating documentary evidence and personal accounts within a narrative framework. In doing so the evaluation was operationalised into three phases, firstly case reviews of clinical documentation against benchmark standards of care to explore the policy and practice context of end-of-life for three deceased frail older people. Secondly the narratives of health care professionals that supported the identified deceased frail older people were collected to examine in more depth their decision-making in delivering care. The final phase was to draw the narratives and documentary evidence together forming grand narratives, the story of decision-making of care at end-of-life for frail older people.

3.4.1 Identification of cases for review

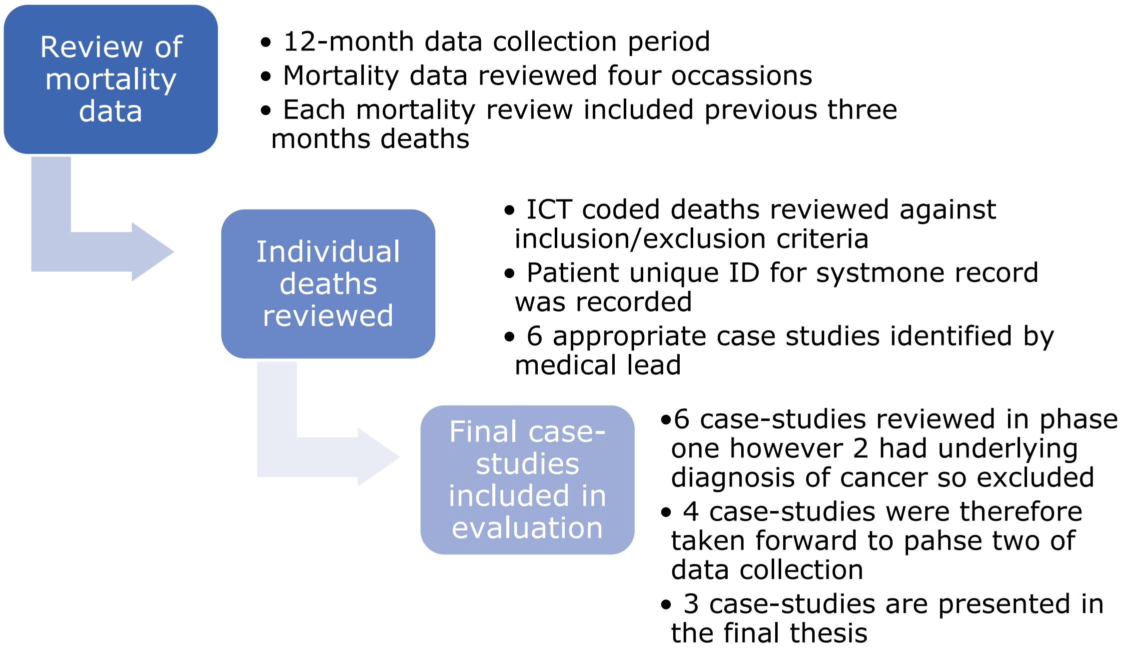
The evaluation was conducted in collaboration with a local NHS Trust to provide a discrete contextual basis of the evaluation and therefore make a more meaningful contribution to informing local practice. The medical lead for older persons across the county and ICT within the local trust acted as a gatekeeper within the evaluation, adhering to the local trust Research and Development (R&D) approval of the evaluation. The gatekeeper identified all deaths of frail older people using the local trust mortality register. The mortality data for the local NHS trust was stratified to identify deaths that occurred within the previous three-month period to ensure that during interviews participants would be able to recall effectively the identified deceased patients. The mortality register identifies deaths across the whole community trust and therefore the criteria for the case study review within this evaluation are presented in table 3.1 over-page.

Criteria	Rationale
Deceased frail older person between stage 7-8 on clinical frailty scale at the time of care	The clinical frail scale 7 -8 indicative of approaching end-of-life (within next 12 months)
75 years and older	Considered to be old within the context of NHS policy and frames service provision.
No known life-threatening diagnosis (for example cancer)	People with a specific life-threatening diagnosis are generally under the care of specialist services and therefore provided with a differing process of care.
Community dwelling at time of death	The provision of community-based care within the patient’s own home rather than a formal care environment.
Death within last three months of ICT involvement	To ensure professionals recall the patient and care provided with more accuracy
Received input from ICT within the last episode of care prior to death.	To ensure professionals recall the patient and care provided with more accuracy

Table 3.1: Deceased frail-older-person case review criteria

3.4.2 Overview of the process in identifying the final three case reviews

The mortality data for the trust was reviewed by the medical lead on four occasions at three monthly intervals during the 12-month period of data collection as outlined in diagram 3.1. This ensured that across one calendar year the seasonal influences on healthcare utilisation and ageing processes (such as winter crisis and seasonal illness) were accounted for. Those patients who were coded as ICT on the mortality register were individually reviewed and the selection criteria applied. The patient’s clinical record was viewed by the medical lead to ensure ICT care was provided as in some cases referrals are not accepted or patient tracking is activated although the patient may be in hospital.



Review of mortality data

- 12-month data collection period
- Mortality data reviewed four occassions
- Each mortality review included previous three months deaths

Individual deaths reviewed

- ICT coded deaths reviewed against inclusion/exclusion criteria
- Patient unique ID for systmone record was recorded
- 6 appropriate case studies identified by medical lead

Final case-studies included in evaluation

- 6 case-studies reviewed in phase one however 2 had underlying diagnosis of cancer so excluded
- 4 case-studies were therefore taken forward to pahse two of data collection
- 3 case-studies are presented in the final thesis

Diagram 3.1: Process of identifying final case-review

Six case reviews were identified however **three** are presented in within the final thesis report. As outlined in the above process diagram six cases were reviewed in phase one however two were excluded due to not meeting the evaluation criteria. Four cases were taken forward to phase two however, the context of case review four was significantly different. It was evident that the fourth case review was a single episode of care within a 48-hour window unlike the previous three where care was provided over the last 12 months of life. The professional's input was provided as intermediary whilst waiting for care from specialist palliative care services as the frail older person was already identified as imminently dying. This fundamentally presented a different contextual basis of care, altering the decision-making of professionals and therefore was excluded from the final evaluation data set.

3.4.2 Overview of three case reviews

An overview of the three case reviews is presented to provide an appreciation of the resulting process of evaluation centred on the care and death of these people. The individual cases have been pseudonymised as Albert, Brenda and Colin.

Case-study one: Albert

Albert was a 91-year-old man who lived at home with his wife in a house, he had a past medical history of Chronic Obstructive Pulmonary Disease, Ischaemic Heart Disease, falls and increasing frailty. Albert was referred to ICT on discharge following a lengthy admission to hospital for a recurrent chest infection. Albert was well known to the ICT service and had been supported by them on many occasions in the last 24 months of his life. Albert's health was in significant decline, his wife and family were providing increasing support to care for him at home. The ICT remit with Albert was a facilitated discharge and the team that supported him included, nursing, occupational therapy, physiotherapy and rehab assistants. On his final episode of care within ICT it was identified that Albert had notably deteriorated and was requiring additional support for all his personal care, was not mobilising, appeared fearful and remained in bed most of the day. Whilst under the care of ICT Albert was admitted to hospital during the evening as an out of hours emergency and died within a few hours of transfer.

Case study two – Brenda

Brenda was a 95-year-old widow who lived alone in a small flat supported by her family. Brenda had no formal care support and was referred to ICT on several occasions during the last year of her life. Brenda's family provided much of the informal care and on several occasions requested input from health and social care, expressing concerns about their mother's health and wellbeing. Brenda was initially referred for rehabilitation following the concerns identified by her family, Brenda declined support and refused to participate in the rehabilitation interventions that were planned and was therefore discharged from ICT. Brenda was frail, had a history of falls, low mood and urinary tract infections and was re-referred to ICT by her family one week later. During this, her final episode of care with ICT Brenda declined admission to hospital on several occasions stating a preference for no medical intervention. The ICT that supported Brenda included, nursing, occupational therapy and rehab assistants. Brenda died at home in her own bed one week later following support from ICT, palliative care and specialist homecare.

Case study three – Colin

Colin was an 83-year-old man who lived with his wife in a large Victorian house and had a large extended family supporting the couple. Colin had been discharged from hospital following a prolonged admission to an acute trust on a medical ward. Colin had heart failure, reduced mobility, fatigue, shortness of breath on exertion and frailty. Colin was referred to ICT from the acute trust to support on discharge and provide a period of rehabilitation with intensive carer input twice a day for personal care from a crisis response team. Colin expressed a preference to remain and home and not to be readmitted to hospital. The ICT that supported Colin included, nursing, occupational therapy, physiotherapy and crisis response care assistants. Colin had fluctuating health whilst being supported over the two-week period of ICT and on the second planned week of ICT support Colin was admitted to hospital and died within 12 hours.

3.4.3 Phase one: review of deceased frail older person's care as documented in clinical records

The clinical records of three deceased patients were reviewed against best practice guidelines in the care of frail older people and end-of-life care as indicators of high-quality care provision previously identified in chapter two.

As part of the R&D approval I was provided with direct access to clinical records via an existing NHS smartcard that I held. This logged my actions within the clinical records as an administrative role, limiting the features available to me as a "nominated researcher" within the local trust. ICT use an electronic clinical records software SystmOne (https://www.tpp-uk.com/products/systmone). The records are shared between primary and secondary care providers as a strategy to promote seamless continuous care and therefore are complete accounts of any contact across health care team for the older person, including interactions with their carers. ICT have developed protocols and clinical templates within SystmOne to record standardised care; in addition, individual professional clinical interactions are recorded for each visit to the patient and/or carers. The notes form a chronological account of the process of care provided to each person within ICT. The notes were reviewed within the tabbed journal format as this provided both the template assessments and individual professionals accounts. Within the episode of ICT care for each case study the documentation was read several times to familiarise the context of care for the identified deceased patient.

Following this the documentation was reviewed to locate within the care episodes features of the key benchmarks of frailty and end-of-life care. An overview of the benchmark areas is provided in table 3.2 below.

End-of-life care					
Benchmark Policy	Five priorities care of the dying person	Advanced Care Plan	Advanced do not resuscitate (if appropriate)	Discussion preferred place of death	Achieved preferred place of death
Frailty					
Benchmark Guidelines	British Geriatric Frailty Guidelines	Common Geriatric Assessment			

Table 3.2: Benchmark policies and guidelines used to review documentation

The CGA is internationally considered to be gold standard assessment tool in the care of frail older people (Clegg *et al* 2013; BGS 2011; DoH 2014; Kings Fund 2014; Stuck *et al* 2002) and integral to the NHS care-pathway for frailty (DoH 2014). The CGA however is time intensive within clinical practice and therefore the British Geriatric frailty guidelines offer a more pragmatic tool which is informed by the CGA principles and is useful for time bound areas of practice. The benchmarks at end-of-life are informed by a variety of national policy and guidance including Five priorities of care of the dying person (LACDP 2014), End-of-life Care Strategy (DoH 2008, 2013) and National Voices (2015), promoting the recognition of personalised care, choice and dignity at end-of-life. (Refer back to chapter 2: critical review of policy and practice for further details)

ICT SystmOne clinical records do not have a specific template for assessment and management of frailty or end-of-life care however some features were embedded within core ICT protocols. This resulted in the documentary review becoming complex moving through the tabbed journal in association with the review framework in appendix one to map against benchmarks of care.

3.4.4 Phase two –Healthcare professionals narrated decision-making processes in caring for a frail older person.

It is critical that evaluation in end-of-life utilises the best method to enable participants to share their experiences whilst preserving ethical integrity ensuring that participants are supported during the process. It has been noted that research and evaluation involving people within end-of-life care contexts is fraught with ethical challenges particularly in balancing the potential emotional burden and potential benefits of participation (Hardy *et al* 2012, Gysels *et al* 2008, Addington-Hall 2002). Predominately interviews are commonly used within qualitative research. Corbin and Morse (2003) explored the advantages of in-depth interviews and concluded that they provide the opportunity to develop research in areas that are complex, sensitive and under-represented. Narrative interviews provide an avenue for the researcher to pursue a variety of perspectives within to gain new insights, explore meaning or interpret experiences however can be an emotional labour (King *et al* 2013). Harris *et al* (2008) and Kendal *et al* (2007) urged researcher to step outside their "methodological comfort zone" and employ alternate strategies to enable sensitive approaches within interviewing to gain real-life experiences of end-of-life care as the credibility and validity of the interview is determined by the richness of the data.

3.4.5 Outline and justification of the narrative interview process

There is evidence that in end-of-life care factors such as emotional responses, complexity of care and difficulty in articulating thoughts can impact on a participant's ability to contribute to conventional research interviews and therefore strategies to mitigate this needed to be embedded in the evaluation process (Barton 2017; King *et al* 2013; Hardy *et al* 2012). Hardy *et al* (2012) proposes that by assisting participants to explore and articulate their experiences simultaneously through interview and visual means can address some of the potential barriers to engagement in end-of-life care research. Visual methods have been utilised in reviewing patient-based case-studies to enable people to describe and explain their story using tools such as arrows, notes or cards to draw out their narrative of care (Barton 2017, King *et al* 2013, Hardy *et al* 2012). The direction and flow of the conversation being supported using visual method thus enables the participant to consider the experience of end-of-life care in its fullest whilst focus is retained on a defined care context (King *et al* 2013).

The interviews in the evaluation were therefore supplemented using concept care mapping as a visual form to situate the temporality, personal meaning and social context of the narrative to uncover the care experience provided to frail older people. By stepping out of the methodological comfort zone and incorporating both interview and care mapping into this evaluation supported participation and assisted participants in the maintaining emotional integrity within the experience of clinical story-telling. Concept care mapping has its foundation within nursing as a tool to support information gathering and decisioning making in practice (Schuster 2007, 2016). Schuster (2007, 2016) draws on educational theory to propose that concept mapping enables practitioners to assimilate knowledge by integrating new and existing knowledge through the building of diagrammatic relationships identifying what is already known and understood alongside revealing gaps within clinical practice skill, experience and knowledge base thereby transforming practice. Concept care mapping therefore holds commonality with evaluation, a shared purpose of considering existing knowledge and its application to practice.

At the centre of a concept map is the patient with subsequent layers considering their clinical presentation, personal factors and needs culminating in the formation of treatment plans that are underpinned by clinical reasoning and decision-making. Eliciting the narratives in this way is considered particularly beneficial when focusing on sensitive topics as it places less burden on the participant as the centre of the interview process (King *et al* 2013) and therefore the aim of using the concept care map was to place less burden on the participants in being the foci of discussion, instead centring it around the concept care map facilitating the interviews as an open and fluid dialogue between interview and interviewee. The interviews focused on exploring decision-making in determining care, what aspects were addressed and what influenced how decisions were made within the frail older persons care.

3.4.6 Healthcare professional participants

As the evaluation used a case-review approach all professionals involved in the care of deceased *Albert*, *Brenda* and *Colin* were identified in phase one. All professionals associated within the three case reviews were invited to participate in the evaluation. Only professionally regulated qualified grades of staff were invited to participate as they are responsible for the decision-making that underpins intervention plans.

The professionals invited to take part in the evaluation were

- Medical staff
- Allied Health Professionals (Occupational Therapists, Physiotherapists)
- Nursing staff

An email invitation was sent to the identified professionals and included a letter of introduction, participant information sheets and guidelines of the evaluation process (See Appendix two – Participant information). The criteria and rationale for participation in phase two of the evaluation are set out in table 3.3 below.

Participant criteria for professionals	
Inclusion	*Rationale*
Registered Healthcare or Social Care Professional	Qualified professionals assess and plan the patient care and are accountable for the interventions within the ICT team. Support staff are therefore excluded as they enact the care/treatment plans set out by the qualified professionals.

Involved in the delivery of end-of-life care within local trust for the identified deceased frail older person	To be able to directly recall, discuss and share their experience working with the specific case study patient(s)
Exclusion	*Rationale*
In receipt of end-of-life care provision	The emotional burden of participation would be unethical in discussing death and dying
Recently bereaved	The emotional burden of participation would be unethical in discussing death and dying

Table 3.3: Healthcare professional participant criteria

18 professionals were invited to participate across the three cases including medical, nursing, occupational therapists and physiotherapists. Of those 3/18 were no longer working within NHS, 3/18 were on extended leave and 2/18 did not respond to the invitation.

3 nurses, 4 occupational therapists and 3 physiotherapists participated, and 0 medical staff chose to participate in the evaluation.

In total 10 narrative accounts were analysed and are presented in this evaluation.

3.4.7 Interview process

The evaluation utilised in-depth interviews supplemented by concept care mapping as a form of elicitation to collect professional’s narratives. The venue for the interview was determined locally to facilitate engagement within the evaluation process and all participants chose to be interviewed at their clinical base. As part of the R&D approval from the local trust it was agreed that NHS sites could be used to conduct the interview.

The interviews were arranged at mutually convenient times and were allocated within clinical workloads to facilitate engagement in the evaluation process. The interview format was broadly structured to include an introduction to the evaluation with an explanation of care mapping and interview process. The care mapping process (an example of a care map is provided in Appendix three) provided a structure to the interview. The concept care maps were concentrically formed placing the older person at the centre of the map as recommended by Schuster (2007, 2016). Typically following the same phases of construction but were open to individual interpretation by the participants:

- Context of the care of the frail older person to provide an understanding of the referral process for each professional and the purpose of the visit from ICT
- Identification of the frail older persons (including family and carers) needs within the remit of ICT
- Interventions completed to address the needs of the frail older person and where appropriate their family or carers.
- Onward intervention and multi-agency support needs identified

The main body of the interview was unscripted to allow the participants to recount their story of care and decision-making. Open and challenging questioning were used throughout the interview to ensure clarity and depth to the discussions. During the interview the participants mapped out the care of the case study individual on to an A3 sheet of paper to support the discussion of the process of decision-making.

The concept care maps enabled the participants to remain focused on the case study and supported their recall of events surrounding the process of care. During the construction of the concept care map discussion of the professional's role and decision making in the process of care provided talking points centring on the following topics

- Exploration of how the older person and carers needs/wants were incorporated into the focus of care delivery as a basis of decision-making
- Discussion of the professional's role in end-of-life care and how it is determined within care of the frail older person focusing on decision-making

Using a funnelling-approach the interviews were brought to conclusion by taking the discussion to broader issues and included

- Consideration the underpinning ethos of focus of care and decision-making in end-of-life care delivery
- Exploration of what features contributed to the quality experiences of end-of-life care within the scope of practice

Within the interviews participative building of the concept care map enabled free discussion with the participant, to help understand their reasoning process and decisions that led to the care provided to each case-study patient. All participants were offered an opportunity to further clarify or comment on the case study before the interview was drawn to a close. At the close of the interview participants were informed once again of the withdrawal points of the evaluation and signposted to support networks within the local trust should they wish to access them following on from the interview.

The interviews lasted between 90 -120 minutes. They were transcribed verbatim and returned via email to each participant to verify the accuracy of the account. Offering the opportunity to add any further information to the narrative account. Following email confirmation by the participants of acceptance of the transcripts they were no longer able to withdraw from the evaluation process.

3.5 Ethical issues

The University of Northampton Research Degrees Board along with the local trust R&D Team reviewed the project according to standards of research governance. As the final evaluation study was an amendment to a previously NHS NRES approved project advice was sought to ensure adherence to approval processes. As part of the ongoing discussion with the local trust R&D team, NRES guidance and clinical partner the evaluation was reviewed. It was agreed that for the following reason NHS approval for the evaluation was deemed at a local trust R&D board level and in tandem with the University Research Degree's and Ethics committee.

1. The study is an evaluation
2. The focus of the evaluation is of existing practices and care in one trust (single site)
3. The study is not seeking to access patients or carers directly
4. No identifiable data is collected (deceased patient ID is used)
5. The healthcare professional interviews pseudonyms will be assigned to ensure confidentiality and anonymity

3.5.1 General ethical standards within good clinical evaluation practice

Evaluation involving people is socially important but morally fraught as it exposes people to risk for the advancement of knowledge and therefore ethically justified evaluations must satisfy several conditions. These include (i) validity of the evaluation in contributing to knowledge review and in the case of the evaluation, practice-based knowledge, (ii) a balance of favourable benefits over risks for the participants and (iii) a fair selection of participants. These conditions are based on underlying ethical principles of autonomy, beneficence, non-maleficence and justice. The principle of autonomy in bio-medical ethics is concerned with upholding the decision-making capacities of autonomous individuals; within evaluation this is translated into two separate processes providing information to support decision-making and consent. These consequently then address the principles of beneficence and non-maleficence in balancing benefit and risk in ethically permissible evaluations in supporting evolving clinical practice through applied ethics (Beauchamp and Childress 2013).

All participants were fully informed about the nature and purpose of the evaluation before they could consent to participate. Obtaining informed consent from the participants was an essential component of the evaluation and underpinned dually by the principles of autonomy and non-maleficence. All participant are registered practicing healthcare professions therefore their capacity to consent was not questioned directly. Of greater significance was ensuring voluntariness of participation, which according to Beauchamp and Childress (2013) refers to the degree to which a person's action is without control by another person's influence. It was vital to recognise the inherent power relationship within the evaluation as impacting on voluntariness, Karnieli-Miller *et al* (2009) reflects that in practice there are no definitive, correct or optimal relationships in research and evaluation to manage power imbalance. I was also aware of the competing roles that I held as influencing power relationship. I am a practising occupational therapist within end-of-life care and therefore could be viewed as a specialist, I am also an experienced academic who has been involved in the education of professionals both in occupational therapy and wider delivery of post graduate training to nurses and therefore could have encountered participants within working practice.

The recruitment process thus needed to provide a distribution of this power base allowing participants to engage with me as the evaluator, counterbalancing other roles that I continued to hold. An alternate email address via the NHS.mail account was created to communicate through and participants were sent information regarding the evaluation, consent process, case study scope and patient ID to view prior to considering participation allowing them to view with transparency any involvement in the evaluation. It also located them as experts in the delivery of care to their patients' group with the aim of equalising the power relationships and in control of their input to the evaluation (Karnieli- Miller *et al* 2009). All participants received written information describing the aims of the evaluation and what was expected if they participate in the process including the contact details of the me as the evaluator, support organisations and, for quality assurance purposes the supervisory team contact details were also provided. In addition, all participants were provided with an opportunity to pose questions to the me regarding involvement in the evaluation as discussed in the recruitment strategy. The purpose of providing information is recognised as addressing the innate connection between autonomy and decision-making within health and social care practice. Disclosing information to potential participants in a variety of modes supports adherence to the International Ethical Guidelines for Biomedical Research (2001) in enabling potential participants to access appropriate, timely and supportive information to make an informed decision. To ensure informed consent all participants were provided with the opportunity to receive and discuss the participant information concerning the nature of the evaluation. It was made explicit that their participation was confidential throughout the data collection, analysis and dissemination process. Explicit withdrawal points were identified with participants as the return of transcripts, this was set out in all supporting documentation and discussed in person when gaining consent prior to the interview.

It was also critical that the participant information specified my ethical and professional requirement to disclose outside of the evaluation process any content that could be indicative of poor practice. The process of this was reiterated in person within the opening of the interview process and the mechanism used was underpinned by local trust clinical reporting processes. This duty of candour that all registered healthcare professionals must adhere to arose from the outcome of the Francis report (DoH 2013a) which has subsequently has been devolved into professional regulations and codes of conduct such as the Health Care Professions Council - standards of proficiency and conduct for Allied Health Professionals (2016) and the Nursing and Midwifery Council professional regulations (2015).

Informed consent addresses decision and authorisation of participation. This aspect of the informed consent process used what is termed as *process consent* recognising the fluid and dynamic nature of consent as consistent feature when researching with vulnerable populations or emotive topics such as this evaluation (Dunning *et al* 2013, Dewing 2008). Process consent is outlined by Dewing (2008) as context-specific, acknowledging the situational nature of capacity that is often present when researching emotive topics such as end-of-life care. Process consent is viewed as a responsive approach to ensuring that consent is appraised within the evolving context of the interview rather than adopting a universal approach to consent as a one-off event. Given the nature of discussion focusing on the death of a patient there was the potential to evoke personally emotional responses. Within the interviews many of the participants reflected back on previous experiences of death and bereavement and therefore it was important be responsive to the welfare of the participant and safeguard their well-being. Taking this approach enabled me to respond to the needs of the participants within the interview and on occasions paused to allow time for reflection or support to be offered within the interview. Participants if they became emotional or expressed personal conflicts were asked if they wish to continue with the interview and all chose to complete the interview.

It was fully anticipated that the interview process could evoke personal issues as the discussion focuses on the death of a patient and therefore may expose personal vulnerability in managing and coping with grief, loss and bereavement in practice and personally. It was therefore essential to safeguard the welfare of both me and the participants throughout the process of the evaluation. To explore this potential vulnerability, Kipnis (2001) taxonomy of biomedical research vulnerability was applied to the evaluation process. The taxonomy as set out below allows strategies to address vulnerability to be established in the design of this evaluation.

Communicative	when there are clinical or psychological implications for the person's ability to communicate. These may be due to distress, symptoms or cognitive changes.
Institutional	where people are under the authority of others such as healthcare providers or professionals or external reviewers.
Deferential	where people are subject to the informal interest of others such as a researcher or evaluator
Medical	where people are living with serious health related medical conditions.
Social	where people are socially or institutionally disadvantaged, this may be for example due to social class, diagnosis or educational level or power relationships

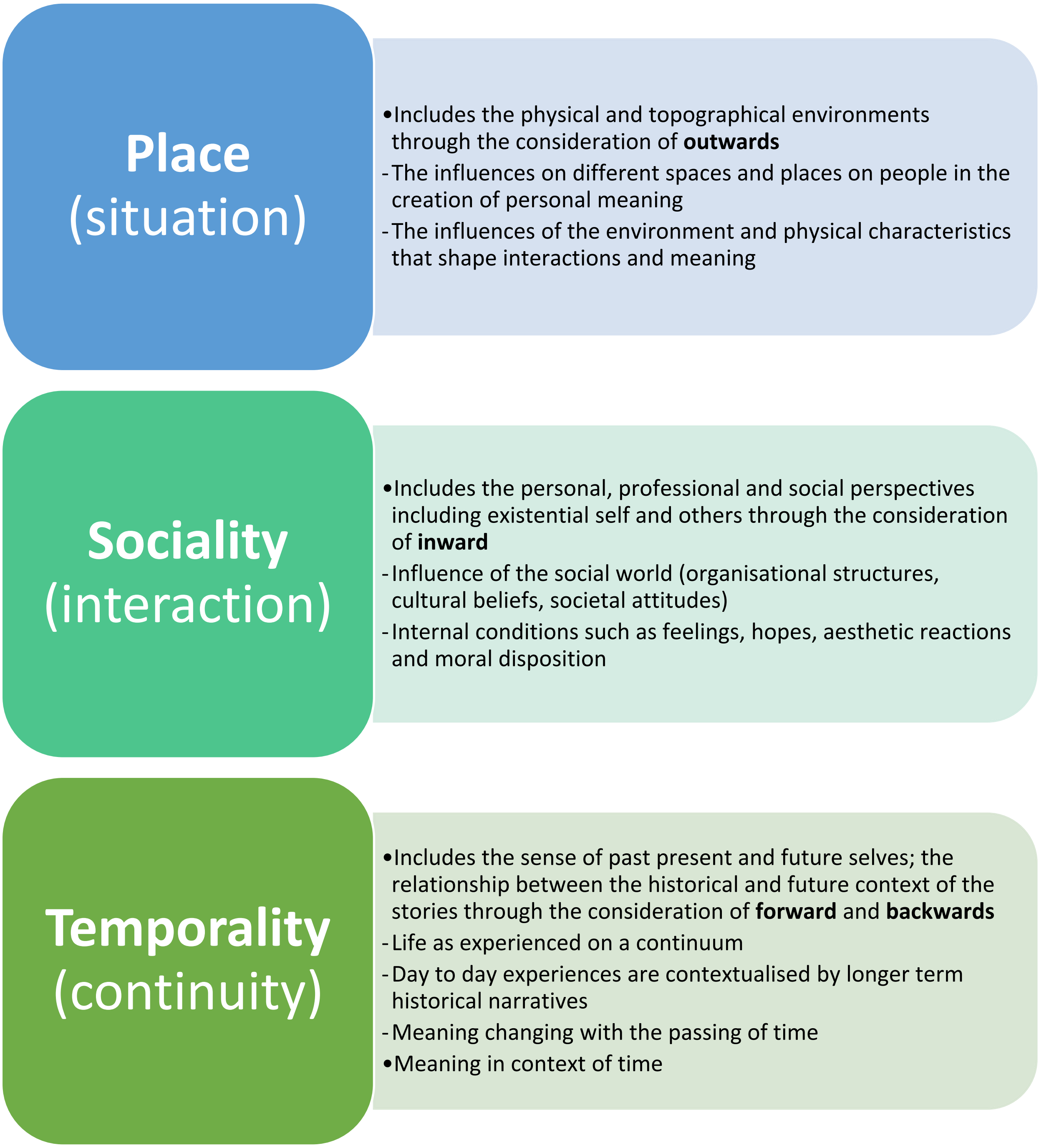
Table 3.4: Taxonomy of biomedical research vulnerability adapted from Kipnis (2001)

The evaluation had the potential to expose differing levels of professional and personal vulnerability for both the participants and me. The interview process focused on participant's recalling, recounting and analysing their professional input to the care of vulnerable deceased person culminating in a consideration the quality of care provided and therefore could lead the participant to re-examine their decisions and standard of care exposing areas of good practice and potentially areas for development. Just as this could provoke sensitive issues for the participate so it could for me as the evaluator. To counterbalance this, I utilised supervision, reflective logs and external support via my clinical practice to consider my professional learning and welfare needs. An overview of the key ethical issues and strategies to address these are contained in Appendix four and were the central concern of the university ethics review panel and trust R&D team. The main areas of consideration were related to institutional and social vulnerability and strategies to manage these were embedded throughout the evaluation process with the relationship between me as the evaluator and participant critical to this.

3.6 Data analysis

The evaluation has two phases of data collection to examine the narrative of professional decision-making in the care for frail older people. These phases included using documentary evidence alongside personal narratives from health professionals building together to form a multi-dimensional picture of decision-making. Through the interview the *temporality*, *sociality* and *place* of the narrative was located. The care maps and documentary review form a contextual story of decision-making. The documentary review and interviews form chapters of the *whole story of decision-making* using Connelly and Clandinin (2000) commonplaces as a framework.

The conceptual basis of the analytical framework developed was informed by Connelly and Clandinin (2000) multi-dimensional three commonplaces and was interpreted within the evaluation framework over-page (diagram 3.3) providing a lens to view the narrative accounts that considered the interplay of time, space and people so critical in healthcare. The analytical process therefore aimed to balance the need to both hold the narrative as whole, but also to dissect them as component parts to explore the chapters of experience in the story of care of frail older people at end-of-life.



Place
(situation)

- Includes the physical and topographical environments through the consideration of **outwards**
  - The influences on different spaces and places on people in the creation of personal meaning
  - The influences of the environment and physical characteristics that shape interactions and meaning

Sociality
(interaction)

- Includes the personal, professional and social perspectives including existential self and others through the consideration of **inward**
  - Influence of the social world (organisational structures, cultural beliefs, societal attitudes)
  - Internal conditions such as feelings, hopes, aesthetic reactions and moral disposition

Temporality
(continuity)

- Includes the sense of past present and future selves; the relationship between the historical and future context of the stories through the consideration of **forward** and **backwards**
  - Life as experienced on a continuum
  - Day to day experiences are contextualised by longer term historical narratives
  - Meaning changing with the passing of time
- Meaning in context of time

Diagram 3.2: Interpretative narrative framework informed by Connelly and Clandinin (2000)

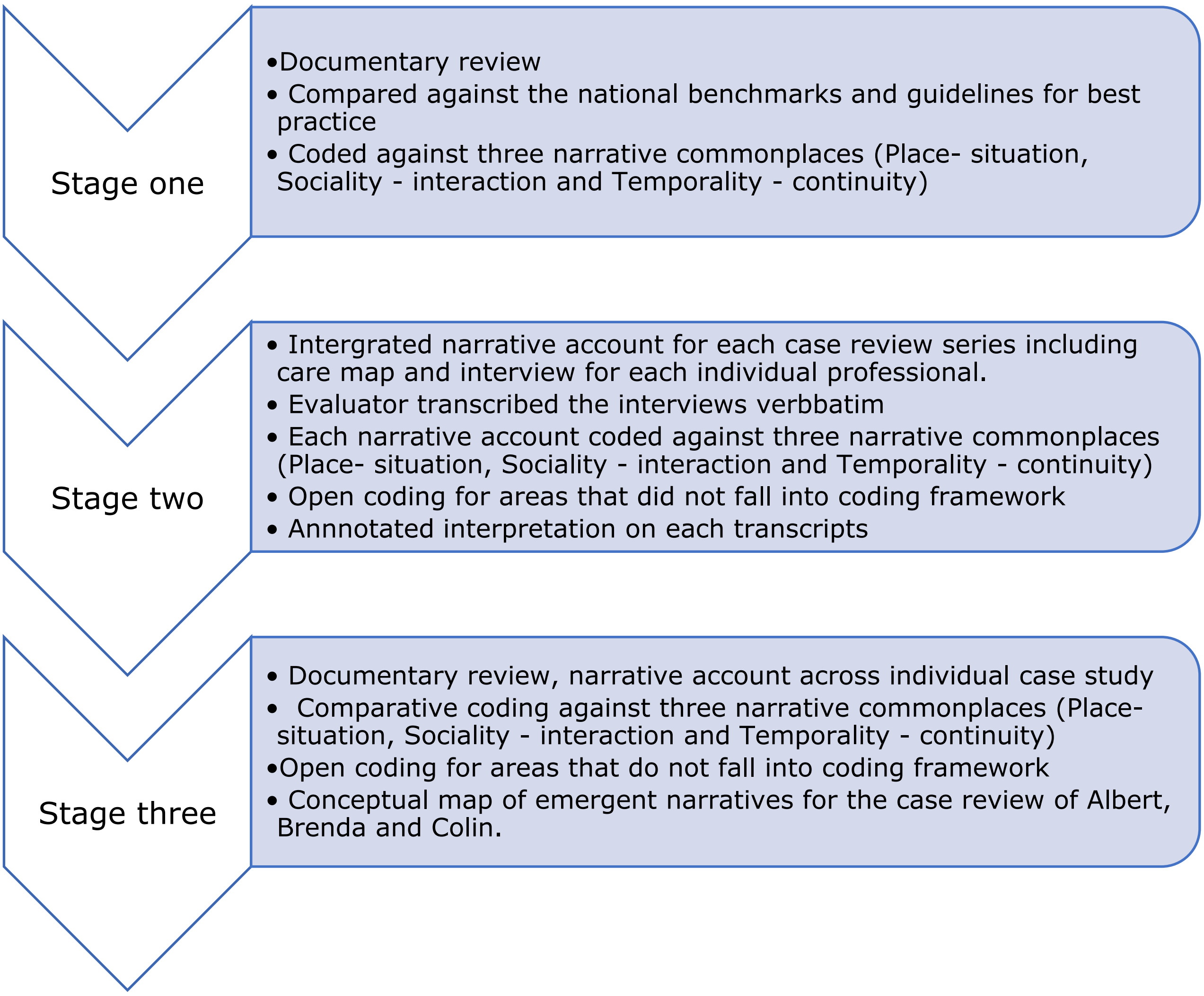
The data analysis process was undertaken in an iterative manner moving between the review of clinical documentation, interview transcripts and care maps for each case and across each case review to develop an integrated whole story of care for frail older people. The data is therefore presented in this manner and does not separate the documentary review from the narrated accounts.

3.6.1 Data analysis stages - Individual case study analysis process

A separate data set of case review was produced for *Albert*, *Brenda* and *Colin*. The following diagram describes the data set for each case review.

Diagram 3.3: Case review data sets

The six stages of the analysis process are outlined for each case review, below describes stage 1-3



Stage one

- Documentary review
- Compared against the national benchmarks and guidelines for best practice
- Coded against three narrative commonplaces (Place- situation, Sociality - interaction and Temporality - continuity)

Stage two

- Intergrated narrative account for each case review series including care map and interview for each individual professional.
- Evaluator transcribed the interviews verbbatim
- Each narrative account coded against three narrative commonplaces (Place- situation, Sociality - interaction and Temporality - continuity)
- Open coding for areas that did not fall into coding framework
- Annnotated interpretation on each transcripts

Stage three

- Documentary review, narrative account across individual case study
- Comparative coding against three narrative commonplaces (Place- situation, Sociality - interaction and Temporality - continuity)
- Open coding for areas that do not fall into coding framework
- Conceptual map of emergent narratives for the case review of Albert, Brenda and Colin.

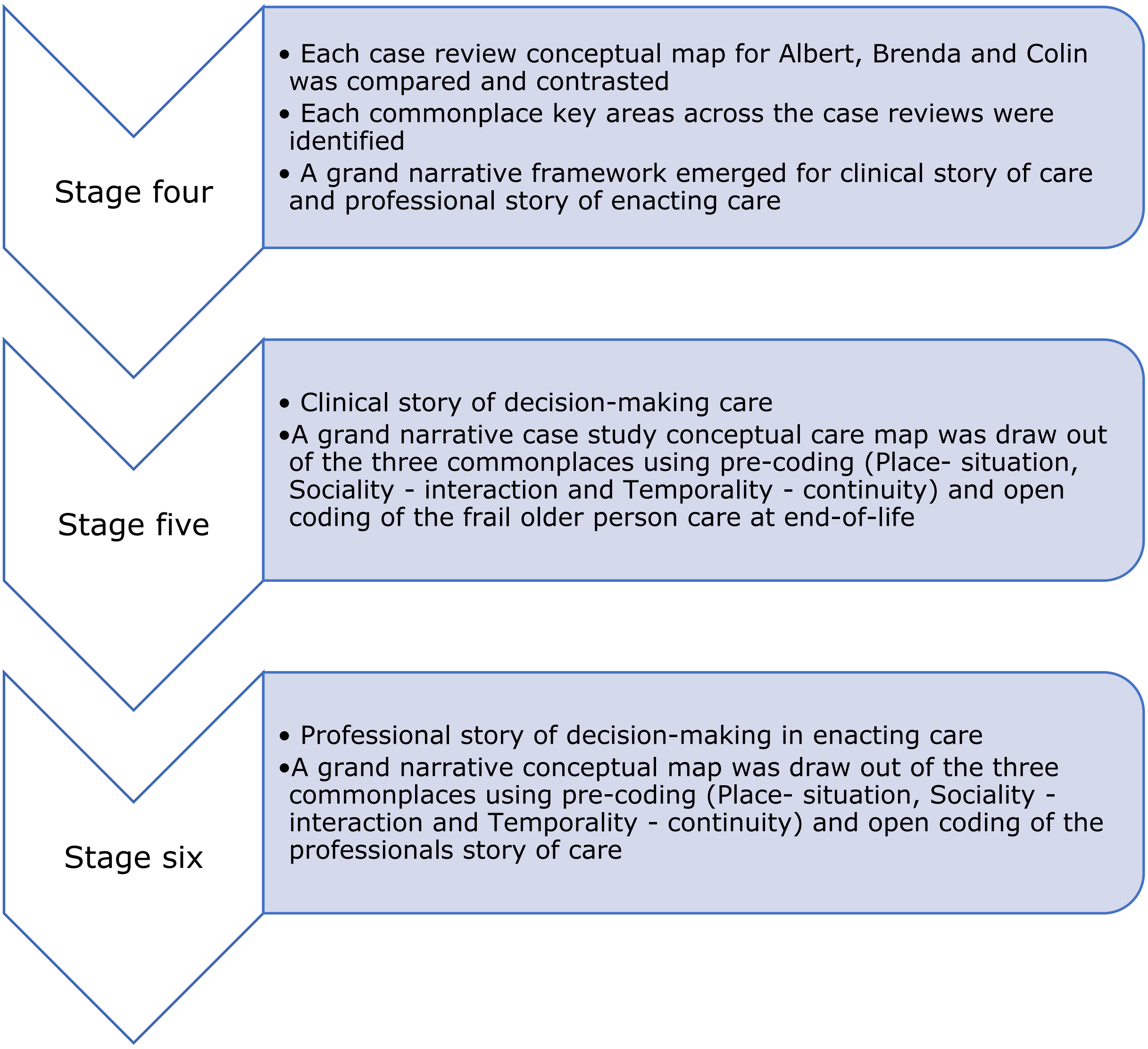
Diagram 3.4: Outline of the process of the individual case study analysis stages 1-3

The review of clinical documentation of care against best practice in of end-of-life care and frailty provide a contextual appreciation of the narrative of decision-making. This contributed to locating the *place* of care within broader socially defined narratives of everyday life. The cultural and institutionalised influences on what is considered *acceptable* care for older people at end-of-life is narrated through national policy and subsequently implemented within local practices of service contexts and termed as "quality markers" which are specified and recorded within patient care records. To view the narrative of care through this mode of text allows a complete consideration of the commonplaces of narrative inquiry, exploring the context of the *whole story of decision-making of care*. The analysis of the review of documentation is therefore embedded within the narrative accounts and not separate as it has been woven into the three case studies.

The iterative analysis of the individual narrative accounts and across each case review was undertaken to gain a holistic view of the story of the decision-making of care for the frail older person. It is recommended by King *et al* (2013) that the two forms of data be analysed in an integrative manner allowing for a greater richness of interpretation. The interview transcripts and care maps were therefore integrated as one form of data and are not presented separately. The interpretative framework informed by Connelly and Clandinin (2000) provided a lens to analyse the case study narratives integrating the directional dimensions of the clinical, professional and personal stories of care.

3.6.2 Integration of case narratives

The final part of the analytical process stages 3-6 brought together all the case review narratives to present grand narratives integrating the three commonplaces to represent a whole story of care and decision-making.


Stage four

- Each case review conceptual map for Albert, Brenda and Colin was compared and contrasted
- Each commonplace key areas across the case reviews were identified
- A grand narrative framework emerged for clinical story of care and professional story of enacting care

Stage five

- Clinical story of decision-making care
- A grand narrative case study conceptual care map was draw out of the three commonplaces using pre-coding (Place- situation, Sociality - interaction and Temporality - continuity) and open coding of the frail older person care at end-of-life

Stage six

- Professional story of decision-making in enacting care
- A grand narrative conceptual map was draw out of the three commonplaces using pre-coding (Place- situation, Sociality - interaction and Temporality - continuity) and open coding of the professionals story of care

Diagram 3.5: Outline of the process of the integrated case study analysis stages 3-6 leading to grand narratives

Presented above in diagram 3.5 this stage of analysis is outlined. Grand narratives (also known as meta-narratives) according to Bold (2012) are produced when all stories are brought together using multiple data collection methods, each adding to the interpretation of events to explore the complexity of relationships within and external to the social situation. The grand narratives offer insight into the wider political, social, professional and cultural dimensions of caring for our most aged who are approaching death. Grand narratives are often practice focused drawing on multiple modes of data, ensuring rigorous analysis to inform plausible practice development (Bold 2012). The aim of which is to foster reflection of personal practice, encourage comparison, leading to re-storying individuals own practice thereby transforming service wider practice and potentially the care of frail older people at a local and national level.

3.7 Grand narratives

The grand narratives are drawn from the following three case reviews of care for *Albert*, *Brenda* and *Colin* are presented in the following chapter

Grand narrative one

The clinical story of care providing a contextual account of frailty and end-of-life from professional perspective. The grand narrative combines the three commonplaces of place, sociality and temporality within the following themes

- Retold experience of frailty at end-of-life within the context of an ICT
- Importance of place and space in the experience of care at end-of-life for frail older people
- The passage of care for the frail older person as they approach death

Grand narrative two

The professionals' stories in supporting a frail older person reaching end-of-life. The professionals' stories were analysed within and across the professional groups of nursing and therapists. The grand narrative combines the three commonplaces of place, sociality and temporality within the following themes

- Tensions arising from changing the culture of care
- Medicalisation of professional identity
- Collision of personal and professional lives within practice

This chapter has provided a detailed account of the evaluation process and underpinning theoretical perspectives including consideration of ethical parameters. The following chapters therefore sets out the findings of the evaluation, presenting an in-depth analysis and contextual interpretation of frailty at end-of-life and professional decision-making.

Chapter 4

Grand narrative one- the clinical story of care of a frail older person reaching end-of-life

Grand narrative one findings are presented within this chapter; focusing on the clinical story of care of three deceased frail older people. The three case studies are entwinned to provide the story of care, throughout the findings all participants have been pseudonymised with accounts drawn from the documentary review, interviews and care maps produced.

The grand narrative combines the three commonplaces of place, sociality and temporality within each of the following themes

- Retold experience of frailty at end-of-life within the context of an ICT
- Importance of place and space in the experience of care at end-of-life for frail older people
- The passage of care for the frail older person as they approach death

The analytical overview of each of the case reviews are presented below and are formed from the documentary review, professional's interview and care map.

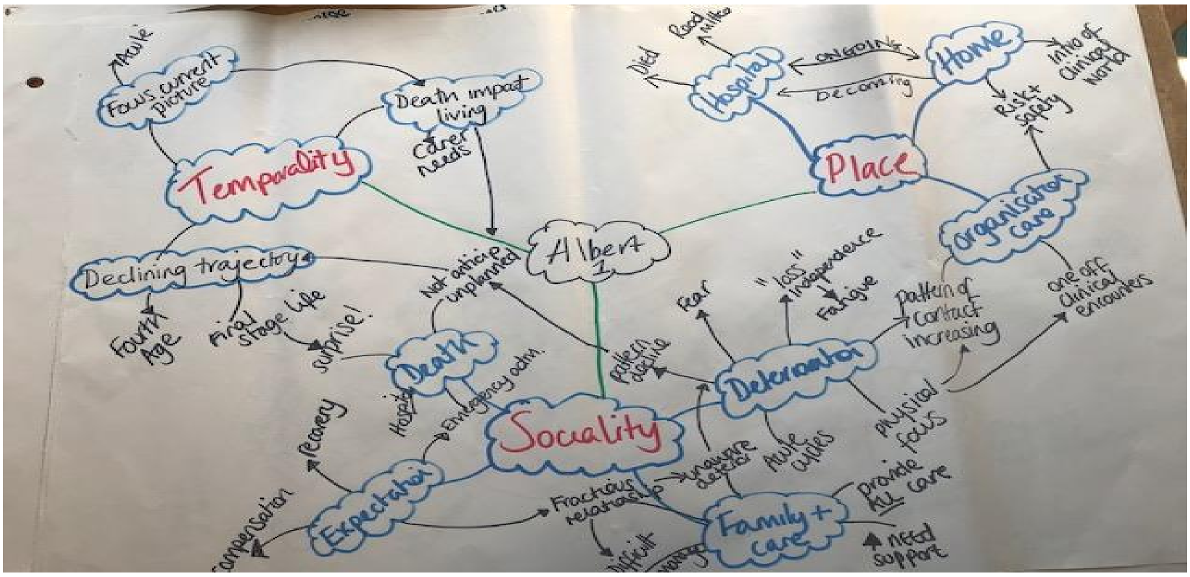


Image 4.1: Case-review one: Albert

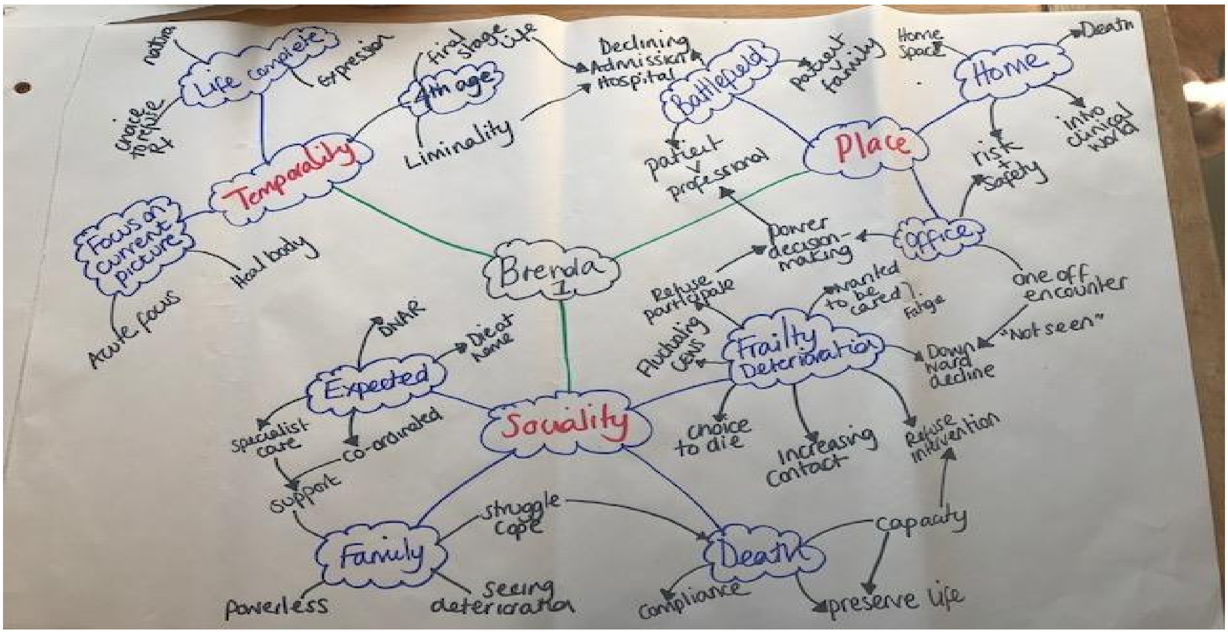


Image 4:2 Case review two – Brenda

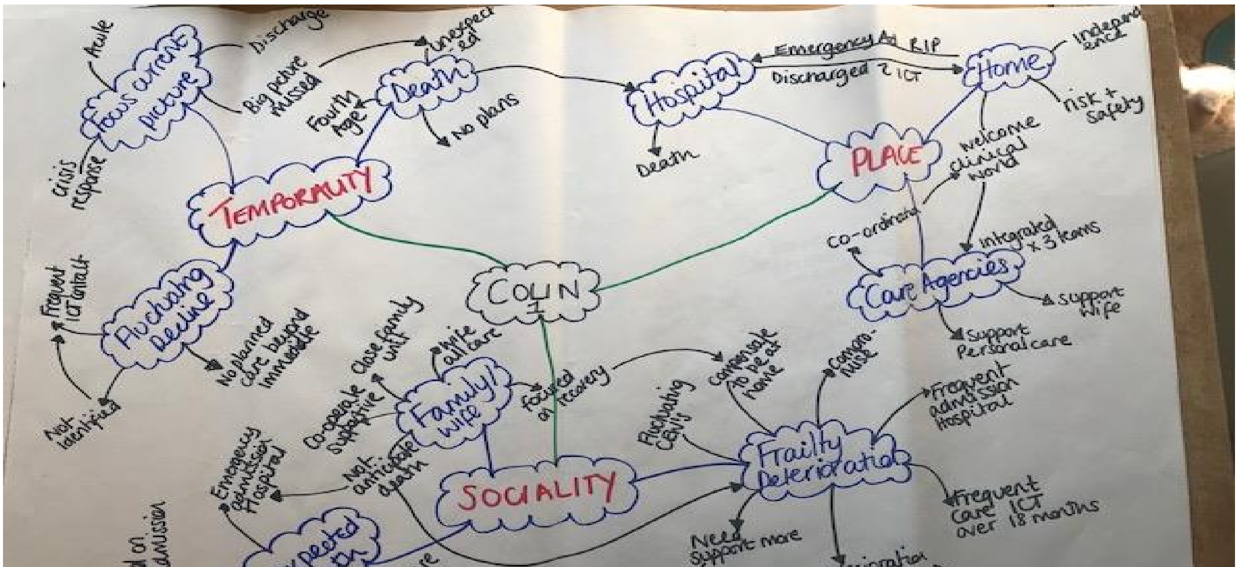


Image 4.3 Case review three – Colin

These mind maps of analysis were integrated to form the final grand narratives of the clinical story of care for Albert, Brenda and Colin.

4.1 Retold experience of frailty at end-of-life within the context of an ICT

Providing a clinical picture of frailty, the culture of care in managing frailty and end-of-life within the context of an ICT service is set into two sections:

- Clinical picture of frailty as assessed by professionals
- Family and carer involvement in decision-making

4.1.1 Clinical picture of frailty as assessed by professionals

Across all three case studies the clinical picture of frailty shows declining trajectories of health. Albert, Brenda and Colin had multiple episodes of care within the last twelve months of their life. The analysis exposed experiences of frailty to be related to frequent episodes of acute ill health, a loss of strength and reserve which, in turn impacts upon functional abilities leading to a loss of independence. The findings of the grand narrative are presented firstly to provide an overview of frailty as experienced by Albert, Brenda and Colin and then illustrates how these influenced decision-making.

Albert had been consistently known to the service over the last 12 months and his health deteriorated on each episode of care and participants one and two reasoned that

"*I tried to explain to Mrs.A that because of these recurrent infections his baseline was shifting each time and each time* [looking back at notes] *that we were involved what four times, I think, he was getting worse and worse and worse and his baseline was shifting further back*" P2

And this deterioration had prompted professionals to organise high levels of support at home including the provision of specialist equipment and home care

"reduced mobility, he required personal care, he required assistance with all his ADL" P1

Brenda had sporadic contact with ICT over the last 12 months of life with intense contact in the 4 weeks prior to her death. The account of Brenda changes significantly from an independent 90-year-old to a frail dying lady. Participant eleven completed the initial assessment and recounted a first impression of Brenda

"she was sat by the window in a single armchair, she looked quite, quite neat, she looked quite neat, she wasn't like immaculate but she was she didn't look unkempt, she talked a lot about her son and the family seemed quite involved" P11

However, the recent episode of ill health had impacted on Brenda
"*she had had a fall and had been treated for a UTI and it had decreased her confidence levels*" P11

but interestingly participant eleven did not recognise these traits to be associated with frailty, thus this did not appear to resonate as influencing decision-making in assessing Brenda’s care needs going on to state

“I don’t remember her looking particularly frail or thin”. P11

During the following four weeks Brenda health deteriorated, and she required increasing level of support from her family and ICT. Participant six recalls on first meeting Brenda describing her as frail

“she was in her 90’s and she was she was very frail, she wasn’t eating she wasn’t drinking, she wasn’t acutely unwell” P6

and the final ICT team member to see Brenda reported

“she is down for not resuscitation [she] *was very, very, settled by the time I went in* [in bed]*”* P3

The narrative accounts of Brenda demonstrate a rapid deterioration in health over a four-week period, from a mild urinary infection to end-of-life.

Colin was referred for rehabilitation, with the aim of enabling him to remain at home following a prolonged admission to hospital. All the participants identified that Colin presented as *“deconditioned”* following a pattern of acute illnesses associated with his underlying co-morbidities. Colin’s clinical picture was unstable throughout his care, with his health fluctuating on each visit. Participant nine was the first to assess Colin on discharge from hospital and recounted

“my diagnosis was basically that he had got reduced lower limb strength and exercise tolerance due to a prolonged stay in hospital and required some exercises” P9

which is different to participant eight who reviewed Colin on two occasions.

“Colin presented as, well was really quite poorly. He had difficulty with eating and swallowing he had some exercises but not sure where they came from, but he hadn’t been doing them, but he did try but I think he was struggling with them” P8

The fluctuating and declining health of all the frail older people was identified by all the participants in all the cases studies. However, in the documentary review this was rarely reported formally. Across all case studies there was no documented discussion relating to advance care planning for any of the older people, despite continued deterioration in health within the last 12 months of life. Although underlying diagnosis and co-morbidities were recorded there were no specific management plans to consider these in relation to risk of frailty or end-of-life within the clinical records.

The changing picture of health was reported across all the case studies as impacting on the frail older persons capacity to care for themselves and was reported as a loss of functional ability. The identification and assessment of functional ability is a central to the remit of ICT and therefore an area of concern for referral into the service for Albert, Brenda and Colin as participant one and four suggest,

"*In terms of his referral to the team, this is a gentlemen who had reduced mobility, he had, he required personal care, he required assistance with all his ADL as in activities of daily living he was supported by his wife*" P1

"she was referred by the GP, so she came on because she was unwell, she had had two falls, got a UTI and wasn't coping yeah [with everyday life needs at home]*"* P4

The care maps and interview process revealed a picture of declining levels of functional ability as central to professional's identifying frailty. The deterioration in the older persons capacity to undertake functional activities such as mobilising, personal care and domestic tasks are characterised by a loss in physical capacity, strength, depleted personal reserve and motivation for activity. The professionals balanced these against the service remit of increasing independence and addressing acute illness. With Albert the introduction of equipment aimed to maintain independence however, offers a paradox in recognising his abilities were deteriorating and he was no longer independent

"*we thought would be useful for Albert to be able to reposition, on the bed, it's about pressure care* [as he was spending all day in bed due to fatigue and ill health] *and it's about maintaining muscle strength, joint integrity so that he can you know, keep a greater degree of independence."* P1

Similarly, for Brenda and Colin changes in physical function were noted and compensatory strategies introduced. For example, Colin was observed to have reduced tolerance to activity and counter measures to maintain his mobility despite deterioration were implemented. The overriding goal of independence in functional abilities to mediate frailty influencing both professional and personal decision-making.

The changes in functional capacity for the older people were considered to influence their sense of independence, which impacted on their confidence and perceived ability to cope at home thus guiding personal decisions on care preferences. The most startling of these was in the case of Brenda. Brenda had originally been referred for support in managing a UTI due to non-compliance with medication. Brenda had various elements of support introduced including equipment, rehabilitation assistants to provided personal care and meal support, alongside family who were providing daily support. Brenda was initially identified as

“bit low and in need of some support” P11

but her attitude towards ICT was identified to hamper this

” she just wanted to be left alone, I didn’t get, the sense that she wanted us there” P11

and that she therefore declined ICT support, even though it was identified as needed and mapped into her care plan. Brenda in contrast to Albert and Colin did not wish to engage with the ICT team and participant five reflected on the challenge this brought within the service context

“she just didn’t really want anyone involved because yeah if you are independent and then you have people coming in and helping you and yeah the dignity of that is not what or rather its indignity, you know if you are proud and you don’t want other people to help you wash and if you are tired and you actually you just want to stay in bed and do that.” P5

Brenda’s physical health was considered *“stable”* as she had no acute signs of infection however as participant six and three reflected when they became involved in her care less than two weeks later it appeared as if she has chosen to die, and refused both medical and rehabilitation interventions

“the lady was in bed and she was in her 90’s and she was she was very frail, she wasn’t eating she wasn’t drinking she wasn’t acutely unwell so I sort of did my assessment and said she wasn’t acutely unwell nothing actually identified other than she wasn’t actually eating or drinking on talking to her she basically said I want to die” P6

The narratives account of the experiences of frailty as influencing decision-making expose the complexity of understanding the impact of frailty on everyday life and the idiosyncratic ways in which this is interpreted by the older person within their care preferences.

Albert and Colin were referred to ICT on discharge from hospital, both experienced a significant downward shift in their levels of independence on returning home and therefore needed support to manage this transitional process, in readjusting to being at home. They were reported to lack confidence in their mobility and were *“struggling”* at home. Formal and informal care was provided, and they were reported to rely on others to make decisions about their care. In the case of Albert, the fluctuating nature of managing frailty meant a greater reliance on gaining the perspective of carers and shared decision-making between the patient, carer and professionals.

"I only met Albert on one occasion and at that time his physical health was the overriding impression was that he was quiet, he didn't communicate a great deal, very little verbal communication and actually appeared quite lethargic so any of the conversations that we had to have we tended to have with his wife who gave us and reported feedback on what we needed to know" P1

adding

"he wanted to get back up and walking again, we didn't have that [loss and decline in health] *conversation about what was going on cos it was quite hard and stressful situation."* P2

Adjustments to physical independence and decision making were attributed by the professionals to changes in mood and outlook on life. For Colin and Albert this was evident in the narratives, with an underlying expression of fear, low mood and quiet acceptance of loss. However, none of this was directly discussed with Albert or Colin. The interaction with ICT predominately focused on independence, no matter how small the perceived gain to be, as participant eight reflected on the aims of intervention.

"trying to get him back to his level of fitness that he was before, not even to get to that level but to stay at the level they are at" but that *"quite often they go downhill, when you get disillusioned, your body just goes fweept* [imitated downward trajectory] *and it is scary."* P9

In contrast with Brenda all the interviews brought out her sense of defiance and determination in setting her own care preferences. To be cared for as she reached her end-of-life rather than maintaining a personal sense of independence. It was only following a concerned call by her family that Brenda was revisited after her initial refusal to accept care, as participant four recalled in meeting Brenda

"she wasn't taking her medicines, she looked dehydrated, her skin was all dry and her tongue was black, at great risk of falls and of death if she refused to go into hospital" P4

with a follow-up visit the same day by participant six recounting their experience meeting Brenda

"basically she said I have taken to my bed you know, this is what I am going to do, she didn't want to live and so she didn't want resuscitating. I am happy, quite happy with that thank you I am, I will just lay here and die. I've had a good life I am in my nineties what have I got to look forward to I am tired and I just have had enough" P6

Brenda's family were integral to her care and all the participants reported discussion with family members in coming to a shared understanding of care for Brenda. One consistent challenge was to balance the competing interpretation of Brenda's outlook and mental capacity to make decisions to decline interventions against medical advice, participant six describes

"I had to actually explain to them that it actually wasn't their decision it was their mums she was my client and it was her decision and you know we had to respect her wishes basically which understandably it is their mum who looks like she is starving herself to death so it was quite stressed really." P6

The clinical picture of frailty at end-of-life is one that is characterised by an entwined relationship of fluctuating health, loss of physical capacity and reserves that impact on the older person's sense of independence, with a greater reliance on formal and informal care as they approach end-of-life. The importance of understanding the whole person is evident within the narrative accounts of decision-making and this includes interpreting the experience of frailty within the context of their whole life and preferences as they approach end-of-life.

4.1.2 Family and carer involvement in the care of frail older people at end-of-life

The involvement of family and carers supporting frail older people at end-of-life was evident across the case studies. Their involvement was regarded as taking a holistic view of the person, in understanding the support provided by the family unit and thus their expectations of caring for the frail older person. Within the process of decision-making professionals recognised and valued the carer's perspectives but were equally challenged in managing expectations within shared decision-making.

The professionals all made home visits, often with family members present and were included in the discussion. On occasions permission was sought from the older person to contact family members separately, in doing professionals reflected this enabled a whole person approach to care. Therefore, providing insight into the everyday life of the older person and their needs from differing perspectives. In the cases of Albert and Colin both were married and therefore the main source of support was their wives; as participant one and two state about Albert and his wife but were echoed in the account Colin,

"I went out to see Albert and his wife, they came as a package" P1

and reiterated that because of the entwined relationship decision-making was often shared

"When the wife agreed, Albert agreed" P2

Their wives were identified as their main carers and provided support for them at home including personal and domestic tasks. During their final episode of care both couples had formal support introduced into their home as concerns were raised over how their wives were coping with the impact of caring for them.

In the case of Albert, the concerns were voiced clearly *“the wife and she was not coping well with it at all she was really unwell actually I think she had a chest infection, she was just very overwhelmed”* P2

Whereas with Colin there were subtle concerns raised

“my impression is that the wife was doing a lot doing more than I realised and I think that was through conversation with her, I think she supported with all food, and I think she sort of although formal carers were going in twice a day I think it is just my impression of her over time was that she was doing more and more and I think that is something we don’t always pick up on and I think that she probably had a lot on her plate actually looking at it and she had drawn back from that and I think that that is a big issue.” P9

The relationship between family and Brenda offers a different picture, Brenda was a widower and her support network was formed of her children and grandchildren therefore, the dynamics within the relationships was bound within parent-child dyad.

Brenda had been refusing formal care and expected her children to provide her care as participant eleven reflected

“they were going in for and they are going in at least once a day to see her, but she wanted them to go in she didn’t want any additional help” P11

In contrast to Albert and Colin where there was acceptance of shared decision-making with their wives, Brenda’s decision was called into question by her family. They struggled to accept her declining treatment and intervention as participant three recalled a discussion with the family.

“they got to the point where they had accepted that she was making her own decisions and he told me that she was very stubborn and that she had you know this was her way and that you couldn’t change her mind” P3

The intensity of family involvement was also different between the case studies, Albert and Colin lived with their wives and had support from formal care agencies however Brenda lived alone within no formal care arrangements. The intensity of support provided by the family was viewed by participants as an indicator of declining health and therefore influenced professional decision-making. As indicated by participant eleven in discussing a conversation with Brenda’s family to support determining care needs

“I made a phone call to the son to establish their feelings, they expressed concerns over the level of input that Brenda was needing [from them]” P11

And participant eight describing the deteriorating health of Colin

“my first visit he was upstairs, well when I saw him he was downstairs, but he was sleeping upstairs and then the carers and family were having increased difficulty in getting him downstairs, cos they were really struggling and really concerned, he was up lots in the night for the commode and bottle with wife’s help.” P8

For Albert and Colin there were no formal discussion of their ongoing management of care or support at home even though it was identified within their narrative accounts as influencing decision-making around the priorities of care. Albert and Colin's wives were both identified as struggling to manage at home, support was provided via rehab assistants to encourage independence in personal care as a strategy to reduce carer burden. Despite this perceived support in addressing care priorities, Albert and Colin were readmitted to hospital through out of hours emergency care and died in hospital less than a day later. Brenda's defiance against being admitted to hospital and refusal for intervention resulted in a documented DNAR and she persistently requested to be able to die at home. Brenda died at home with her family less than two weeks later from her second point of contact with ICT in her final episode of care.

4.2 Importance of place and space at end-of-life for frail older people

Exploration of the culture of care within the service considering the impact of introducing the clinical world into the older persons home concluding with the significance of the place of death for the frail older person.

The findings are presented in three sections

- Culture of care within ICT in managing frailty
- Introduction of the clinical world into the home of the frail person
- Significance of the place of death

4.2.1 The culture of care within ICT in managing frailty

The remit of ICT has changed over the past several years from a six-week rehab led service to an acute, crisis intervention approach, consequently the culture of care and caseloads continues to evolve. The culture of care was implicitly discussed by all participants highlighting differing value bases across staff groups. The remit of ICT is summarised by participant eleven

"service for admission avoidance and facilitating early discharge from hospital, it is about avoiding hospital in like our focus on acute infection which is something that potentially is reversible however if it is not reversible we will signpost you to the right services and we will take care of you until that is available and it's about helping you to regain your independence" P11

The focus on an "acute" nature of ICT was echoed by the participants, with this lens of practice influencing the culture of care provided thus infiltrating decision-making. In the stories of care for Albert, Brenda and Colin all were described in terms of their illness characteristics. The description depicted them as acutely unwell with functional limitations, interventions therefore address the impact of illness thereby restoring functional capacity to increase longevity of life. As illustrated by participants two and four,

"*he had been in bed for such a long time that he wasn't mobile so we were thinking get hospital bed in get pressure care in to get him sat upright, to get some fluids in him to push it through a little bit to get rid of this water infection to get him up a bit and moving on his feet.*" P2

"*I think it is something that is very easy to put right here I think that if had got her on the fluids if we had got her on intravenous antibiotics we maybe tweaked her meds a bit you know they might another two or three years*" P4

The focus on the physical characteristics equally influenced the culture of care; all the participant spoke freely of the older persons physical health needs however, during the interview prompts and question were used to draw out emotional and psychological perspectives. As participant one responds when asked about Alberts psychological and emotional needs

"*that may have taken place with Albert and his wife and in conjunction with his family and we'd be making provision where we can and within the realms of our service… I only met Albert on one occasion and at that time his physical health was the overriding impression*" P1

In the case of Brenda, participant eleven and five within their assessment noted low mood and lack of confidence. However, this was not followed through within the treatment plan or subsequent contact as participant eleven reflected on their decision-making

"*it looks like it was to make sure that she wasn't unwell from the urine infection, that was my focus, and it looks like I went in with that in my mind, and rather than looking at everything else that was going on*" P11

recalling

"*of initial thoughts was that she had this UTI that she needed to be treated and things like that and then that sort of never happened, I think yeah the next visit didn't quite, the next visit didn't really cover any of that kind of her lack of confidence or anything*" P11

The importance of active participation in care was implied in the case studies by the participants, described in differing ways such as "*rehab potential*" within case study one and three or "*willing to engage*" in case study two. Active participation was interlinked with promoting independence to enable the person to remain at home; a key driver for all the participants in reversing the impact of acute illness. Participant seven recounted the focus of the intervention with Colin as

"*maintain him at home, really making sure he was well enough to be at home and that he had the right support systems in place for him to remain at home really*" P7

And participants eleven, five and four found it a challenge to work with Brenda describing her character as influencing the possibilities of care as she was unwilling to engage.

"*she was quite difficult, I think it was quite difficult to get her to walk for me I think it was quite difficult to get her to stand*" P11

"*she wasn't a very nice lady, very stubborn adamant,*" P4

In contrast participant six spoke of Brenda's resilience and strength as a positive attribute, especially in her choices at end-of-life.

"*she was a very, very strong lady* [determined to remain at home] *that strong in the face of your family sort of really pushing you and pushing you* [to eat and drink], *she wanted to do it her way and you have got to respect that really*" P6

The introduction of the clinical world into Brenda's home was filled with tension between ICT, family and Brenda over her decision-making and choices. Brenda chose to decline intervention and both ICT staff and family struggled with this enacted choice, as participants four, five and six voiced. For participant four and five the tension was between the identified needs and refusal to engage in treatment

"*Why would you want to die, when there is no need for that? Don't get it I don't get it and I had explained all that to her and I always explain to people like her*" P4

"*if she wasn't well those* [rehab and independence] *things might just have not been her priority.*" P5

Whereas for Participant six initially there was a need to reconcile the remit of ICT with Brenda's choices

"*I reconciled it with sort of talking to her and sort of realising what I was doing was actually projecting what I thought should happen on to her and had to take a step back and sort of really sort of listen to her*" P6

The overarching remit of ICT is one that is located within an acute framework with intensive support to reverse and mitigate the impact of illness, predominately focusing on physical illness. The aim being to promote independence, maintaining people at home however this relies on active participation by the patient and family. Tensions arise when there are differing perspectives over the care needs and plans within the introduction of the clinical world into the person home as they approach end-of-life.

4.2.2 Introduction of the clinical world into the home of the frail older person

ICT is community based and therefore care is provided in the person's own home, all the participants reflected on the importance of recognising the home of the frail older person and the impact the delivery of care has on the home environment. The introduction of the clinical world to the older person home has two facets; firstly, the provision of aids, adaptations and equipment to facilitate independence and provision of care. Secondly professionals and care staff enter the home to organise and plan care through shared decision-making.

The participants voiced that issues of loss and assertion of control were perhaps connected to the tensions evident for the older person and family in navigating life with increasing levels of frailty. Participant one and two spoke about the introduction of a hospital bed and carers to support Albert at home,

"she was sort of trying to ignore the fact of how unwell Albert was and the fact that he needed a hospital bed" P2

P1:p5 *"turning their home into a hospital style environment where it is actually their reality of the condition is being faced and it is a slight loss of it can be perceived as a loss of control…..where it is actually the reality of their condition is being faced"*

and in the case of Albert and Colin the introduction of the hospital bed meant a move from sleeping with their wife to sleeping alone in a separate room as they approached end-of-life.

"having the wife with him for reassurance as they have done all their married life being next to each other you know changing it now putting Albert in a totally completely different room" P2

In the case of Albert and Brenda prescription of large pieces of medical equipment such as a hospital bed was overwhelming. As participant one and two in the case of Albert reflected

"impact of introducing what is perceived as hospital equipment, it is changing their environment from a home into a hospital style environment." P1

"Mrs A was very reluctant to accept any sort of equipment provision" P2

Brenda was prescribed a hospital bed. The plan agreed by ICT and the family was to move her into the bed to facilitate care however, Brenda adamantly refused as participant three who ordered the bed recallsivi

"*she refused to like point blank to get in the bed* [referring to hospital bed that was ordered]*,"* P3

Participant three reflected that the decision to provide a hospital bed was made for health and safety reasons, to meet carers needs but that they recognised Brenda was unlikely to have wanted to move into the bed. Later reflecting on a conversation with a colleague at her joy when Brenda

"died in her own bed as she chose." P3

There appears to be a conflict within the home environment whereby equipment is introduced against the preferred wishes of the older person and brings about a medicalised home as a consequence of balancing the risk and safety of carers with the older person’s care and comfort. The place of decision-making within the narrative accounts is evidently influenced by the physical and sociological meaning of home and work. The professionals accounts recognise a tension introducing the clinical world into the patient’s home and therefore shared decision-making becomes a process of negotiation and compromise in managing both the expectations of the patient, carer and themselves in supporting the frail older person. Conflict arises when the professional’s capacity to intervene based on their professional decision-making is refuted by the patient.

4.2.3 Significance of the place of death

The place of death was raised as significant in the documentary review and narrative accounts of the participants across the case studies. In the narratives of Brenda and Colin home features centrally in the provision of care, with a preference to remain at home a key focus of intervention. With Albert there was a recognition that perhaps he was too unwell to be at home and care should have been provided within an acute setting.

None of the case histories documented a preferred place of care as part of the initial assessment. Given the deteriorating trajectories and their respective ages (83, 91 and 95) there were no recorded conversations about advance care planning, preferred place of death or anticipatory needs at end-of-life. The deaths of Albert and Colin occurred in a hospital emergency care environment during out of hours admissions, and for Brenda her act of defiance meant she died at home, in her own bed with her family present. It was only when her death was imminent that her preferred place of death was recorded and subsequently achieved.

The participants expectation of death influenced the place of death, Albert and Colin were unexpected and as participant two recalls

“*we knew that we were going to have these infections and stuff, but we didn’t think that he was going back into hospital to die*” P2

The culture of care influenced professionals’ expectations of death even in frail older people with continuing deteriorating trajectory of health

“I don’t think we could have done anymore as a service or as individual professionals to have foreseen the trajectory of the disease or anything that would have prevented that from happening, we didn’t expect this to be an end-of-life scenario.” P1

For Colin, his admission to hospital and death was also unexpected however participant nine discusses that although Colin was not termed as end-of-life he was old and his death could be predicted and participant seven reflected back on the fluctuating picture of Colin's health

"he just presented like somebody who was declining…just had this feeling and then the family when they are talking as if they don't really understand what this is all about what's going on here….so but for me in my head I am thinking in my head I am thinking this isn't good" P9

In the accounts of Colin, it was reiterated by many of the participants that Colin wanted to remain at home and did not wish to return to hospital however, that is where he died after an emergency admission.

"he was pleased, pleased to be at home with his wife, pleased to be back umm rather than being hospital, so he was pleased to be back and was keen to avoid going back into hospital" P7

In contrast Brenda chose to withdraw from life, she refused medical intervention, would not eat or drink and as participant six describes *"she took to her bed"*. Within the scope of ICT the route to Brenda being identified as end-of-life was one of conflict, where establishing mental capacity was reiterated in all the narrative accounts of Brenda's refusal of care as participant three summarised,

"I think the reasons for being end-of-life weren't really clarified…She was assessed to have mental capacity and said that she was very stubborn umm and was aware that she would die if she didn't go into hospital and was at risk of falls and fractures and adamantly refused to be admitted to hospital and obviously it is important to respect peoples wishes and she was able to make that choice for herself." P3

The focus of care shifted following the assessment of participant six, moving away from an acute reversible perspective of care to one that recognised Brenda's actions within the context of her life. The subsequent discussion with Brenda, her GP and family in establishing a DNAR directive and therefore instigated end-of-life care at home.

"she wanted to die and she had capacity which was the key thing so she was quite happy with a DNAR which obviously had to be sent to the GP to be done…I think I might have said something about you know, you know she's their mum but basically they have got to respect her wishes you know and she said she had had a good life and the one thing they could do for her now was give her a good death to achieve the death that she wanted and it was to keep her at home" P6

The narrative accounts indicate that death and the place of death are not routinely considered by the professionals within the process of decision-making. Consideration of the broader picture of frailty and ageing were not evident as influencing factors within the decision-making of the professionals until the proximity to death was imminent. The accounts reveal the importance of home for the frail older people however two died in hospital in emergency situations without advance plans in place.

4.3 The passage of care for the frail older person as they approach death

Considers the focus of ICT interactions with frail older people and how end-of-life is viewed as influencing professional decision-making and is presented in two sections

- Focusing on the current view: risk of decontextualising the frail person in life
- Revisiting end-of-life as a cycle of frailty within ICT

4.3.1 Focusing on the current view: risk of decontextualising the frail person in life

The organisation of care within ICT is one-off clinical encounters, the service is provided county wide and staff are deployed daily via a handover system depending on the needs of the service and current caseload priorities. Most of the participants had visited the older people on one occasion (the exception were participants two and eight who visited twice) during their final episode of care. The clinical encounters are scheduled throughout the day with approximately 45 minutes per visit. The participants reflected on the challenges of this working pattern, often feeling they only saw a snapshot of the person's life focusing only on the current picture.

"I went in with that in my mind, and rather than looking at everything else that was going in, yeah I think it's very difficult but I think I was probably (pause) you know you have a snapshot in time to establish all this evidence" P11

Participants recounted that this meant they did not always have a clear picture of the person and ongoing plans for care, this influenced building therapeutic relationships to enable shared decision-making.

"each person is going out differently, cos each person assess differently and each person will you know have their own sort of [intervention] *that they want to do and sometimes you know you can build up a rapport with a patient but then you can't follow that over"* P9

From the documentary review it was evident that in all the case studies there had been interaction with ICT across the last 12 months of life for the frail older person. Only in the case of Albert was there a recognition of the pattern of deterioration. The care of Albert was primarily provided by the therapy team, who had been involved over the past admissions to the service and as participant one and two recalled office-based discussion.

"a bit of an MDT with the therapists and we were discussing our concerns about Albert, the therapists that I spoke to hadn't seen Albert on this time around, but they knew him from previously he was on the books" P2

Whereas with Brenda and Colin the participant focus was purely based within the current episode of care and as participant eleven reflected

"I didn't realise that, no see when we get given handover we do just get like a little line of them, you get like the address of them, you have a bit of feedback about why they have come onto the caseload" P11

Reflections from participants three, five, nine and eleven reveal this can result in care being disjointed, losing sight of the bigger picture of the person's life.

"they [patients] *feel that they are being assessed all the time and never looked at as an individual really, I don't like that we don't have continuity of care, but I think that* [continuity] *is best for the patient, you know you can see changes"* P9

with participant eleven reflecting

"that comes down to a bit of continuity doesn't it, if you'd had time to see, if you had gone out before to see her, you would have noticed the difference" P11

It is apparent from the narrative accounts that both professionals and the patients valued continuity of care. From the professionals' perspective they could endeavour to understand the complexity of the issue within the older person's life and therefore support their reasoning in setting out care plans that were based on shared decision-making anticipating future care needs.

4.3.2 Revisiting end-of-life as a cycle of frailty within decision-making in the context of ICT

The participants spoke about death as part of the landscape of ICT in working with frail older people, often this was reflective. Offering in hindsight their interactions with Albert, Brenda and Colin, as a route to look for indicators that death was part of the cycle of life. In the cases of Albert and Colin death was not considered within the scope of their practice and therefore the focus of their reflection was in seeking to understand how the trajectory toward death could have been predicted and in some ways prevented.

There was limited consideration of Albert's perspective and how a discussion of end-of-life may have been introduced to support him and his wife through a declining trajectory of health. As participant one and two recall, conversations about Albert's deterioration were frequently discussed within the team, but never directly with him.

"there were lots of conversations with us in here (referring to the office/team base) about our concerns but probably not so much with Albert because it didn't feel appropriate to do so" P2

Later recounting that Albert's wife was equally struggling to comprehend the declining health of her husband *"because his wife was so stressed and wasn't well herself I don't know how much she could have fought Albert's corner I think she didn't have an understanding of what was going on I think she just thought oh he's got another infection but why has he got another infection on top of another infection she was just very overwhelmed."* P2

Similarly, with Brenda the initial process of care within ICT was focused on reversibility. A possibility that Brenda had reached a point in her life where it felt complete, acceptance that she was ready to die was simply not visible in many of the accounts until reflecting in the interview.

"*it is not always reversible, and perhaps this had been coming for a while and she had given up and I didn't recognise those symptoms*" P11

The choices that Brenda made to disengage in life seemed to some participants contradictory, as they struggled to align Brenda's choices and their own perception of her needs. As participant five recalled

"*knew she would die if she didn't go in yeah, it just feels a waste to me I suppose I don't, I really don't understand it*" P4

As the trajectory of end-of-life became more evident with Brenda the opportunity to discuss death as part of care was more apparent, as participant three and six recounted

"*I think when it comes from an outsider too cos you don't have quite the same worry about the starting you know starting the discussion* [difficult conversation about death] *with them* [family and Brenda] *do you*" P6

Most of the participants were surprised to hear of the death of the older people, for some they were unaware of death until they received an invitation to participate in the evaluation. The language of death in the interviews was associated with words such as unexpected, clinical investigation, underlying conditions and prevention. The management of a patient's death within the organisation meant it was often removed from sight as clinical investigations were often completed in isolation from those professionals involved. The participants spoke of death as a shock, with little opportunity to understand the context of death as participant one shared

"if we have a bereavement while client is on our caseload the report with go to the lead consultant and there will be an investigation if it is an unexpected death but that not generally shared with anyone that is has been involved, there has not been never been any feedback [about a death]." P1

And participant four and five reflected how the organisation of care contributes to the invisibility of death with frail older people,

"*cos I am just the first person in* [Brenda had been seen by ICT a couple of weeks before] *and we don't know that she is at that stage yet* [dying] *so I wouldn't be thinking that*" P4 “*obviously there is no caseload for us so its umm I am not even sure that I knew that she died.*” P5

and more widely influences opportunities to develop skills in managing conversations around death and dying. The invisibility of death was reflected on by many of the participants.

“*especially the age group that we have got the 70 and 80-year-olds, they are very pragmatic, I think we are afraid of having those* [death] *conversations with patients.*” P9

“*think we are just expected to get on with it* [managing death and dying situations in practice] *you know death is sort of underneath the acute…*” P11

Reflecting on death through the narrative interview participants accounts indicate that the organisations cultural response to death influenced decision-making processes of professionals. The way death was decontextualized through discussion, reporting and the management appears to be within a punitive approach, as a service failure and therefore the openness to discuss death in practice is limited.

4.4 Summary of grand narrative one

The findings indicate that Albert, Brenda and Colin experienced frailty as a process of decline over the last 12 months of their life, which was largely reflected in the accounts of the professionals rather than the clinical documentation. Their pattern of heath was unstable and unpredictable with frequent episodes of acute illness, loss of functional capacity and increasing informal and formal care that often resulted in frequent admissions to hospital. The professional accounts focused on key indicators of ageing but did not term these as frailty in their decision-making. The focus of professional decision-making was to promote independence through medical intervention and provision of equipment and care to compensate against the acute episode of ill-health the older person was experiencing. The cultural shift from a rehabilitation service to acute crisis approach was evident as a source of tension in how care was therefore organised and delivered influencing the professional decision-making process. There is an overt focus placed in practice on managing acute illnesses, with predominately physical health needs considered and therefore does not fully acknowledge the whole person perspective. The organisational changes are implicit in altering continuity and thus the capacity professionals have to develop relationships to support shared-decision making. This has led to the wider scope of supporting frail older people in planning for end-of-life to be omitted within the service context leading to an invisibility of death, other than as a failure to reverse the impact of acute illness.

Chapter 5

Grand narrative two– the professional's stories of decision-making

Grand narrative two findings are presented within this chapter, focusing on the professional's story of care of in supporting a frail older person reaching end-of-life and influences upon decision-making. The professional's stories were analysed within and across the professional groups of nursing and therapists. Throughout the presentation of the findings all participants have been pseudonymised. The grand narrative combines the three commonplaces of place, sociality and temporality within the following themes:

- Tensions arising from changing the culture of care
- Medicalisation of professional identity
- Collision of personal and professional lives within practice

5.1 Tensions arising from changing the culture of care

The evolving remit from rehabilitation to acute care has moved the service approach from one that was based in therapy, to a crisis management process. This change has meant the organisation of care has shifted from caseloads to one-off clinical encounters, whilst this has brought about challenges, it has also offered the opportunity to develop new areas of expertise. The following findings are presented in three sub-sections:

- Evolving service remit
- Impact of shifting culture on delivering patient care
- Death viewed as a failure

5.1.1 Evolving service remit

The participants spoke of the shifting service remit from community rehabilitation, when the service was originally developed to more recently becoming acutely driven intensive approach. This is reflected in the documentary review and care maps whereby the acknowledgement of future needs, impact of frailty on the totality of the person's life and how this then related to family and carers were far less frequently considered than acute illnesses. The documentary review corroborated this with the focus on the current picture of care for the frail older person and their immediate needs.

In the interview the participants spoke about the challenges of this change, requiring movement from one ideological position of practice to another. Whereby the basis of decision-making transitioned from considering the whole person, to a snapshot of them.

For some participants the transition had been a labored process, as recounted by participants nine and eight

" it's falling to a crisis management now and there is no way that you can rehab somebody in two weeks… quite often you will go in and you can think what am I doing here what difference am I going to make" P9

"I remembered how he was from the previous time I came, and he could hardly barely stand well you know if he was unwell, it is hardly fair to push people when they are clearly struggling" P8

For participant one and three there is an acceptance that their roles have evolved due re-organisation of care

"we were going in with his initial presentation and his immediate needs… I was very much looking at his current presentation in terms of his function, so I would not have delved too deeply with his past medical history or his clinical situation because other colleagues would have done that… because of the structure of ICT we don't carry a caseload" P1

The change in focus from community rehabilitation to acutely driven care has also resulted in a shift towards crisis management interventions. The influence of this change leading in decision-making to balance safety and risk at home for acutely unwell people, as participants one, two, four and eleven's stories indicate. The stories unfold in describing their professional rationale for input to frail older people's care.

"the priority was the hospital bed, that is was safe for him and that it met his manual handling and pressure care needs" P1

"*was just going in looking for acute signs you know this patient needs to go in, you know making sure that they are safe to stay at home,"* P11

Where the risks of acute illness cannot be managed by ICT hospital admission is sought. The participants recalled the core function of ICT in securing emergency care to persevere life. Participant six, one, five and eleven spoke about this influencing their professional approach as illustrated

"*it was a challenge cos we are here to keep people alive basically aren't we,"* P6

"She was at risk of death if she didn't go into hospital, so like my goal was to get her [Brenda] *into hospital"* P5

Consequently, the health context of the people referred into the service continues to evolve in response to the acute rehabilitation and crisis management approach. The range of patients and therefore, what is now viewed by participants as a *"typical ICT patient"* has also changed as participant eleven reflected “*as people are living longer with more co-morbidities and things like that you know ICT we do take a lot of those* [frail older people approaching end-of-life] *people on our books”* P11

Some participants recognised that older frail people may need alternate approaches to care, that encompasses end-of-life needs more openly as offered by participants five and nine

“the expectation doesn’t change from the outside so that’s a bit hard, you know if people were more realistic [at end-of-life for older people] *and say not for rehab…she might have accepted help to have things done for her rather than someone coming in and saying you need to get washed…so I think that would have been better but that’s not really what is expectation is on the box.”* P5

“sometimes they want to see you at the end, they want to be supported by the people who they know, who have sort of been supporting them throughout so it [death] *can actually show less fear for them as well”* P9

However, as some participants discuss underlying ideological perspective makes this counter intuitive to practice decisions

“probably getting my head around the fact that she had made this decision to die and wasn’t going to be swayed from that decision and didn’t want, didn’t want intervention because that is what we do, that’s what we are all about.” P6

The notion of looking back and of hindsight in decision-making was spoken of throughout the accounts and resonated with the loss of continuity. The loss of a caseload and continuity of care that this facilitated replaced by one-off clinical encounters offered a tension for the professionals as suggested by the following participants

“I think that (continuity) is best for the patient, you know you can see changes, and …you see things slightly differently so you should be able to pick things up a lot quicker you know so I don’t like it but it is part of the system now but again I think you are just letting the patients down and you are letting the staff down” P9

“we don’t have enough continuity because if they sent me in maybe three of four day, maybe I would, I would be able to see an improvement or a decline but it is very rare that we follow the same people up” P4

“was that normal for him I don’t know, having not known this gentleman, not met him before I don’t know” P1

Participants reflected whilst challenging, changes to the organisation of care had enabled them to develop new areas of expertise and skills. Moving to an acute illness focus with time-bound intensive intervention enabled some participants to develop as highly skilled assessors and/or diagnosticians. These roles particularly within a nursing context were highly valued. The therapist also valued being able to draw on the senior nurse's advice in the clinical management of patients at home. Where therapists were required to make supported medical-based judgments as discussed by participants one, two and nine

"I think it was that pathway through to getting clinical expertise from our senior nurses is straight forward" P1

"*if we saw that the CEWS* [clinical observations] *were skewed we would get the nurses to come back in straight away"* P9

The change in decision-making toward acute medically-orientated assessment remains a tension in the management of frail older people within the narratives, re-organisation of care support this approach however at the compromise of continuity.

5.1.2 Impact of shifting culture on delivering patient care

The participants spoke of the changing focus of the service context as influencing professional decision-making and its impact on delivery of care to frail older people. The participants approach to delivery of care was problem-solution focused, with many of the narrative accounts detailing complex assessment processes and protocols. The range of protocols used to assess the patient included a community early warning score (CEWS), tissue viability status for pressure care monitoring (Waterlow), physical exercise measurements, mental capacity assessments, diet and nutrition scores (BMI, MUST), body maps for pain and injury and functional activities of daily living assessments. The participants discussed how these informed the identification of needs for the frail older person and therefore the care delivered by ICT. Participant one, seven and eleven narrative accounts describe the process of care

"I felt we had done what we could do in that visit we had identified the major concern of the clinical observations, we had looked at the pressure care [Waterlow score] *which is clearly an issue for somebody who is remaining in bed for 24hrs"* P1

"*MUST is the malnutrition score and it gives an indication of, its weight plus your BMI which then indicates whether someone is underweight or overweight and it indicates the dietician referral or extra support to gain extra weight and calorie*s, *it helps build a picture cos her BMI was 15, the MUST was 2"* P11

An initial problem list was formulated and actioned from the assessments, then care handed over for the next professional. Participants reported this relied on clear documentation of the breadth of concerns, ensuring that patient care was continuous and responsive. The participants spoke openly of the challenges this approach brought to the quality of care patients experienced.

"*my feeling was that we sort of got lost a bit with Brenda where we were going with her or it didn't get a urine sample, or get the blood results so whatever I thought should have happened to that lady didn't happen…. and then I think after that she didn't get another visit, yeah then like an hour later after the nurse had visited she was discharged."* P11

"when you put a big plan together and then you look at it three or four days later and nobody has done it, why did I spend all that time and you think ohhh (deflated sigh) why did I try and sort it out and get things, when other people other people haven't followed it up, that's, that's, frustrating" P4

Additionally, building relationships with patients and having to make recommendation within the cycle of one clinical encounter presented challenges however, this resonated more with in the narratives of therapists than nurses.

"often we are seeing someone we have not met before it's the first contact for the patient and we have to judge their likely reaction to what we are about to propose." P1

"it's not enough for you to be able understand and build up your understanding of patients" P7

The focus on the current clinical presentation and lack of continuity challenged professionals in aligning their reasoning and decision-making within the care of frail older people in ICT. The participants spoke freely of the need for a holistic view of a person. The holistic view was gathered as a one-off encounter at the initial assessment and the assessments were only completed by a senior professional (Band 7 or above) within the team. However, as participant eleven and four and nine's narrative accounts highlights there are limitations in this approach when the drivers of the service influence the way in which patients are viewed.

"*but I think that you go in, and I probably went in focused on that one thing, was just going in looking for acute signs you know this patient needs to go in, you know making sure that they are safe to stay at home,"* P11

"the wife saying "oh I can do that" and so as soon as someone says that you block it, that's finished that is over and done with you" P9

participant 11 reflects this can mean that there are gaps in understanding the perspective of the person and their family.

"from the perspective of continuity and building up a picture that's what it misses, a little bit, cos may be if we got to know her a little bit better and things would have flowed a bit better" P11

The documentary review echoed the narratives of the participants, the preciseness of reporting the patient's assessments and needs varied and frequently omitted discussions around future anticipated needs or patient and family preferences of place care. Instead documented with detail presenting physical characteristics, diagnostic indicators and their impact on remaining at home.

5.1.3 Death viewed as a failure

The recognition of death within ICT for frail older people was discussed within the interview process by all participants. They spoke frankly and openly of their experiences of death. When asked if they were aware that the older person had died most accounts depicted death as a surprise; with participants acknowledging they were unaware that the patient had died, alluding to the normality of invisibility of death within the context of ICT care. In discussing the association between declining trajectories and frailty the participants narratives were often paradoxical on one hand acknowledging that frail older people were the core business of ICT as participant two, nine and eleven discuss in relation to the evolving service remit

"most of our patients to be perfectly honest are very similar to Colin, you know cos they are elderly and frail" P9

and in the same context did not necessarily expect death. Death was not conceived as a probable outcome for the frail older person, despite key indicators of approaching end-of-life, such as frequent hospital admissions and increasingly intense contact with health and social care services.

"yeah it was a bit of a surprise when you look back and to be the fact that he died so quickly …I think as well because we concentrate so much on their observations and that is obviously the way that we pick up you know signs of a poorly patient" P7

Death was implied by some participants to be a failure to reverse the declining trajectories of frailty and was closely associated with the predominate culture of ICT care. Many reflected on the circumstances of death and whether differing clinical input could have prevented or foreseen death.

"I was surprised and shocked that because I felt that she wasn't at that point when I saw her, and I wondered if there was anything that I missed" P11

"you always thinking what could I have done" P8

In contrast participant nine was the only professional who spoke pragmatically about the normality of death for older people, highlighting it should be recognised as part of the landscape of practice within ICT.

"you know these patients if they suddenly go downhill they should be able to have a good death, you know not a sort of rabbits in headlights so something has gone wrong well maybe, everybody you know says something has gone wrong, well maybe it hasn't maybe the patient's body has just decided to give up …but we should be able to see that and support them through that and support that as therapists or nurses" P9

In discussing communication of death within ICT participants were rarely informed of the death of patients. Even participant six who instigated end-of-life care for Brenda was unaware of her death, ceasing to be involved after a single critical clinical encounter with Brenda and her family that changed the focus of care from ICT.

"it was to keep her at home and family onboard so that they could support her and then to get the comfort stuff in place and then get the experts in to support her for the end stage." P6

Many of the participants recounted that the nature of ICT meant that they do not follow through patient journeys. Detaching from involvement following completion of their clinical encounter with the patient, handing over the care to another team member or service. Participants recognised they had little personal capacity to hold clinical ownership of the patients within their professional life, and therefore death of a patient was an infrequent, often a hidden experience as illustrated by the narratives of participant nine and five.

"I suppose in some respects maybe I see patients as not as end-of-life because we don't follow them up and that is a big issue, it is a big issue, so you don't see what the degeneration is in them is or how they die you know or what happened to them during those few months" P9

"it is quite hard but when you only see a person once and you see three more on that day and god know how many the next week it is quite difficult" P5

Unexpected deaths within the service are often reported as critical incidents and are investigated by senior clinical leads with no feedback to the professionals involved in the care as discussed in grand narrative one. On reflection through the process of recruiting to the evaluations the email dialogue had with prospective participants frequently started with of presupposition on their part of *"wrong doing"*. Many participants wrote to me as the evaluator asking if they were being investigated, questioning whether their professional conduct lead to the death of patient. It was then within the process of care-mapping and interview that participants spoke with candour about the need for a culture of openness, to enable the team to reflect, to learn from death within a supportive framework that they felt would contribute ultimately, towards providing higher quality of care to frail older people.

The desire for open conversation about deaths of patients within ICT was recounted by many of the participants. As illustrated by participant one and seven in discussing the importance feedback as a tool to aid professional appreciation of how to identify and manage end-of-life within practice.

"But yes, I think that would be quite nice, it would be nice to have that closure for us as a clinician involved really so that we can conclude our reflections and you know answer the questions for our own learning" P1

As well as professional dialogues around end-of- life, participants reflected on challenges in approaching these conversations in practice. Participant one recounted the need to be better equipped in identify end-of-life in frail older people, *"that caseload is increasing at end-of-life or may be predominately it is about identifying end-of-life it is not necessarily carrying out the care, cos a lot of that care we deflect cos we are not the right service at all, but it is identifying it"* P11

reflecting on the need for a confident professional judgement to do this in practice.

"here it is very different you know we are there but you have, with there [hospital] *you have got machines and monitors that show you if someone is dying and here you are going back to when you first qualified identifying somebody who is dying out in the community, which is difficult and it is easy to get it wrong"* P11

Echoed by participant nine

"sometimes, nurses do have those conversations, I think certainly the senior nurses do, I think therapists probably find it a bit more difficult and again I think it is because we I think we are afraid of saying or writing down end-of-life, you know then all the ramifications." P9

The importance of open communication, managing expectations and preferences at end-of-life was highlighted by participants in achieving a good death experience as illustrated by participant nine

"we need to take them seriously, so they have what you know I call a good death, and be prepared for that themselves and then the family can be prepared for that as well" P9

Participants spoke of supportive mechanisms within the organisation, suggesting how reflecting on death and end-of-life care experiences could be embedded within these, to help recognise death within the culture of care as illustrated by participant seven

" [reflecting on death of a patient] *go through those lessons so the teams involved everyone from staff from all the grades from all the professions and we will have a look and just again do this reflection piece and see if there was anything we should have done differently or if there was anything we missed out"* P7

Several participants reflected on importance in providing more opportunities for conversations in practice around end-of-life for frail older people as illustrated by participant eleven

"earlier conversation probably about expectations of end-of-life and things like that because it is going to happen to us all and when you get to that old age there is more likelihood of it happening and are, umm are we prepared for it? You know what are our expectations, what do we want to happen, when we die, and where do we want to be, that kind of thing, is it practical" P11

The evolving nature of the service from rehabilitation to acute crisis management has altered the pattern of care provided to frail older people. As a result priorities of care have shifted to intense short-term interventions, addressing immediate needs to promote independence at home. The wider view of frailty therefore in this story of care is often hidden from professionals, as one-off clinical encounters focusing on the here and now of practice where the possibility of death is often removed from foresight.

5.2 Medicalisation of the professional identity

The influence of 'medical lenses' for all staff in clinical practice was an implicit feature within all the narratives, influencing the approach professionals adopted in supporting frail older people in ICT. The participants highlighted within their accounts tensions around differing value bases of professional approaches in practice with frail older people and how this influenced their professional identity. The findings are presented in two sub-sections:

- Medical lens in clinical practice
- Valuing differing approaches in practice through learning together

5.2.1 'Medical lens' in clinical practice

The opening of the interviews offered all participants the opportunity to speak freely of their input to the frail older person. For most participants the opening discussion was located within a medical perspective, documenting the clinical observations (CEW's) and presenting physical characteristics of the patient. The importance of these were reiterated throughout the narratives as illustrated by participants one, two and four and was echoed throughout the documentary review of case notes.

"he needed some clinical input because of the symptoms he was presenting with, he would need monitoring of his clinical observations and vital signs" P1

"she had a high resp rate and high pulse, low BP and she had a bit of a temp, I recommended admission and she declined." P4

Centralised protocols and care process such as CEWS and initial assessment were reported by participants to contribute to high quality care for acutely unwell people, as it alerted professionals to underlying medical issues and expediated clinical decision-making- thus ensuring the right care was provided by the most appropriate care teams, as illustrated by participants two and six. Clinical observations were often linked to professional reasoning in understanding the clinical picture.

"Albert retook his observations again everything was within range, temperature was about the same, no real concerns but a different person altogether" P2

" so I sort of did my assessment and said she wasn't acutely unwell but wanted to die" P6

With participant seven reflecting that sometimes it is important to remember to step back, and look at the person not just the clinical observations

"you need to look at more than just the numbers that you pick up, you need to look at the whole person" P7

Only participant eleven opened the interview by recalling the personal perspective speaking of Brenda at home as previously identified in grand narrative one

The foundation of practice in focusing on clinical observations and decision-making was a tension for therapists as illustrated by participants one and eight as placing a heightened level of responsibility on therapist to make medically-orientated decisions.

"*if there was something that we felt was cause for concern at that moment in time we would have acted accordingly, it's something that we do fairly regularly, it's to call an ambulance and hand over care to the paramedics with a view to admission"* P1

"as a service we are all sort of responsible in that way you know if somebodies obs are really deranged and I went to somebody the other day I got there and immediately phoned for an ambulance and then phoned the nurses to let them know the situation " P8

In bringing together the narrative accounts an underlying story is evident, that profession specific reasoning approaches become filtered over time by the influence of crossover roles and team socialisation within a medically-orientated culture, as illustrated by participant four.

"so you worked with doctors a lot, lots of consultants, so you learn from them and their plans" P4

And for participant five a pressure to discharge patients from the service in contrast to their usual professional practice, reflecting that Brenda has been reported as unwilling to engage.

"*I am pretty sure basically I was asked to go and, and, asked to discharge her, I am not normally that quick to discharge people."* P5

These differing perspectives emerged as areas of debate in exploring the contribution of professions to the care of frail older people. There were differing perspectives between nursing and therapist in terms of the focus of practice and therefore how they determined the needs of the frail older people, which was debated keenly by participant nine

"therapy led is you know most of them [frail older people] *patients have got reduced exercise tolerance and their mobility is reduced markedly and their ability to wash and dress and they can't make drinks so those are the basics so that should be therapy led because that is what we do but the nurses don't do that, they are acute"* P9

Adding later

"because you get the revolving door patients don't you and sometimes they get to point where they keep going in and out of hospital and they have had enough of it, they don't want it anymore but I think again I think medical people [we] *take over and that's probably slightly wrong and I think that it is different when you have got an acute patient, but when you have got a chronic patient who is elderly and you know and sort of voices those things to you, we need to take them seriously so they have what you know I call a good death"* P9

Within the narrative accounts, care maps and documentary review, a personalised approach to care was not always evident. Professional stories often relaying the technical aspects of care and decision-making through documentation of the monitoring of clinical observations, instigation of medical investigations, provision of exercises or equipment as summarised by participant seven

"so I did feel that all his sort of basic needs were met and from a safety point of view as well umm and from a medical point of view with his wife being there to support him with medication and things that he was well supported" P7

There is a disjuncture in the accounts between the ideal of a holistic personalised approach and its implementation in practice. The patient's preferences or goals were not recorded within the documented accounts of clinical care and only two of the participants spoke freely of the patient preferences as guiding their decision-making. The influence of medical perspective within professional approaches in ICT is evident in the narratives, care maps and documentary review. The focus on clinical observations informs the prioritisation of needs and therefore the range of interventions provided- whereby the medical and technical approaches provided were reported primarily as preserving life and independence which in some cases was asynchronous with frail older people wishes as they approached end-of-life.

5.2.2 Valuing differing approaches to practice through learning together

Recognising and valuing difference across and within professional groups was referred to by all participants. The value of the differing professions was highlighted as central to professional identity and status within the organisation, team and clinical interactions with patients.

From a therapy perspective there were polarised views of the value and place of therapists within ICT. Some of the narratives revealed a loss of professional voice and value within the wider service context. These were often associated with changing from caseloads to one-off clinical encounters, along with transitioning to an acute service context. For some participants the contribution and value of a therapeutic approach to managing frailty and end-of-life was not always visible within ICT. They spoke of the challenge of working in an environment that is led by another profession, where decisions about the organisation of care were implemented service-wide and yet may be in contrast their own professional ideology and practice. For participant nine the impact was significant, expressing reticence in their professional identity and value in practice.

“a problem here is we don’t have a senior here who is on the same level as the senior nurses so therefore our input doesn’t go into ICT it is basically, I am being sort of blatantly honest, I think most therapists will say the same thing, is that we are not managed well, because we are not managed well because it is more nurse led, even more so since we have gone down to 14 day it is even more so nurse led, so our voice is lost” P9

adding that perhaps a therapy-led frailty pilot project could be developed, but that therapists lack seniority in their voice being heard

“I can’t see why it [therapy-led frailty team] *can’t happen but we need that voice, and until someone gets an 8a level and can stand there at the same level as a nurse management we are not going to have it so we will just continue to fail our patients in frail elderly care as regards maybe not the acute bit but certainly as therapists……but even our senior management don’t see it, they don’t see what the therapists do in the team so it is very sad, a very sad situation for all our old, frail elderly people”* P9

For participant eight the importance of having professional concerns valued by others was raised

“ I did clearly handover to the nurses, cos his respiratory rate was high, his stats were green and I wasn’t able to get his blood pressure and he clearly appeared to be declining in function, why didn’t they go?” P8

Some therapists spoke of the highly specialised nature of professional practice in ICT, offering a pragmatic approach to aligning this in their practice. Balancing the loss of some therapy roles and merging of team roles with the development of specialised areas of practice as participant three recounts, the focus on patient-care should be the central concern.

“there are lots of areas of overlap in the service and sometimes it doesn’t matter as much who does it if it is needed as long as someone does and that the someone that does it has got the abilities and skills to do it really but you know that is sometimes the way that is goes when you work as a team you know that there are going to be areas of overlap but that’s ok” P3

Participants three, seven and eight describe their unique skills in practice within ICT that contributes to their professional identity and value. Reflecting how opportunities for shared working supports a greater appreciation and value of differing professional roles in ICT as illustrated by participant seven.

“sometimes they look at things from a very different standpoint view so it can be positive in that sense so it can be, you know you might pick up something from them so that is quite a positive really, I think, so we do joint visits too if it is quite complex or it is a manual handling for instance, we’d obviously do a joint visit with physio and OT or we can do joints with RA’s (rehab assistants) or with nurses as well on occasions, a completely different viewpoint from a different profession” P7

From a nursing perspective professional identity or value within ICT did not feature as tension within the narrative accounts. The nursing participants accounts revealed conflicting stories of the expected standards of care with their own profession, and the extent to which they match professional rewards of working within ICT. Participant four and eleven spoke of perceived intradisciplinary standards and the moral conduct attached to this as a nurse

“ I can’t be complacent about other people’s lives and trying to do the best for them and I see other nurse go oh whatever and I just find that that just makes me sad, why are we why are we nurses if we don’t want the best….” P4

and as illustrated by participants six in discussing the professional reward in being able to meet the needs of the patient at end-of-life

” yeah it is one of those days where you go home and you think god yeah I did a good job today, so although it was actually a very sad situation it was actually really a nice feeling that you had facilitated or you were trying to facilitate what she wanted and that was really nice, yeah really nice” P6

The importance and value of learning together to consider end-of-life was expressed by all the participants. The narratives reveal a motivation and desire to meet the needs of frail older people in a different manner, by learning together to explore end-of-life care. The development of learning opportunities included formal and informal approaches to support end-of-life care practices. Participants often reflected on the formal cycle of training within ICT, identifying further scope to widen their skills base, provide a space for joint case discussion and interdisciplinary networking. From an informal perspective the opportunity to have conversations about patients within a team environment, to share professional thinking was valued by all participants. However, for many this was recognised as an organisational constraint and not valued by leadership. Participants reflected on the capacity to build opportunities for discussion within the daily structure of ICT, recounting the value of this is less evident from a management perspective than practitioner. Participant three suggests that this can create a loss of professional networking and sharing of ideas or experiences in being able to meet the needs of patients at end-of-life.

“ we don’t have a sit down monthly meeting go over difficult case, but then you have still, you know they have got to have time think about it and time to look on it and if you know working full-time you don’t get much time because you get a caseload, a daily visit… something like that might help cos we would have somewhere to go to pick a brain” P3

The participants spoke of the importance of learning from the experience of supporting frail older people at end-of-life, by opening conversations around death and dying within the team to enable all staff to be responsive, equipped and confident in approaching these conversations with patients and their family.

5.3 Collision of personal and professional lives within practice

The participant’s personal experiences of ageing and death often interjected into decision-making in the care with frail older people, leading to a collision and entwinement of personal and professional values. The findings are presented in two sub-sections:

- Personal experiences of ageing and death interjecting into decision-making in care with frail older people
- Personal and professional values collide influencing practice

5.3.1 Personal experiences of ageing and death interjecting into decision-making in care with frail older people

Experiences of caring for an aged parent or relatives interjected into the narratives of some of the participants, they spoke how the influence of this was borne into professional practice for them on a personal level. It was viewed for some, as offering a window to understand the experience of care provided to frail older people as they approach end-of-life. For others is offered a reflective space to consider their own practice within ICT.

As recounted by participant nine the experience of navigating NHS and private care in supporting older parents was drawn out in considering how care was delivered their own practice. Participant nine’s story was centred on the importance of personalised continuity of care.

“as much as we say oh yeah we are doing right by them I don’t think we are it is quite sad, you know I have got very elderly parents and I, we make sure that the support is there for them and they are happy in their own way, mum has got (diagnosis) but the carers goes and helps her and says let have a shower and sorts it all out and that is how it should be, but whether that is more going into the private sector, they can spend more time with them.” P9

For participant eleven the death of an older grandparent influenced their understanding of the needs of frail older people. In applying learning around of end-of- life care participant eleven related this to the death of a grandparent

" if it had been evident there'd been lots of contacts from health care professionals and things like that in close succession, maybe….. we might of picked it up and my own grandma died and very much followed that pattern and if you have got your own experience you very much help you and the evidence sort of to back it up, it does help you." P11

Following on

"death has sort of been hidden, in hindsight, a bit of my own life and work life it, has sort of come into focus more they are match more." P11

Through reflecting on their own circumstances, participant six recalled a conversation with the family of Brenda, relating this to their own discussion with older parents.

"I had facilitated what she wanted, and I think getting the family on board with her decision, because they are not the discussions you have with you parents are they and really they should be." P6

For some of the participants expectations of care were embedded in personal values and standards. Participant four spoke of professional standards of care being closely aligned to personal values

"I always say I would always look after everybody as I would want to look after my own family" P4

Adding later when describing a situation, they felt was an unacceptable standard of care, relating their own story back to their parent

"I walked in and I thought oh my god I can't believe the state of this man, he looked awful….. so I said to his wife can you get me a comb and I looked at him and thought if this was my father I would be really unhappy" P4

And for participant six, the compromise between their role as a professional and enacting the preferences of a patient compared to what they would want as a child with an older parent was brought to the fore

"I have a lot of respect for her to be that strong in the face of your family sort of really pushing you and pushing you (to eat and drink) and I can understand why and you would do it for your own mum" P6

Offering later, that their approach to professional practice evolved after supporting Brenda and caring for an older family member

"you know when you go in to a situation and assessing and looking at things through a different angle and you think what am I going to do here, …. I am a lot more accepting than I was before" P6

It is apparent from the narrative accounts that personal experiences often interject into decision-making, offering insight into the process of care provided to frail older people. The participants drew from personal experiences to offer tentative consideration of the quality of care experienced, and these were often interpreted through their personal lens of supporting older people outside of their professional role. For some this led to personal and professional thinking becoming entwinned in decision-making.

5.3.2 Personal and professional values collide influencing practice

The entwinement of personal and professional values influenced practice for all the participants and is evident in the narrative accounts of what it means to practice in ICT. The participants spoke of their professional role and identity, enacted through engagement with patients and family in supporting frail older people. For some the change of service remit had resulted in a collision of professional and personal values centering on the perceived standards of care.

The standard of care provided by ICT was discussed by all participants and was often tempered by a recognition of current service constraints within the NHS. The participants discussed how they managed the impact of this on their professional and personal identity. For some participants adapting to the changing service remit and organisation of care resulted in an acceptance of an altered professional ethos and was tied to personal value derived from practice. As illustrated by participant three in coping with fluctuating case allocations

"you can have your visits and then it can change from like one sort of morning at the beginning of the day you might be called off to go somewhere else entirely different but that is just ICT so it is never dull [laughs]" P3

For others resistance to the change was evident in their narrative, for participant nine the changes at this point in their career resulted in disempowerment and redundancy in their professional and personal value as a therapist

"We are not therapists anymore we are assessors and we do limited therapy, so that's why for me, so I have got a few years left so I kind of I can stay here but you know why, I know this is going to stay quiet but why would anyone would come into this team as a young therapist is beyond me cos you do not do physio work, you cannot see you patients, there is not, there is no rehab" P9

A personal tension evident in narratives was how organisational culture and expectations influenced building therapeutic relationship with patients, words such as *"compliance"* and *"against professional advice"* featured across the narrative accounts. For some participants this tension was vocalised such as illustrated by participant five reflecting on the contrast between personal empathy for the patient’s perspective and organisational expectations on them as a professional.

“ I think she was quite fierce because usually I do find different ways to you know to finally get them to comply…..she wanted to know when people were coming in and she wanted to have more scheduled times, which isn’t the type of service offered…but I can see it from the point of view of the client that is awful because you don’t know where you are standing.” P5

Going on to reflect

“I think it is really difficult from a professional point of view………you want to be seen doing everything in your power” P5

For participant four and six the tension between personal values and professional decision-making was evident in the recognition of personal choice at end-of-life for Brenda. The narrative accounts of the participants four and six whilst working with the same patient Brenda, offer differing insights into how personal experiences and values entwine in professional decision-making around end-of-life. Participant four’s interaction occurred first as described

“She, she wasn’t a very nice lady, she was very stubborn, adamant, no intention of being admitted I think she had got heart failure as well, checked her heart failure, I just felt she needed a full medical work up to manage her….Why would you want to die, when there is no need for that, don’t get it I don’t get it and I had explained all that to her and I always explain to people like her” P4

For participant four, the decision by Brenda to refuse intervention and admission did not reconcile personally or professionally. For participant four this was managed professionally by ensuring the patient had mental capacity to make the decision as a way of personally mitigating professional risk

“*I just have to be at peace with myself and that I have done the best I can and I have recommended admission, it reassures me always a lot if the relative is there and is on board with me then I feel they are not gonna, you know I do worry about my registration about being in a court of law.”* P4

In contrast participant six describes their first encounter

“*the lady was in bed and she was in her 90’s and she was very frail, she wasn’t eating or drinking, she wasn’t acutely unwell, so I sort of did my assessment and on talking to her she basically said I want to die, I have had enough I want to die.”* P6

Reflecting, *“I thought she was a strong lady”*

Later adding how they managed to reconcile personally and professionally Brenda’s decision to refuse intervention and admission *"what I wanted to do was to go make her some soup, just try a little soup you know….cos we are here to keep people alive basically aren't we, it's the palliative lot that are there to help them die…. had to step back and really listen to her."* P6

The reflective space created by the evaluation enabled the participants to consider their actions within the care of frail older people and participant eleven reflected that personal and organisational values are embedded in professional actions, influencing decision-making but through the evaluation process and personal experience they were viewing care of frail older people differently. The narrative accounts enabled many of the participants to offer alternate ideas and solutions to manage the care of frail older people within ICT, demonstrating a willingness and motivation to learn from the experiences of the evaluation and reflective space it provided.

5.4 Summary of grand narrative two

The findings indicate that tensions in professional decision-making have arisen as a result of the changing culture and context of care within the service setting. The reorganisation of care and loss of caseloads has brought about both challenges and rewards for the professionals but has also impacted on the care delivery. Decision-making is based on single, short encounters and therefore addresses the immediate needs rather than providing a broader holistic perspective that is necessary for shared-decision making. The clinical encounters are mostly protocol driven with an emphasis on medical management, prioritising and stratifying risk in a problem-solution context and therefore do not fully consider the persons future needs including end-of-life.

The professional identity of participants has become complicit within a medical lens of practice, where technical input is highly-valued, and the aim of practice is to preserve life. The service is operationalised to reserve the impact of illness, where death is considered a failure even in an aged population, this then filters into the thinking of professionals and how they perceived the needs of older people. The interjection of personal experiences of supporting older people offers insight into the professional world, acting as a mediator in considering how care for frail older people is experienced and death could be considered within the service context. The narratives reveal an openness and motivation to learn across professional boundaries in developing an open culture of death as a counterbalance to meeting the needs of frail older people.

Chapter 6

Discussion in developing a broader theoretical understanding of frailty and implications for practice

The discussion chapter sets out the underpinning theoretical and practice-based contribution in understanding frailty and end-of-life within the context of health and social care in answering the aim: evaluating the influence of policy, practice and professional perspectives of what matters in end-of-life care and consider how it impacts upon delivery of end-of-life care.

6.1 Practice implications of the evaluation

The practice-based contribution focuses on the recognition of end-of-life trajectories as part of the clinical landscape of working with frail older people to provide integrated end-to-end care. The first section considers the medicalisation of ageing and frailty within the context of decision-making for professionals within healthcare in the UK. The next section explores the influences of healthcare organisational culture upon decision-making of professions in delivering personalised care to frail older people at end-of-life that. The final section culminates in discussing re-engagement with death as a part of the clinical landscape.

6.1.1 Medicalisation of ageing and frailty within the context of the UK

Ageing has become a global driver in health and social care (NHS England 2014, NHS Digital 2015; Department for Communities and Local Government 2016; ONS 2016a, 2016b, WHO 2017) advocating healthy ageing through public investment to enable older people to have the freedom to live an aged life that is consistent with their life long values as set out in WHO (2017) vision statement for global action. The predominance of active ageing paradigms and advances in medical technology have undoubtedly been a success of the twentieth century resulting in gains in life expectancy and decreasing mortality rates within the UK (ONS 2017). Whilst these gains are widely acknowledged so is it, that as people age they are progressively more likely to live with complex co-morbidities, disability and frailty. Therefore, living longer does not necessarily mean living well (Collard *et al* 2012; Kings Fund 2014; van Wijngaarden *et al* 2016). It is evidenced as differing perceptions of the reversibility of ageing process between the older person and the healthcare professionals, particularly in the case of Brenda. The practice context of ICT places the medical world within the older persons home and in doing so projects its professional lens and values within it. For Brenda the context of her life as told by the professional greatly influenced her decisions as she approached an aged death however this was not then translated into their understanding of her as a person in making clinical decisions. The immediate and presenting underlying pathology focused the interventions offered, influenced by a medical lens of practice to diagnose and treat and yet for Brenda this was not important.

Broadly, the main tenet s of policy and research have focused on reversing the impact of ageing by seeking to understand the influence of physiology, psychology, cognitive and socio-environment has on successfully ageing. This is primarily driven by a socio-medical perspective, with the aim of early identification, diagnosis and treatment of singular diseases; to cure and prevent ill-health (Davis and Brayne 2015, Age UK 2015, Kings Fund 2014). The medicalisation of the ageing process is echoed in a statement made by National Clinical Director for Older People and Person Centred Integrated Care

> *"The proactive identification, diagnosis and management of frailty provide a realistic prospect of an improved seventh age as never before."* Vernon (2016 p1)

Whilst the principle of better aged health has significant merit, there is an inherent risk in taking this singular perspective in projecting a medical lens of ageing. The narrative accounts thus reveal an insidious professional socialisation towards adopting a medical lens of ageing that at times replaces specific professional perspectives. This is evidenced in the narrative accounts where predominately the signs and symptoms of ageing were presented foremost in decision-making. For example the frequency of episodic illnesses, markers of deterioration in physical and functional capacities were identified rather than the older person. Decision-making processes placed an explicit focus on the underlying diagnostic or pathological causes and therefore at times failed to acknowledge the broader context of the older persons in advancing towards end-of-life. Gray *et al* (2016) and Ballard and Elston (2005) argue that the traditional concept medicalisation has evolved, moving away from a paternalistic view of medicine as *"doctor knows best"*, to a wider societal perspective whereby technical and rational medicine is valued and personalised care therefore operates through process-driven checklists.

The adoption of screening tools and standardised initial interview processes undoubtedly contributes to ensuring that appropriate care is provided across the service and was discussed by the professionals in supporting team decision-making. The protocol reflects the medical lens of practice within the service context, with an explicit focus on the medical management of acute episodes of illness and deterioration of function with restoration of previous levels of health or function the optimal outcome. Vincent (2006) argues, prescribed forms of active ageing pervade personal, political and social realities. Vincent proposes that these mould individual's health behaviours within socially constructed "expected normative" pattern of ageing throughout their life-course. This is evident in the narratives of the professionals. For Brenda, the narrative accounts of some professionals were dissonant, at odds with her choice to refuse intervention which could lead to a hastening of her own death. Treatment was viewed as a modality to reverse the impact of ageing holding back death for a little longer. Brenda's decision to refute rehabilitation to give back a sense of independence and decline medical investigations that could provide an answer to greater longevity of life was a source of tension in the decision-making accounts of the professionals. Instead Brenda voiced her life as complete, with a readiness to accept death. Her voice in her care was misunderstood, in some cases dismissed and viewed contrary to societal agendas of sustaining healthy ageing that underpin the service remit. At times her wishes were viewed as antagonistic with descriptions of Brenda's defiance revealing tensions in practice. Professionals accounts of decision-making reveal personal and professional stories of struggling and at times failing to reconcile their own professional values (that were driven by the service remit) with patient's choices, which were the antonym of active ageing. To which professionals' fell back on "mental capacity" as a tool to defend their actions in not being able to persuade Brenda to change her decision. This account of decision-making places central importance on the professional rather than older person and contrasts with the ethos of SDM (Bunn *et al* 2017; Coulter and Collins 2011).

The story of care for Albert and Colin illustrates the interplay between medicine, policy and practice. The professionals recounted agreed goals of intervention reporting the importance of independence to maintain health, mitigating dependency and supporting continued engagement within their home-based roles. These findings are consistent Grenier (2006, 2008) and Nicholson *et al* (2013) affirming older people's desire to retain a life worth living through participation in everyday life. Participation in everyday life ranged from mundane, personal and home tasks through to creating new opportunities for experiences such as expressive arts and creativity. Contributing to adjustment and adaption to the impact of frailty and ageing on self-identity. Adjusting or accommodating how their aged body responded to the demands of everyday life that were once taken for granted. The functions of everyday life, continuing valued occupations and roles represented to others their sense of identity and individuality despite an aged frail body. The accounts of Albert and Colin resonate with the experiences of frailty and approaching end-of-life as depicted by Grenier (2006, 2008) and Nicholson *et al* (2013). However, interventions to address these areas were largely framed within a medicalised perspective; providing exercises and equipment to address the physical impact of ageing and reduction of risk factors. The challenge however, in practice to enable a broader consideration of engagement in everyday life beyond safety, basic personal care task and exercise was discussed by the professionals. For some professional groups there was a dissatisfaction with the approach to care that was placed emphasis on medical and technical aspects above personalised care planning. Within the narrative accounts, professionals spoke of an underlying tension between staff groups and whilst the overarching importance of inter-professional working was emphasised by all, there remained a marginalisation of the allied healthcare professional groups. The impact of service wide changes in the organisation of care towards a medically-orientated process that supported medical and nursing ideologies rather than a therapeutic practice ideology was debated. This was most prominent when discussing personalised, continuous care in being able to proactively meet the needs of frail older people.

6.1.2 Personalised, continuous care of the frail older person

The accounts reported ICT as evolving from 6-8-week rehabilitation to an acute crisis intervention approach. It was clear from the range of emotive responsive that this emerging cultural and ideological shift was still transitioning, necessitating staff adaptation to their roles within the service. The greatest impact for many of the professionals was centred around managing the agendas of personalisation and continuity of care within the evolved service. All the older people had been under the care of ICT on several occasions within the previous 12-months. However, the professionals recounted only visiting the person once or twice within a two-week timeframe and most were unaware of their death. The professionals spoke of the process of holistic assessment and follow up care as being protocol driven with medicalised templates providing the basis for professional encounters. The documentary review concurs with this as the notes are standardised process driven, again with a medicalised view of holism. This is contrary to the BGS and CGA best practice guidelines which encompass a broader consideration of the frail older person daily life including anticipated end-of-life care needs (Rockwood and Mitiniski 2011; BGS 2011; Kings Fund 2014). As Romo et al (2017) and Gramling et al (2015) propose older-people often base decisions on the anticipated outcomes of care rather than consideration of specific interventions in collaboration with their immediate carers.

The Frailty Core Competency Framework (2018b p7) identifies three tiers of competency in the workforce in managing frailty. Tier 1 are those that require general awareness of frailty such as healthcare assistants within ICT who provide personal care support. Tier 2 are health and social care staff who regularly work with people living with frailty but who would seek support from others for complex management or decision-making and could include the range professionals within the context of ICT in this evaluation. Tier 3 are health, social care and other professionals with a high degree of autonomy, able to provide care in complex situations and who may also lead services for people living with frailty. This could include the senior-grade professionals who participated in this evaluation and the accounts demonstrate that they regularly operate in complex clinical situations within the community, requiring a high level of autonomy in clinical decision making. The new core competency framework (2018b) places an expectation on staff at

Tier 2 and 3 to utilise the assessment process of the CGA to support clinical decision-making in working with frail older people. The CGA and BGS can be utilised as tools to facilitate SDM with the older person and their immediate carers and considers the goals of intervention, thus supporting wider consideration of the older person's preferences and needs that is an area of tension in the professional accounts.

There appears to be incongruence within the policy around frailty and care of the older person which is evident in the organisation of care at a service level. On a national level the influence of process driven organisation of care is apparent, the CQUIN for frailty reinforce this. The identification and management of frailty emphasises medical, mental and functional health factors articulating these as the basis of personalised care planning omitting the importance of end-of-life care as integral within national approaches to care organisation (NHS 2014). However, a central component of the frail older people integrated pathway is the recognition that care should be end-to-end, encompassing all stages of the patient's journey "from healthy active ageing to end-of-life care" NHS (2014 p7). End-of-life care and care of the older person share the same common markers of high quality care informed by a variety of national policy and guidance including Five priorities of care (LACDP 2014), End-of-life Care Strategy (NHS 2008, 2013) and National Voices (2015); promoting the recognition of personalised care, choice and dignity at end-of-life. The importance of co-ordinated and integrated care for frail older people is reiterated across NHS policy and research (NHS 2014; Kings Fund 2014; National Voices 2013; Ellins *et al* 2013) - with older people highly valuing continuous care delivered by familiar clinicians including at end-of-life (Rolland 2013, Haggerty 2012, Health Foundations 2011a). In contrast poorly co-ordinated and disjointed care is associated with poor quality and reduced satisfaction increasing older peoples sense of vulnerability and invisibility in society (Grenier 2006, 2008; Williams *et al* 2007; Bravell *et al* 2010; Hurd-Clarke *et al* 2012; Hewitt *et al* 2013; Nicholson et al 2012 and van Wijngaarden *et al* 2015). Professionals reported frequent patient dissatisfaction with ICT approach to care and was reiterated in the accounts of Albert, Brenda and Colin's quality of care. In addition, the AHP's spoke of a *"loss of caseloads"* as impacting on the continuity of care that in turn influenced decision-making in being able to view the person within the context of their life.

The re-organisation of care within the service context was identified by some as contributing to invisibility of death. Most of the professional accounts of decision-making failed to recognise end-of-life as part of the trajectory for frail older people and for some death was not an expected or welcomed part of their clinical landscape in working with older people. In contrast Gray *et al* (2016) urge that at the intersection of primary care, secondary and intermediate care (ICT) there needs to be an understanding of the point at which the benefit of intervention is outweighed by the harm of further intensive medical intervention. In doing so, transitions to appropriate compassionate, supportive care and palliation can be facilitated. Albert and Colin both died in hospital following an unplanned emergency admission. Albert died in an emergency care unit and Colin on a medical assessment unit, both experiencing a series of medical investigations and intervention during their final hours of life. The professional narratives spoke of surprise and shock at learning of the "unexpected" death of Albert and Colin; referring back to their assessment process and protocols of practice as tools to diagnosis impending death. They continued to offer justification as to why their deaths were not predictable despite chronological documentation in the medical notes of deterioration across the last 12-months of life. For Brenda, only during the last days of her life were her choices recognised and enacted thereby supporting her wish to die at home. The trajectories of Albert, Brenda and Colin were consistent of an aged frail death. They do not follow a predictable or measured decline; instead everyday life is experienced as fluctuating periods of stability and erratic decline in personal capacities (Vernon 2017; Bravell *et al* 2010; Nicholson et al 2012; van Wijngaarden *et al* and 2015 Williams *et al* 2007), whilst they may not always be predictable they can be anticipated and therefore proactively co-ordinated and planned for in advance (Vernon 2017).

6.1.3 Re-engagement with death as a part of the clinical landscape

Ageing brings about questions of mortality and although death is anticipated it is done so with duality of life; frail older people often live with the shadow of death as a part of their natural course of everyday life (Grenier 2006, 2008; Lloyd-Williams *et al* 2007; Hurd-Clarke *et al* 2011 and Nicholson et al 2012). It is evident across theoretical constructs and research that ageing is heterogenous and factors that influence perception of satisfaction are inherently personal. Whilst some older people express having lived a fulsome life and despite inevitability of death, they wanted to continue to be able to experience everyday life as life "well lived" - whereby satisfaction is gained from participation in everyday roles and tasks (Nicholson et al 2012, 2017). Others however, experience a disconnect between what they wanted to "do" and can "do" in orchestrating everyday life in an aged frail body; leading to feelings of personal discontentment, anguish and invisibility within wider society (Grenier 2006, 2008; Lloyd-Williams *et al* 2007; Hurd-Clarke *et al* 2011 and Nicholson et al 2012, 2017). Contrastingly others have a sense of a life complete, ready and welcoming death (van Wijngaarden 2015, 2017). It was evident in the case studies that death was a shadow in the everyday life for the frail older people and their families. Albert, Brenda and Colin, the respective ages of 91, 95 and 83 years old had multiple admissions to hospitals, increasing contact with health and social care providers and informal care. Yet none of the records indicated a proactive dialogue or recognition of approaching end-of-life. The Frailty Index (2011) would indicate that on last presentation to ICT Albert, Brenda and Colin would be assessed between 7 severely frail - 8 very severely frail and therefore at significant risk of death within the next 12 months. Reid *et al* (2015) reported that identifying impending death and end-of-life is problematic for many health professionals as it challenges their ability to decision-make in an objective evidenced based manner as it is often fraught with uncertainty. This would appear to concur with the experiences of Albert, Brenda and Colin whereby recognition of end-of-life trajectory was not considered within the decision-making processes of those involved in their care.

The service protocols used by the professionals do not routinely screen for frailty despite this being a recommendation of the frail integrated care pathway and CQUIN (NHS 2014). The narrative accounts rarely identified frailty or end-of-life as clinical descriptors of Albert, Brenda or Colin. It was only during the culmination of the interview process when the professionals often reflected back on frailty and end-of-life, discussing how frailty and death was invisible in practice that there was a recognition of a need for greater awareness of both within the service context.

The recognition and value of death as a part of the clinical landscape was a consistent thread across the narratives of the professionals. During the process of recruiting participants to the evaluation email dialogue around the case study, death was often positioned within a contextual culture of wrong doing. Often framed within an "investigation" and all participants asked me (in some cases rhetorically) as the evaluator if in some way their actions or omissions of care had contributed to the death of Albert, Brenda or Colin. This continued influence of medicalisation moving beyond life and into death as Bakewell (2016 p228) interjects

> *"There's one consideration that you, medical people have left out, dedicated as you are to making the quality of old age better, and that is death. Statistics ...suggest that what people ...fear most ...is chronic illness and incapacity and mental illness. What our society needs to do is to talk about dying. Because it's waiting for all of us."*

The participants spoke of the importance of reversing illness and decline in old age, deferring death and therefore when death occurred it was viewed as a critical incident and in some cases a failure to cure. Karsoho *et al* (2016) discusses co-existence of two dominant logics at end-of-life; "dying well" promoted predominantly through palliative care professionals and "lifesaving" mainstream medicine whereby interventions are directed at curing disease with the central goal of preserving life and comfort care a secondary consideration. This interplay is evident in the case narratives. The overriding intention for Albert, Brenda and Colin was to cure or control the ageing process slowing down decline, holding back death. The narrative accounts reflected the influence of "lifesaving" medicine, and only in the case of Benda when her decisions to decline intervention drew her life to an end and death identified as imminent, were her choices recognised and enacted to support her wish to die at home gaining support from palliative care. For Albert and Colin their deaths were dominated by "lifesaving" dominant logic, with intensive emergency care intervention in the last hours of life.

Professional narrative accounts expressed sadness of their "unexpected" deaths and a desire to understand what went "wrong" in failing to "reverse death". The recognition of death and dying process in the care of older people is not a new area of concern. In 2011 the Health Ombudsman documented inadequacies of care for older people approaching end-of-life. Latterly, the need to balance competing influences of treatment modalities to preserve life alongside comfort and care within the context of an older person life was reviewed within the LCP (2013) indicating unlawful discrimination, with older people experiencing limited availability of the full range of end-of-life care options. The review of the LCP (2013) and recent Gosport scandal (Guardian 2018) reveal the inappropriate use of medication contributed to the premature deaths of many older people, furthering the societal debate around over-palliation of older people and the importance of maintaining duality with "lifesaving" approaches.

Increasingly there are calls from palliative care specialist to integrate a "diagnosis to death" approach to care (Murray *et al* 2017; Bone *et al* 2016) in response to unpredictable trajectories of health for older people living with non-malignant disease such as frailty. Central to this is the opening of discussion around end-of-life and advance care planning for older people who experience heterogenous decline and episodic care within the community (Bone *et al* 2016). ICT sits at the interface between secondary and primary care delivering care at a point of crisis; intervening to maintain the person's ability to remain at home and therefore places them in the frontline of managing frailty proactively. This context of care offers the potential to identify end-of-life, thereby instigating conversations around ACP. Communication around death, dying and ACP presented consistently within the narrative accounts resonating with wider professional and societal discourses. Grenier (2006), Lloyd-Williams (2007), Bravell *et al* (2010), Hurd-Clarke *et al (*2012), van Wijngaarden *et al* (2015) indicate that older people through planning and preparing for death assert autonomy as an expression of their final rite of passage and ownership of their own death. However, Albert, Brenda and Colin were not offered the opportunity to discuss and make ACP's. This is not uncommon in practice (Grenier 2006; Bravell *et al* 2010; Hurd-Clarke *et al* 2012; van Wijngaarden *et al* 2015). Barclay *et al* (2011) reported that healthcare professionals largely focus on disease management, and end-of-life care is rarely discussed as evidenced within the professional accounts.

6.1.4 Summary

The practice implications have centred around the process of care for frail older people and how medicalisation of ageing and death has resulted in process orientated, asynchronous technical care that seeks to diagnose and treat illness and functional decline within a deficit-based decision-making approach. Independence and risk management are the foci of decision-making with the aim of promoting active healthy ageing with an absence of end-of-life care. This approach is in part influenced by incongruence within policy related to frailty, care of the older person and NHS targets often orchestrated within medicalised perspective.

6.2 Theoretical implications of the evaluation

This component of the discussion will explore the theoretical contribution of the evaluation to understanding frailty within scope of critical realism. In doing so I will argue for an extension of active ageing to encompass an integrated perspective of end-of-life drawing on the fourth age as a tenet to aid understanding the completeness of frailty trajectories for older people. Finally, the discussion will be drawn together considering the concept of professional lenses that may blind clinicians to death as a natural part of an aged life within modern society.

6.2.1 Extending active ageing paradigms to encompass explicitly end-of-life

Active ageing emphasises the importance of older people to take responsibility for constructing a long and healthy life for themselves by maintaining an active engagement in a range of health promoting activities enabling them to live longer without care despite limitations and ultimately dying in their prime (Ponzo 1992; WHO 2002; Liang and Luo 2012; Zaidi *et al* 2013; Lloyd *et al* 2014; Bulow and Soderqvist 2014; van Dyk 2014; Lloyd *et al* 2014; Foster and Walker 2015 and Timonen 2016) and offers a clear paradox to the experiences of Albert, Brenda and Colin. As Vincent *et al* (2006) argues the future of ageing is uncertain; culturally bound, heterogeneity and diversity influencing normative expectation of ageing. The narrative accounts of Albert, Brenda and Colin demonstrate the influence active ageing paradigms had in leading powerful social change of attitudes towards ageing. The focus of active participation in everyday life and healthy ageing philosophies enacted in the decision-making of both professional and older person and at times led to a reactive approach at the end-of-life of their lives. It is widely acknowledged that the process of ageing is fluid and greatly influenced by the individual’s everyday life, where social status, wealth and economic variations impact on transition in old age and end-of-life. This evaluation does not contradict the underpinning tenet s of active ageing but calls for a recognition that death is a part of the landscape of ageing and through an integration of the constructs of end-of-life the care of older people may be more inclusive and meet their individual and family's needs.

Active ageing is closely aligned in practice to the ethos of rehabilitation as defined by the International Classification of Function as *"to achieve optimal functioning in interaction with the environment"*(Stucki *et al* 2007 p 279) often operationalised into service designs within health and social care. The ICT service remit echoes this, providing interventions to maintain physical health through assessment, treatment and rehabilitation in the patient's own home. In the case of frail older people this fails to acknowledge the interplay between loss, adaptation and accommodation of fluctuating episodes of decline and approaching end-of-life in a co-ordinated, proactive manner (Bravell *et al* 2010; Health Ombudsman 2011; Healthwatch 2013; van Wijngaarden *et al* 2015; Nicholson et al 2012, 2017). The accounts of care for Albert, Brenda and Colin illustrate this disjuncture in the experience of frailty and appropriateness of care approaches as they approach their end of life. Emerging palliative care philosophy and practice has recognised the role of active ageing strategies in end-of-life, with an emphasis to *"enable people with life-limiting and terminal conditions to live as independently and fully as possible."* Hospice UK (2015 p2). Hospice UK (2015) cite there pervades a reductionist view of rehabilitation as solely associated with recovery whilst contrastingly palliative care centring only on death and dying. Therefore, this has led to a reluctance to integrate the concepts within policy and practice. The impact of this reluctance has led to professional misunderstandings of how they may align thereby gatekeeping opportunities for patients to experience enhanced integrated care at end-of-life (Leslie *et al* 2014; Maddocks and Payne 2015; Platt-Johnson 2007).

The aim of active ageing is to maintain and promote health, this premise is shared with palliative care. Within palliative care the focus moves from recovery to maintenance of quality of life, with habilitation rather than rehabilitation central to care (Hospice UK 2015). Habilitation as an emerging concept offers the opportunity to integrate supportive and palliative paradigms into active ageing policy and practice. Habilitation as proposed by Jennings (2013) recognises that care focuses on improving quality of life, enabling active participation in valued activities of daily living without the unrealistic expectation of returning to previous levels of function. The professional accounts of decision-making often discussed the importance of establishing and returning to baselines of physical function and reducing risk as a precursor to intervention goals with active participation an expectation. In contrast, Hospice UK Rehabilitation Strategy (2015) affirms that within palliative care the aim is to improve participation in everyday life where the person has the capacity and desire to engage. Essential in this approach is SDM in recognising the transition toward end-of-life when deterioration is inevitable thus leading to integration of rehabilitation, habilitation and palliation.

6.2.2 Integrated paradigm of active ageing

The findings of the evaluation indicate towards the need for an integrated approach to frailty, considering end-of-life as a transitional process within active ageing paradigms. It is evident in evaluating professional decision-making that frailty is transitional in nature and encompasses a wide spectrum of care needs including early intervention and end-of-life-care. A transitional approach to frailty as I have proposed in diagram 6.1 embraces the two dominant logics in end-of-life "lifesaving" and "dying well" in synergy (Karsoho *et al* 2016), rather than as competing ideological spheres for the professional in managing the tension between service remit, patient and professional expectations of frailty, ageing and death (Gilleard and Higgs 2010).

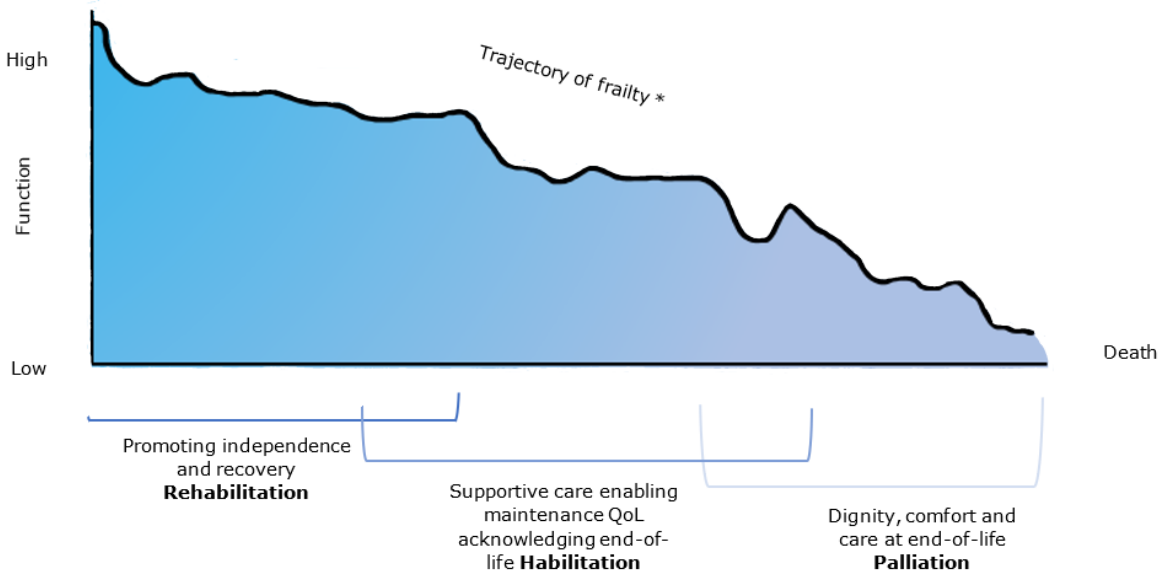


Diagram 6.1: Transitional active ageing paradigm that encompasses end-to-end trajectory of frailty.

* An illustrative example of frailty – it is important to recognise that trajectories are not universal and are influenced by the individual and their circumstances.

The medical and societal discourses around frailty focus on the importance of healthy active ageing; health and social care strategies promoting personal independence thereby reinforcing the importance of autonomy and agency in ageing successfully (WHO 2013; NHS Five Years Forward 2017; General Practice Forward View 2016) and is incorporated into the proposed paradigm as the emerging transitional phase of frailty above as depicted in CFS levels 1-5. The aim of intervention in this phase promoting recovery through rehabilitation, therefore being consistent with active ageing and the core focus of ICT.

The accounts reported ICT aims as "*enabling independent living*" or "*returning to their previous level of fitness*", whereby "lifesaving" logic heavily influenced decision-making. However, for Albert, Brenda and Colin patterns of deterioration, increasing episodes of acute illness were described as "*shifting of baseline further back each time*". It could be argued Albert and Colin within the proposed transitional active ageing paradigm had moved into the supportive care phase, where a habiliative approach would be situated CFS levels 6-7. The provision of personalised enablement and care to maintain quality of life, through chosen participation in meaningful areas of everyday life, importantly acknowledging death and dying therefore mediating the dominance of "lifesaving" logic towards "dying well" logic and palliation.

The final transition of the proposed transitional paradigm is palliation (Levels 8-9 Frailty Index Rockwood *et al* (2005) 2007-2009. Version 1.2) and is where Brenda's story of care resonates. For Brenda the dominance of the "lifesaving" logic greatly influenced professional's decision-making and attitude to care therefore failing to provide a personalised, proactive plan for end-of-life. Instead the final weeks were depicted in the accounts as tense and fraught. Only with the actions of one nurse in connecting with Brenda and respecting her choices did the path of care change. Within the professionals' narratives who supported her during the final week of her life the importance of dignity, comfort and compassionate care as essential in ensuring her good death was shared, with the dominance of "dying well" logic influencing care decisions.

The proposed adaptation to the active ageing paradigm is tentative and requires more extensive investigation to fully articulate the transitional stages, implications for theory development and practice contexts contributing to a broader understanding of frailty.

6.2.3 Critical realism lens of frailty at end-of-life

The final section returns to explore critical realism, arguing for a transitional end-to-end view of frailty thus providing critique to the medicalisation of ageing, frailty and death that has contributed to professional blindness of normalcy of an aged death.

Taking a critical lens examining accounts of supporting frail older people, the evaluation highlighted with clarity the dominance of positivist ontology operating in health and social care micro environments. Shaping professional ideological positions, influencing their decision-making around the care of frail older people and echoes the dichotomies of ageing presented by Liang and Luo (2012); Lassen and Moreira (2014); van Dyk (2014); Nosraty *et al* (2015) and Timonen (2016)- whereby there is a paradoxical in promoting autonomy and independence amongst a group of people who are simultaneously depicted as vulnerable and dependent. This paradoxical position was equally apparent in the decision-making process of professionals as evidenced the importance placed on mental capacity in decision-making and active participation in rehabilitation.

In addition the value of singular forms evidence to underpin decision-making through protocols, assessment and observation to catalogue illness and functional markers of old age is accepted as common practice. The overriding aim of practice is to ameliorate these, to hold back death a little longer. To seek universal outcomes for all despite recognising the importance of personalised care. The accounts reveal the medicalised premise of care, common use of technical language such as "*mental capacity*", "*reversibility*" "*CEW's*" documenting the person through the practice lens of evidence to support decision-making. The professionals rarely spoke of psychological, emotional or mental health needs. Instead their accounts were dominated by the physical, bodily functions of Albert, Brenda and Colin; with a focus on curing the broken part of the body therefore not considering the totality of the person or context of everyday life in navigating frailty and approaching death.

Within decision-making the application of knowledge alongside experience punctuated the narrative accounts where professional ideologies and personal values collide. For some professional's the increasing awareness of ageing and death through caring for family members interjected into their professional consciousness influencing approaches to practice and challenging the dominance of a medicalised view of ageing and death. Pastrana *et al* (2008), Zimmerman (2012) and Arber (2008) discuss the absence of personal perspective of end-of-life as often emanating from a necessary conformity of modern healthcare that relies on coherent decision-making across team and service contexts. Incongruence remains in practice where holistic personalised approaches can be reduced to protocol driven care that is more amenable to a practical medicalised view of care thereby obscuring the personalised lens. End-of-life is reduced to generalisable markers of physical decline and protocol driven symptoms control which can be controlled therefore delaying death. Importantly the evaluation gave voice to frail older people and through their accounts professionals articulated the importance of personalising care, approaching a broader rehabilitation context, for some this resonated deeply in returning to the roots of professional ideology and values exposing what had been obscured by a dominant medicalised culture of care.

Operationalisation of policy and practice of active ageing was evident in considering how death and dying were approached within ICT. The organisation of care leading to the invisibility of death in practice and therefore professionals only recognising the final week or days of life in clinical practice, often discharging the patient to other services as soon as they can. The narrative accounts situated end-of-life and palliation as best provided by the experts of care such as palliative care services and not within the realms of ICT, again blinding professionals to the normalcy of death within clinical practice. An acceptance of the normalcy of death within clinical landscape was viewed by the professionals as essential in enabling ICT to learn from the experiences of death and dying within their service context moving beyond a culture of failure to cure, toward an open dialogue of death as part of the care of frail older people (Timonen 2016).

In returning to consider frailty as transitional, it provides an opportunity to evaluate active ageing and the boundary between the third and fourth age from a different perspective contributing to broader understanding of frailty, ageing and death. Gilleard and Higgs (2010) and Lloyd *et al* (2014) propose people leave the third and enter the fourth age when it is determined by others that they are no longer able to manage their everyday lives. Twigg (2006) and Lloyd *et al* (2014) discuss the contrast between third and fourth ages highlighting that the closeness of the fourth age to death may explain why the period is characterised as devoid of personal meaning, confounded by experiences of loss. The narrated stories of Albert, Brenda and Colin place them at the intersection between the third and fourth age however rather than a clear boundary the accounts reveal a transition when living with frailty. Albert's story of care documented his deterioration and in the final episode of care he was depicted as holding transient personal agency and meaning fluctuating with the ebb and flow of the pattern of illness and recovery that had characterised the last 18 months of his life. For Colin the story of care transitioning towards the fourth age narrated an extended hospital stay as contributing to an increasing level of frailty and vulnerability however the professionals spoke of Colin's valued role within the family and desire to remain at home adapting to his fluctuating levels of ability to participate in everyday-life. For Albert and Colin the professionals' story of care depict a different experience of third and fourth age to those of proposed by Lloyd 2000; Lawton 2000; Nicholson *et al* 2012 and West and Glynos 2016 as devoid of personal meaning.

Social construction of the fourth age has been characterised by theories, gerontologists and researchers as one that depicts a loss of personal agency, bodily self-control with ever increasing difficulty in adjusting to losses in later life (Baltes and Blates 1990; Baltes and Smith 2002; Gilleard and Higgs 2010; Lloyd *et al* 2014 and West and Glynos 2014). In contrast the narrated account of Brenda spoke of her personal agency in declining treatment, refusing intervention and equipment and preference of family to provide her care. The professionals spoke of Brenda vocalising her acceptance of end-of-life and welcoming of death. However, it was the professionals who struggled to accept her decisions and reconcile their personal and professional ideologies to recognise Brenda's choices at end-of-life. The demarcation between the third and fourth age therefore resonated in the stories of professionals more so than the accounts of care for Albert, Brenda and Colin which indicated a more transitionary process. Lloyd *et al* (2014) asserts that active ageing as an ideological framework underpins healthcare priorities and expectations reinforcing a moral precedent on older people to remain self-reliant. Gilleard and Higgs (2010) argue there is often a contradiction in practice for professionals in addressing unsuccessful ageing and blinding them to the normalcy of an aged death. Where death is situated as being meaningless and the preservation of life being sacrament within modern secular society (Twigg 2006 and Lloyd *et al* 2014).

6.2.4 Summary

A transitional understanding of frailty offers a critical lens through which to recognises the individual needs of older people; one that embraces a wider societal dialogue around active ageing and end-of-life as synonymous tenet s underpinning research, policy, practice in responding to the challenges of a global demographic ageing profile.

Conclusion, limitation and recommendations

The chapter draws together the evaluation to present final conclusions, reflecting on the limitations of the evaluation and providing a summary of the key implications for future practice. The stories of care were told by caring, motivated, passionate professionals who were clearly driven to provide the best care for the patients that encountered ICT services- speaking with an honest reflective approach and a willingness to learn from the experience of the evaluation. They spoke of a desire to change practice for all frail older people including those who are approaching end-of-life, recognising that the service needs to move beyond its current diagnosis focus and embrace a broader interpretation of holism.

7.1 Conclusions

- The UK has an ageing population. As people age, they are progressively more likely to live with complex co-morbidities, disability and frailty. However, living longer does not equate to living well. Negotiating the transactions of everyday life in an aged frail body impacts across a person's life and influences how they approach death.

- The paradigm of active ageing underpins national and local organisational policy and thus influences practice. Policy agendas are rationalised through healthcare service contexts, thereby focusing on promoting independence, reversing illness and functional decline through a medicalised lens of practice. Professional accounts reveal a tension, whereby the culture of care dominated by a medicalised lens of ageing and death is translated into process-driven personalisation, with decision-making focused on the reversibility of illness to sustain life.

- Death in clinical practice is viewed as a failure to reverse ageing, therefore remains hidden from view limiting opportunities to develop clinical decision-making skills in this aspect of practice to deliver planned and responsive end-of -life care.

- By taking a critical realism lens the accounts reveal a transitional trajectory of frailty, one that encompasses a broader consideration of the intersection between the third and fourth age. Therefore, offering the opportunity to consider active ageing from a different perspective contributing to broader understanding of frailty, ageing and death.

- Frailty is characterised by a transitional process of adaptation to loss and therefore a broader interpretation of the space between the third and fourth ages in practice would allow for end-of-life care to be planned proactively along a continuum.

7.2 Limitations of the evaluation

The evaluation sought to explore frailty, ageing and death through the narratives of healthcare professionals to evaluate the influence of policy, practice and professional perspectives upon the delivery of end-of-life care; in doing so the limitations must be acknowledged.

1. The most significant issue is the omission of the older person from the narrated accounts of care further contributing to the marginalisation of older people from contributing to research, evaluation and development of policy underpinning health and social care. There were multiple organisational and societal barriers presented in accessing older people and the difficult but pragmatic decision to alter the course of the doctoral investigation resulted in a loss of contribution of the older person. This has deeply resonated throughout the evaluation process therefore the analytical process places emphasis firstly on the narrated story of care for Albert, Brenda and Colin. However, it must be recognised that the narrative accounts should not be offered as a substitute voice to frail older people but are a descriptive lens into the everyday life of living and dying an aged death as told by the providers of care, and are therefore influenced greatly by differing professional discourses.

2. It is essential to acknowledge that the evaluation is context specific to ICT and therefore the remit of the service has been determined by the priorities of the local clinical commissioning group for the geographical area and may have influenced in part the way care is organised and delivered. Within the evaluation process therefore it is important to recognise both national and local policy and practice influences that inform care of frail older people.

3. The professional accounts included AHP and nursing perspective and although medical staff were invited to participate none chose to. ICT is delivered within multi-professional team approach including doctors therefore to provide a truly representative account a medical perspective would contribute greatly to further

understanding the complexity of care and underpinning decision-making influences.

7.3 Recommendations for practice, research and policy

Whilst acknowledging the evaluation limitations the findings have contributed to a broader understanding of frailty, ageing and death. Although the evaluation is context specific the recommendations resonate across local and national research, policy and practice areas to inform the approaches in supporting frail older people.

Recommendation			Rationale
Practice- based	1	To develop workforce skills to assess and plan care using the complete CGA as the basis of personalised care.	Using the CGA framework by skilled multi-professionals requires investment in staff development and resources to deliver. The use of the CGA encompasses a broader consideration of the older person including physical, pyshco-social and environmental challenges and resources and therefore provides a more holistic perspective of the person to inform care planning.
	2	To incorporate routine identification of frailty within the initial assessment process as specific diagnosis to inform care organisation.	To meet the 5YF ambitions (NHS England 2017) in identifying frailty as a discrete diagnosis and develop professional recognition of the incidence and prevalence within the service context.
	3	To develop workforce skills to identify and manage frailty trajectories including end-of-life utilising the S4H core capabilities framework	To ensure professionals are appropriately equipped to manage the whole trajectory of frailty within the community and develop clinical decision-making skills required.
	4	To review the organisation of care considering continuity and personalisation providing ALL	To respond to the preferences of older people as indicators of high quality care as being personalised, continuous

		professional groups with an equal opportunity to contribute to the discussion	and integrated. High quality care relies on effective integrated multi-professional working, differing professional perspectives need to be recognised and valued to challenge the medicalisation of frailty, ageing and death.
	5	To consider AHP leadership of rehabilitation within service to incorporate broader remit of delivering personalised care	It is recognised that AHP are highly skilled experts in delivering personalised holistic care with an underpinning professional culture that bridges nursing, medical and social perspective. AHP are cited to be informed risk takers drawing in and engaging the unique skills of differing professions to lead innovative service delivery. (Jennings 2013; Hospice UK 2015 p45). In developing leadership roles these need to be of sufficient seniority to influence change across the organisation of care.
	6	To develop workforce skills in taking a proactive approach to advance care planning with frail older people	To provide opportunities and training to supplement an augmented community approach to advance care planning using the locally developed trust-based tools therefore equipping older people with the information and support to consider their needs and preferences at end-of-life.
	7	To develop workforce skills in identifying earlier the end-of-life care needs of frail older people and developing appropriate pathways of care within a generalist community team approach.	The use of recognised toolkits such as NHS (2017) “Find your 1% at end-of-life” to ensure a service-wide approach to the identification of people approaching end-of-life incorporating specialist palliative care and community teams in developing a co-

			ordinated approach to care of frail older people. Embedding communication skills and supportive care approaches to enable an open culture of acceptance of death and dying in supporting frail older people.
	8	To underpin the assessment process of practice within SDM	To implement service wide training and support to practice SDM including the revision of templates to emphasise the importance of considering the patients preferences and long-term needs (as identified within the CGA).
Policy	9	Policy development as a balanced approach to active ageing that recognises and values the transitional process of frailty towards end-of-life.	To provide critique to the prevailing dominance of active ageing through publication and dissemination of evaluation findings. Highlighting the importance of a professional dialogue around integration of “lifesaving” and “dying well” logic to inform policy making.
	10	Develop and implement a local policy for the end-to-end management of frailty incorporating rehabilitation, supportive care and palliation.	To utilise the NHS integrated frailty pathway and evaluation findings to implement a frailty pathway across primary and secondary care to improve the quality of care provided to older people.
	11	Inclusion of SDM within frailty pathway	To provide coherence between NHS policy guidance on EoLC, frailty and care of older person embedding SDM within the integrated frailty pathway.

	12	Explicit inclusion of end-of life-care policy within NHS constitutional reform and review of priority setting for 5YF ambitions (NHS England 2017)	To review and reintroduce national strategy for EoLC as a basis for NHS constitution ensuring that this aspect of service provision is explicit within 5YF (NHS England 2017) ambitions review.
Research	13	Through co-production raise the voice of older people in establishing their experience of frailty and priorities for care in transitioning towards end-of-life.	The voice of the older person is critical to understanding and designing services that meet their needs and provides critique to the dominance of the medicalisation of ageing and end-of-life.
	14	Develop an understanding of ACP for frail older people	To investigate the role and nature of ACP strategies with frail older people to understand potential contribution in EoLC planning to support SDM.
	15	To develop research opportunities that explore the idea of a "life complete" for frail older people and their attitudes towards end-of-life.	The voice of the older person is critical in exploring fragility, completeness of life within the context of increased longevity of life providing a lens to appreciate what matters in the lives of the very old.
	16	To further develop the transitional approach to frailty incorporating rehabilitation, habiliation and palliation.	To provide an opportunity to explore the transitional approach to understanding frailty and potential phases that may inform clinical practice to support older people across their life course.

Table 7: 1 Recommendations for practice, policy and research

7.4 Summary

The evaluation recommendations focus on developing the competencies of professional decision-making by utilising recognised tools to support the identification of frailty as a discrete condition, so that care planning can be responsive and target to the needs of the older person. The use of the CGA supports this process by guiding professionals to consider the holistic needs of the older person within the context of everyday life including end-of-life-care and relies of a participatory approach to shared-decision making. In order to achieve this, there needs to be investment in developing the leadership of all professional groups especially AHP in contributing to Frailty pathways within the trust, thus ensuring the care is targeted at the three core transitional phases of rehabilitation, habilitation and palliation. In doing so the divergence between policy and practice can be challenged thus incorporating end-of-life care explicitly into NHS organisational goals for older people. In addressing this divergence further research is necessary to underpin a greater depth of understanding of the experience of frailty and the priorities of older people as they approach end-of-life thus contributing to professional knowledge in decision-making.

Epilogue

This thesis began with my narrative of the death of my Grandpa, he died in 2000 and in the following eighteen years my Grandma has lived alone in the home they shared. She is now 90 years old and until the last three years could be seen walking the street of the village helping the old people. She is now the last of her generation, all her friends and family of the same generation are long gone before her. She has grieved every one of them, reminding her that she still has life to live. The last three years however, have been a different. She has gone from being able to take care of all her own needs to relying on family to support her every day. I have been inside the space between the third and fourth age.

The last year has been the hardest, countless admissions to hospital following a series falls, she has been operated on five times in the last year alone to fix the components of an aged-body, but she has now said no more. Each time the part has been fixed to some extent, but as a consequence causes an issue elsewhere in her aged body. Sepsis took hold of her and has ravaged her body and to some degree her spirit lost the fight, although her body is healing.

Now time is achingly slow, as the days drift into one another she struggles to hold on to the routine of everyday life. The difference being this time I could see it coming, we have a plan, we have talked with Grandma about what is important to her and what her choices are as she continues to age. I perhaps have had the deepest of conversations with her, we have spoken about death and I get the sense that she feels ready to die, when it comes it will be welcomed and not desisted. We will grieve for her, as she is the core of our family, but we are resolute that we have done our best and that she will have lived a life to the fullest and chosen the path of death that is in keeping with her well-loved life. All we must do now is get the professionals to listen to her decision.

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Appendix One

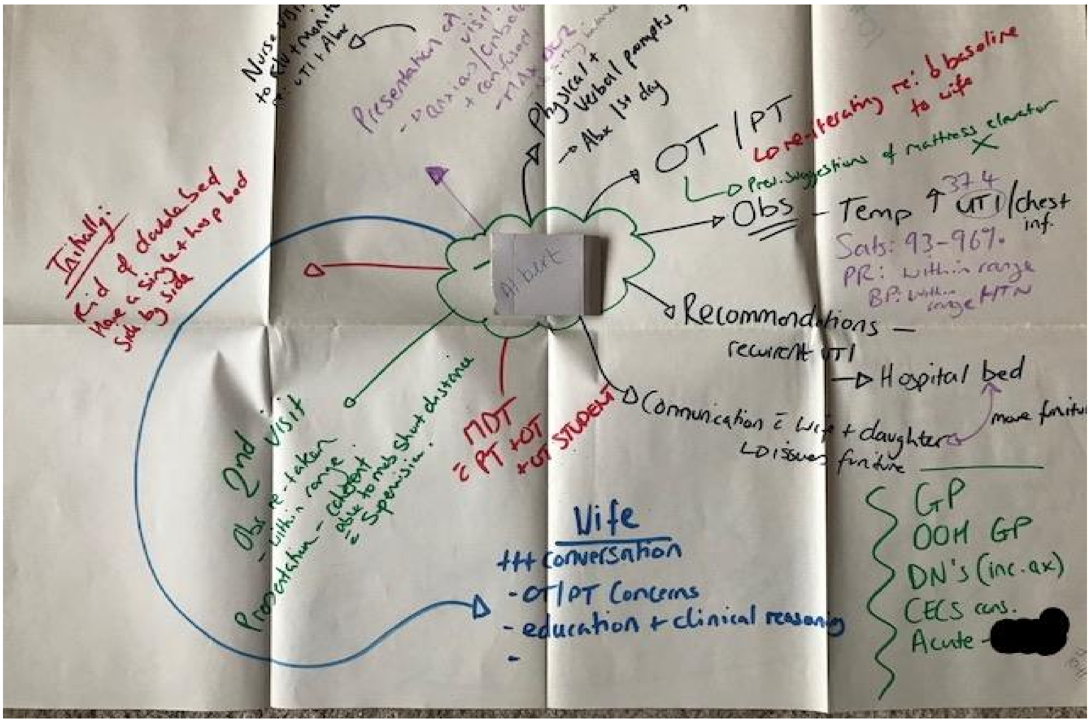
Documentation review tool

Case reviewy: *Overview of case:*	
End of life care benchmarking	
Audit Item	*Comments*
Five priorities care of dying 1a. Recognition that person is dying and communicated clearly 1b. Decision about care are in accordance with preferences, needs and regularly reviewed 2. Sensitive communication takes place between staff and the person who is dying and those important to them. 3. The dying person, and those identified as important to them, are involved in decisions about treatment and care. 4. The people important to the dying person are listened to and their needs are respected. 5a. Care is tailored to the individual and delivered with compassion 5b. An individual care plan in place	
Documentation of ACP	
Documentation of DNAR (if appropriate)	
Discussion preferred place of death	
Achieved preferred place of death	
Frailty Benchmarking	
BGS Frailty Guidelines 1. Diagnose underlying illnesses and formulate care plan 2. Review medication 3. Define impact of frailty on daily life including carers input 4. Design an comprehensive individual care and support plan 5. Identify maintenance plan 6. Access points for escalation if deterioration 7. Urgent care plan (including hospitalisation)	
Common Geriatric Assessment 1. Medical domain a. co-morbidities and disease severity recorded b. Medication review undertaken c. Nutritional status reviewed d. Problem list made 2. Mental Health a. Cognition b. Mood and anxiety c. Fears 3. Functional Capacity a. Basic activities of daily living b. Gait and balance c. Activity/exercise status d. Instrumental activities of daily living 4. Social Circumstances a. Informal support available from family and friends b. Social networks such as visitors and day time activities c. Eligibility for being offered care resources 5. Environment a. Home comfort b. Facilities available c. Safety	

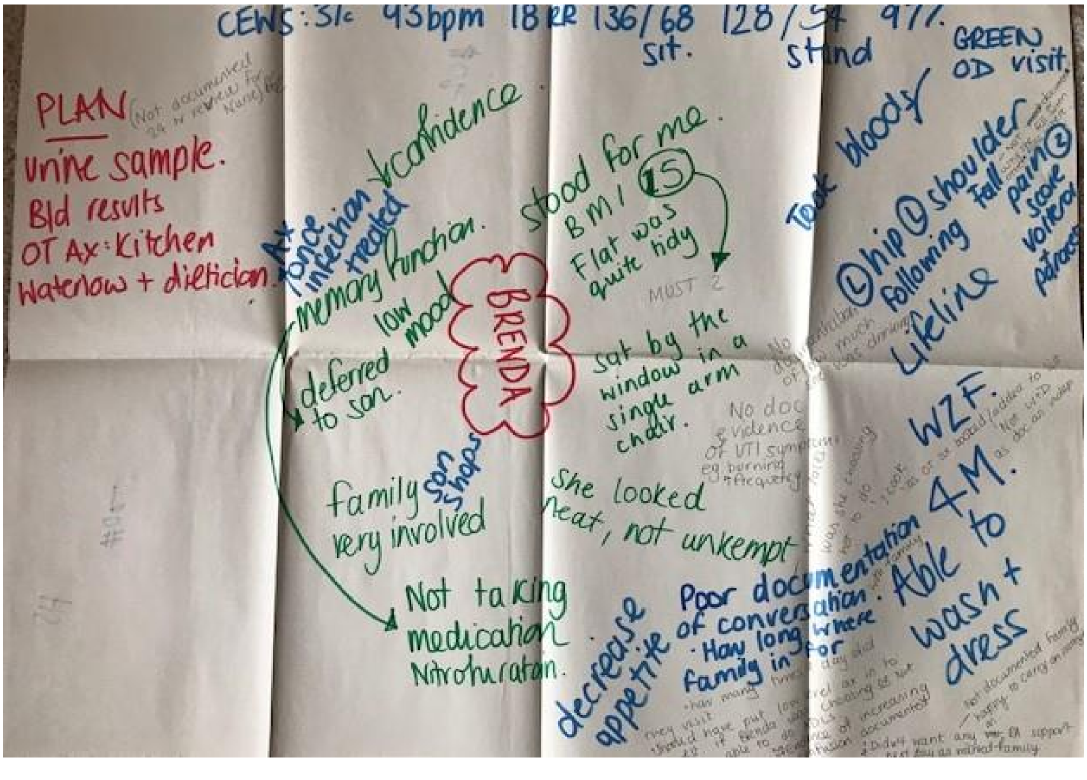
Appendix Two

Illustrative examples of care maps from interview

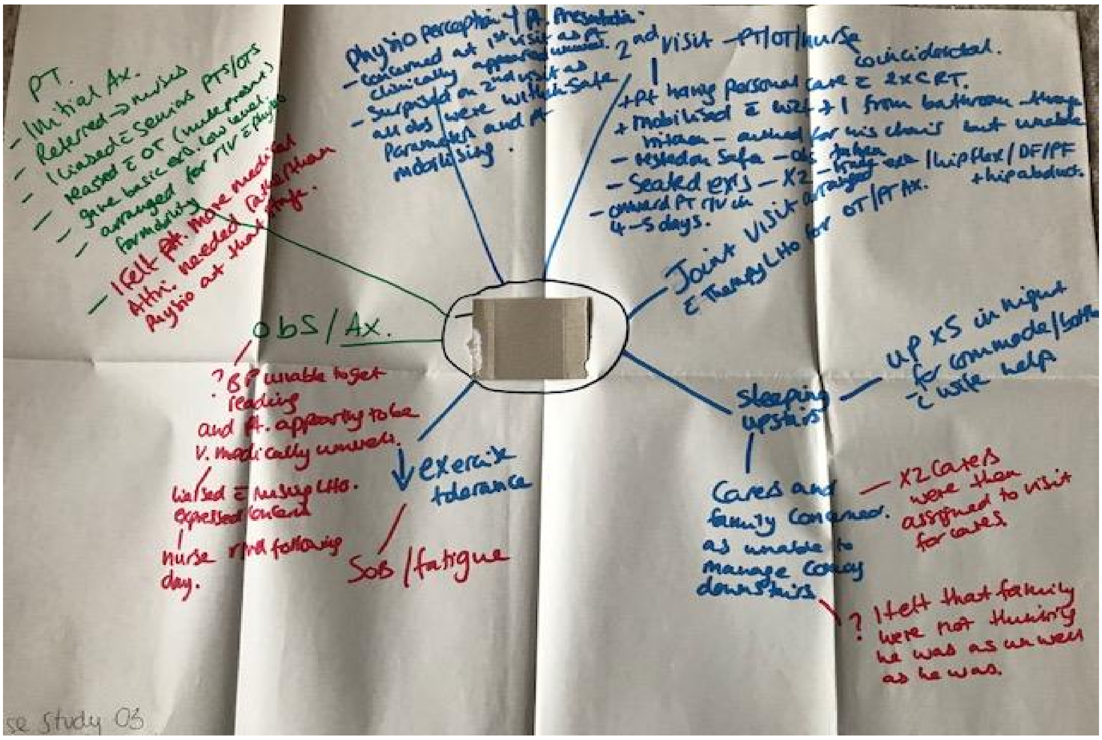
Example of participant care map from case review 1



Example of participant care map from case review 2



Example of participant care map from case review 3



Appendix Three

Participant information

Professionals Participant Information Sheet

THE UNIVERSITY OF NORTHAMPTON

Evaluation of end of life care provided to frail older people.

We invite you to take part in a research study.

Please take the time to read the following information carefully before you decide whether to take part in the research. It is important that you understand why the research is being done and what it will involve. You are free to decide whether or not to participate in this research. Please feel free to ask the researcher if there is anything that is not clear or if you would like more information.

Why are we doing the study?

This study seeks to understand the experience of care provided to frail older people. We are gathering the views of health and social care providers in order to explore how older persons needs are determined and what their experiences of care are with the aim of informing future service planning.

The research is using a case-study approach and you have been identified as part of the health and social care team for an identified deceased older person and are therefore being invited to participate.

If you take part you will provide us with important information to help understand the needs of older people and their carers' and how these are currently met within Northamptonshire health and social care services.

What will I be asked to do if I agree to take part?

Participation in the research involves taking part in a one to one interview. The interview will last approximately 60 minutes. The interview will be audio-recorded. The research is using a case-study approach and therefore the questions will ask you to consider the care of a specific older person who accessed care prior to death from within your area of practice.

Contents

How to contact us

If you have any questions about this study please talk to the researcher who organises it:

Kim Stuart

(01604) 892915

kim.stuart1@nhs.net

The researcher will ask you questions about your experiences of working with the identified older person including how their needs and priorities of care were established and anticipated at end of life. The interview will be audio-recorded and held at a convenient location and time for you.

The focus of the interview will be:

1. Discussion of the your role in end of life care and how it is determined within the service
2. Consideration the underpinning ethos and focus of care within your role in end of life care delivery
3. Exploration of how the older person and carers needs and or wants were considered within delivery for your service.

A copy of the interview will be sent to you to read and if you wish you can add comment on them. These will need to be returned to the researcher in a pre-paid envelope.

What are the possible effects of taking part?

There are no anticipated physical risks to you by taking part; you are free to choose to participate and can withdraw from the research until the transcripts have been returned to the researcher.

Whilst the research is focusing on your provision of care for the identified older person the over-arching topic is end of life and this is a sensitive topic area. The researcher has experience in working in end of life care within health and social and is able to provide immediate support in the interview and can signpost to support services following the interview should the need arise. You can choose to cease the interview at any time.

What will happen with the results of the study?

A final report will be produced as part of the researchers Professional Doctorate and upon successful completion the results will be shared with the Northamptonshire Healthcare Foundation Trust with the aim of developing future services.

A summary of the research will be reported to the Research and Development network within Northamptonshire to share the outcome and recommendations in addition the findings may be more widely disseminated through presentations and peer-review publications.

You will be asked if you wish to receive a copy of the summary by the researcher Kim Stuart.

Research Team

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Support contact information

- CRUSE Northamptonshire 0844 477 9400
- NHFT – support available via Occupational Health (01536) 494736

Appendix Four

Application of taxonomy of vulnerability in biomedical research

Research Process	Ethical Issue	Vulnerability taxonomy					Strategies to address
		Communicative	Institutional	Deferential	Medical	Social	
Case Study identification	Ensuring deceased patient anonymity			✓		✓	No identification of patient identity Use of NHS ID only Use of pseudonym in case study reporting
Review of clinical notes	Identifiable case study information			✓		✓	No identification of patient identity Use of NHS ID only Use of pseudonym in case study reporting
	Data collection onsite		✓			✓	Use of computer on site at local trust Individual log-in to access patient data Record of log-in held within patient records ensuring transparency of access Research passport and trust access secured Identification of evaluator onsite during data collection phases
Consent	Appropriate timely information	✓	✓	✓	✓	✓	Evaluator dialogue Participant Information Sheet
	Support	✓	✓		✓		Evaluator dialogue

							Participant Information sheet sign-posting
	Monitoring signs of possible distress	✓		✓	✓		Evaluator clinical skills and professional experience in recognising and managing emotional distress Suspension or cessation of interview
Confidentiality	Maintain interview anonymity and confidentiality	✓	✓	✓		✓	All potential participants are communicated with individually Participation is confidential Participants were anonymised, and pseudonym assigned Only professional designations are reported
	Maintain patient anonymity	✓	✓	✓		✓	Interviewee free to use patient’s name during the interview but during transcription these were pseudomysed. Interview recordings were deleted once analysis was completed.
	Maintain associated staff and patient relative’s anonymity	✓	✓	✓		✓	Interviewee free to identify patient’s relatives name during the interview process but during transcription these were pseudomysed. Any members of staff that were identified by name during the interview process were referred to as professional designation only during transcription. Interview recordings were deleted once analysis was completed.

Interview	Monitoring signs of distress	✓		✓	✓	✓	Evaluator clinical skills and professional experience in recognising and managing emotional distress Suspension or cessation of interview
	Emotional burden	✓		✓	✓	✓	Evaluator clinical skills and professional experience in recognising and managing emotional distress Funnelling approach to interview questions Suspension or cessation of interview Sign-posting support services within local trust and service area
Safeguarding	Identification of practice concerns	✓	✓		✓	✓	Evaluator clinical skills and professional experience Access to clinical lead to discuss any concerns Adhere to local trust and professional standards
	Post interview support for participants	✓			✓	✓	Sign-posting support services within local trust and service area
Distributed benefit and risk	Report dissemination		✓	✓		✓	Ensure that the dissemination of the report is handled sensitively to the context of ICT
	Communicating practice implications		✓	✓		✓	Discussion with the clinical lead the practice implication and avenues to disseminated within local trust