Identifying social and interpersonal influences on frailty trajectory, self-management and personal responses to change

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Abstract

Background: 'Frailty' means different things to different people but is used in healthcare to reference a specific presentation. A concept analysis exploring how different stakeholder groups conceptualised frailty suggested older people may understand the antecedents, attributes and consequences of frailty differently to health and social care professionals. The influence of social factors on frailty has gained attention as the rhetoric around Ageing Well focuses on prevention and the role of the wider 'neighbourhood'. A scoping literature review indicated a paucity of UK-based research into social and interpersonal influences on frailty trajectory, self-management and personal responses to change.

Aim: This study aims to address this gap by identifying social and interpersonal influences on frailty trajectory, self-management and personal responses to change in a UK-based community setting. By identifying these influences, systems of health and care may better manage frailty as a holistic condition.

Methods: A 12-month longitudinal study, using qualitative interviews and participant diaries. Recruitment was through Integrated Neighbourhood Teams. Five interviews were completed between two participants, and transcripts thematically analysed alongside participant diary data. Frailty status was assessed following each interview and a Clinical Frailty Score recorded using participant accounts of their own health and support needs, and researcher observations.

Analysis: Transcripts were reviewed against the 6 domains of the frailty fulcrum. Trajectories of continuity or change within each domain were considered longitudinally, within participants accounts.

Outcomes: Frailty remained consistently high within some domains whilst simultaneously lower in others. Frailty levels in the 'systems of care' and 'physical environment' domains remained high, whilst in the 'psychological status' and 'social environment' domains progression was slower. Strategies, resources and interpersonal influences on anticipating and responding to change were highly personal. This study contributes to the growing

evidence that acknowledgement of social and interpersonal influences on frailty, may enhance care opportunities.

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Abbreviations

ADL – Activities of Daily Living

BADLs – Basic Activities of Daily Living

BGS – British Geriatric Society

CFS - Clinical Frail Scale

CGA – Comprehensive Geriatric Assessment

DES – Direct Enhanced Service

DoH – Department of Health

eFI – Electronic Frailty Index

EFS – Edmonton Frail Scale

FI – Frailty Index

FP – Frail people/person

GP – General Practitioner

HRA – Health Records Authority

IADL - Instrumental Activities of Daily Living

IRAS – Integrated Research Application System

MCA – Mental Capacity Assessment

NHS – National Health Service

NICE – National Institute of Clinical Excellence

NSC – Non-specialist clinicians

ONS – Office of National Statistics

OT – Occupational Therapist

PAM – Patient Activation Measure

PIC – Participant Identification Centre

PIP – Participant Information Pack

PEO – Person-Environment-Occupation Performance

POA – Power of Attorney

QOL – Quality of Life

RCOT – Royal College of Occupational Therapists

REC – Research Ethics Committee

SNOMED-CT – Systematized Nomenclature of Medicine – Clinical Terms

UEA – University of East Anglia

UK – United Kingdom

VAS – Visual Analogue Scale

WFOT – World Federation of Occupational Therapists

WHO – World Health Organisation

Dedication and Acknowledgements

I am grateful to my endlessly encouraging and knowledgeable supervisors Prof. Fiona Poland and Dr Linda Birt, whose experience and guidance have kept me going every step of the way. I would like to thank the teams who supported the identification of participants, without whom this study would not have been possible. And of course, 'Susan' and 'Margaret'[1] who so graciously welcomed me into their homes and shared insights into their lives to support this study. A special mention also to my husband and family – without you I could not have worked towards this ambition.

Use of names

For ethical reasons the participants in this study have been anonymised. I chose to retain a sense of personhood in reporting participant accounts by using pseudonyms selected from records of the UKs most popular names for each participant's birth year in acknowledgement that names anchor a person in their own generational and cultural context. No gender changes were made.

Professionals identifying potential participants for this study using a script and checklist are referred to as 'Triage Professionals' to avoid identifying any individual or profession. Where the involvement of professionals - either current or historic - has been described within participant accounts, names of professional roles have been retained to reflect the nuance and complexity of interpersonal relationships, although individual names or identifiable details have been removed. Multiple recruitment sites were used across an Eastern Coastal region. Location details for the included participants have been removed.

A reflexive journey

Sitting at a dimly lit desk at my family home, I'm looking for a place to start in describing the journey of last six years of my doctoral study. My life and career have been so intrinsically entwined into this doctoral process, that I cannot truly write this final piece without including something of myself as clinician, as a developing researcher and now from an entirely different career space in the process. Just as my participants are real people bringing real experiences to this study, I must also acknowledge my own presence in this process and my own reflexivity and development running parallel (perhaps interwoven) with the research process.

[1] Pseudonyms used throughout this paper to protect the true identities of these two women

I began this exploration as a part time Occupational Therapist in a newly formed 'Frailty Service' – new and unfamiliar territory for the whole team. The doctoral journey for me started with an ambition to fill the blank canvas of clinical practice in frailty with all the colours of what evidence based, person-centred frailty care could and should be. With one foot at the time still in the role of 'new mum' and one stepping back part time into my career, starting this doctorate was a response to the 'newness' of both my personal circumstances and to frailty as a clinical area – an opportunity to build strength, whilst reaffirming my sense of self alongside parenthood. Back in 2019, the new doctoral student queuing for a campus ID card with a blank notebook in hand could never have foreseen what the next six years would hold. – from the reality of being a key worker doing home visits through a global pandemic and all it might mean for the most vulnerable people at the heart of my study, to the doors opening for me professionally and all affecting my family life and career. This would shape me both professionally and personally and continuously challenge my thinking often unexpectedly. When I later found I was working in a more system-focussed space I was then able to draw upon my journey to challenge others' thinking about how best to consider frailty.

For the sixth, and hopefully final summer I'm at my laptop with the blinds down, while the sun determinedly fights through the gaps at the edges and I can hear the bustle of family life around me. I'm trying to harness the mental whirlwind of all I have read, heard and experienced through six years of study and am looking for those elusive 'right' words to do justice to the time invested by the people who graciously invited me into their homes and shared a window into their lives and experiences.

Over the duration of this study my professional role has changed and become more 'system focussed'. As a result, my own learning and reflexivity within this study has shifted somewhat beyond a focus on individual clinical practice and towards the implications of psychosocial factors in living with frailty beyond interactions with health and care services. 8 chapters describe my research journey into social and interpersonal influences on frailty over a 12-month period from the perspective of two people living with different stages of frailty. It's also the parallel story of professional development the doctoral journey also facilitated. In this study, the term 'influence' refers to how interpersonal and social factors may affect how the person living with frailty perceives and responds to their own needs, including self-management and support seeking behaviours. Outside the study itself the 'influence' of this journey continues to be experienced in my thinking and understanding of frailty. Within the following chapters I share my personal reflections and how my own experiences shaped the research.

Introduction

The British Geriatrics Society (BGS) define frailty as "…a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves" (2014), however conceptualising and responding to frailty continues to be a subject of dispute. There is growing interest in the influence of psychosocial factors on frailty, but limited UK based research into their role over time in relation to changes in frailty status, and therefore implications for clinical practice. Typically considered across a progressive scale, recognising frailty in a person may be an opportunity for community-based Neighbourhood Teams to offer early support to prevent, reduce or delay its progression therefore enabling more years lived well.

An early concept analysis found that psychosocial contributors may precede frailty onset in older people, and that there may be opportunities to delay the progression of frailty. To examine this further the aim of this study was to increase understanding of the role of psychosocial influences on frailty trajectory, by exploring older people's perceptions of how psychosocial factors influence self-reported frailty status over time. A qualitative longitudinal methodology enabled a detailed and in-depth exploration of individual experiences. Interviews with older people in their own homes enabled a contextual understanding of living with frailty at home.

Research questions

Consistent with an exploratory aim, research questions were broad, enabling participants to talk about what was important to them.

a. How do people living with frailty in the community use psychosocial factors to maintain physical, psychological and social stability?

b. How do people living with frailty in the community anticipate, experience and respond to physical, psychological or social change?

c. Is there a relationship between the role of psychosocial factors during periods of instability, and frailty levels calculated using self-reported support needs?

Research objectives

Wider objectives were to understand more about the relationship between frailty trajectory and psychosocial factors from the perspective of the person living with frailty.

1. To increase understanding of the mechanisms which lead to transitions between frailty levels for people living with frailty in the community and how people with frailty or risk of frailty experience those transitions.

2. To understand what people living with frailty see as relevant psychosocial influences on frailty trajectory.
3. To understand which factors influence help-seeking and self-management decisions, and personal responses to change.

Study design

Recognising that psychosocial influences on frailty may be highly personal, a constructivist grounded theory epistemology was adopted, which takes the stance that 'truth' emerges from individual engagement with the world (Moon and Blackman, 2014). Grounded theory also has particular strengths when exploring how things change over time (Merriam, 2015). Recognising the limitations of cross-sectional study designs in the existing literature, a longitudinal study design supported exploration of frailty change over time and an understanding of personal responses to change in real time.

Participants were recruited via community health and social care teams and were interviewed up to three times over a 12-month period, in their own homes. Interview transcripts were thematically analysed against holistic domains of frailty and coded in relation to experiences of change and stability.

Thesis outline

This thesis explores the influences of psychological and social factors on frailty for older people living at home. These influences are developed over the following chapters.

Chapter One provides the national context for this work as viewed from my current professional perspective: the shift towards prevention rather than reaction, and from acute care to community.

Chapter Two describes a concept analysis completed in 2020, exploring in detail different perceptions of frailty as a concept, using Delves-Yates' (2018) model. Findings suggest people living with frailty may perceive a stronger emphasis on psychosocial factors as antecedents or management strategies for frailty in comparison to healthcare professionals. Seven different stakeholder groups were identified and discussed.

Chapter Three presents the findings of a literature review, which focussed on current evidence exploring psychosocial influences on frailty. Several gaps were identified which were used to inform the research questions and aims of this study.

Chapters Four and Five describe the study methodology and research design, including an overview of participants recruited.

Chapters Six and Seven provide detailed illustrative cases for the two recruited participants. Analysis of data from interview transcripts, my own researcher diary and participant diaries is presented. These cases drawn upon Maslow's hierarchy of needs and Cialdini's principles of psychosocial influence to explore interpersonal relationships and responses to change over time. Transcripts are also analysed in relation to holistic frailty domains to consider how frailty progression is presented by the participant within each domain.

Chapter Eight provides discussion and comparison of themes between the two participants, a critique of the study design, implications for future practice and thesis conclusion.

Chapter 1: Neighbourhoods and Left Shift

This chapter describes the wider health and social care service context within which I have developed and undertaken this study, including the shift towards preventative care rather than reactive care, and the increasing focus on care closer to home. I describe how frailty definitions have developed over time from a focus on physical health state to a more holistic, biopsychosocial understanding of frailty. I present current definitions and models of frailty, the distinction between frailty and other related but separate concepts and approaches to identifying frailty. I conclude by describing opportunities for community proactive management of frailty as a holistic and progressive state.

1.1 Neighbourhoods and the "Left Shift"

A life well lived is perhaps the most universal and fundamental of ambitions – to be granted not simply a *long* life but to maximise the years of our lives spent living *well*. With population growth and life expectancy at an all-time high within the UK (ONS, 2021), demand on health and social care in its current form is set to outstrip capacity. This crescendo of demand on community services comes alongside drastic NHS and Social Care budget cuts; a combination which will make innovative change and collaboration in supporting people to age well not just desirable but a necessity (Darzi, 2024). Central to the national conversation around new ways of working is the notion of Neighbourhood – conceptualised as geographically defined areas at population sizes around 50,000 (Gov.uk, 2025). The principle of Neighbourhood working is at its heart about working together to meet the needs of a local population in a way that is tailored to local and individual needs. Neighbourhood working is about the coming together of community partners

including statutory services and the voluntary sector. It uses population health data alongside local knowledge to identify vulnerable people within the Neighbourhood and to help keep people well for longer (NHS England, 2025), thus emphasising collaborative working to deliver joined up care closer to where people live. Neighbourhood working coupled with a shift in focus from reactive care towards proactive and preventative approaches – commonly referred to as the "left shift" (Darzi, 2024, p74) - insight into trajectories of deterioration in a way that engages a wide range of stakeholders has never been more needed. Neighbourhood Teams must take an evidence-based approach to identify those most vulnerable to crisis events in the community and put in place proactive and preventative measures if they are to succeed in keeping people well and at home for longer.

1.2 Frailty as vulnerability

Since the early 2000s frailty as a concept has gained increasing global attention within healthcare and academia and become prevalent in UK healthcare policy and clinical practice as a way to identify and respond to potential vulnerability, (Manthorpe and Iliffe, 2015; Provencher et al., 2012). However, a universally accepted definition remains somewhat elusive (Schreuders et al., 2019; Tomkow, 2020). In 1994 the UK government commissioned a review of the care of frail elderly people (Tinker et al., 1994) and frailty was characterised as a state applicable to over 65s with chronic illness, or a mental or physical condition causing long term functional loss, however conceptualising and responding to frailty continued to be a subject of dispute. This focus on functional deficit is echoed in the World Health Organisation's glossary of terms (WHO, 2004) which defines a frail older person as "an older person in need of a substantial level of care and support" p30, however contemporaneous and subsequent definitions have predominantly stemmed from the medical and geriatric sciences which focus upon frailty's pathophysiology and clinical presentation (Waldon, 2018; Fried et al., 2004; Markle-Reid and Browne, 2003), and present frailty as a category of disorder (Grenier, 2007).

The British Geriatrics Society (BGS) define frailty as "…a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves" (2014), however older people asked about perceptions of frailty by Warmoth et al. (2016) did not equate comorbidity alone with self-identifying as frail. In 2013 Clegg et al, describe a specific trajectory associated with frailty: susceptibility to a pronounced sudden deterioration followed by a recovery process that never quite reaches its starting point. Thus, those living with frailty deteriorate neither steadily nor predictably, nor have any assurance of regaining all previous abilities [figure 1]. Frailty is therefore recognisable retrospectively by its trajectory of sudden unexpected deterioration and a more pronounced response to stressors. As the deterioration

results from a unique interplay of intrinsic factors and the nature of the stressor in question, frailty deterioration is difficult to pre-empt, and therefore an opportune but challenging area of focus for Neighbourhood Teams.

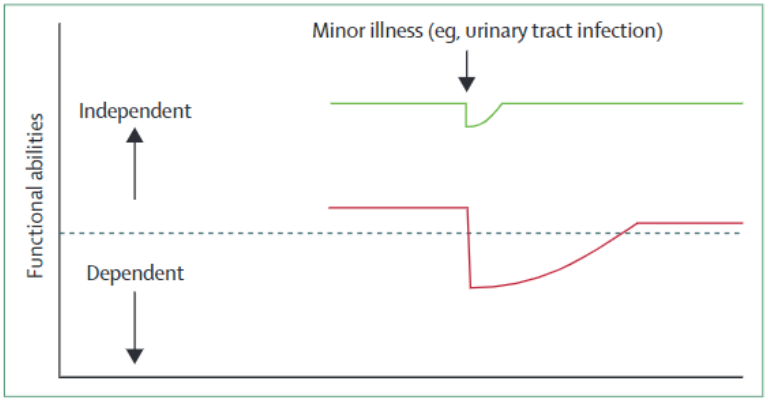


Figure 1: Vulnerability of frail elderly people to a sudden change in health status after a minor illness, Clegg et al. (2013)

1.3 Identifying frailty

Despite increasing global attention within healthcare and academia a universally accepted definition of frailty remains elusive. Towards the end of the twentieth century frailty was synonymous with institutionalisation and failure to thrive (Kwak & Thompson, 2021), however over time the notions of disability, comorbidity and frailty have emerged as separate and distinct conditions. To define and differentiate between these conditions, criteria have been identified and developed into theoretical models. Theoretical models are used within academia to specify the variables which contribute to or influence the phenomenon of interest, and aim to explain the meaning, nature and challenges associated with a phenomenon.

There are currently two broad models of frailty; the Phenotype Model (Fried et al., 2001) which describes a group of characteristics which predict poorer outcomes when three or more are present together (unintentional weight loss, reduced muscle strength, reduced gait speed, self-reported exhaustion and low energy expenditure); and the Cumulative Deficit Model (Rockwood et al., 2005) which describes an accumulation of deficits from a much broader group of (mostly physical) *potential* deficits which produce a 'frailty index' and a more graduated scale of frailty levels. Freer (2019) differentiated between the two models by the representation of the actual vs potential presence of frailty.

The characteristics used within the earlier Phenotype Model are representative of pathophysiological explorations of frailty such as those presented in Waldon (2018), which have

demonstrated associations between hormonal changes and the development of sarcopenia (Junius-Walker et al., 2018; Sezgin et al., 2019), changes at a cellular level, and interrelated systemic impairments (Junius-Walker et al., 2018) which have a "domino effect of health destabilisation" (Waldon, 2018, p489). The phenotypical characteristics are not allocated any hierarchy within the original model, and subsequent studies have shown that any of these five characteristics can provide a starting point of deterioration (Xue, 2011). Weakness has been noted as the most common first manifestation, with exhaustion and weight loss tending to present later (ibid). The presence of two or more of the five characteristics is said to indicate a clinical state of 'pre-frailty', widely thought to be the most effective point at which to direct interventions (Provencher et al., 2012), however the model takes a 'medical model' approach, omitting the potential influence of psychological, environmental and social factors.

In the second model, the Cumulative Deficit model, Rockwood et al. (2005) describe the gradual accumulation of deficits typically associated with ageing, which cumulatively increase the risk of adverse outcomes (British Geriatrics Society (BGS), 2014). The original version included a Frailty Index (FI), calculated by counting the deficient domains and comorbidities identified during a comprehensive geriatric assessment (CGA) (BGS, 2019), out of a possible 70 and dividing the number by the number of deficits considered. This has since developed into the electronic frailty index (eFI) which is automated to use SNOMED-CT data from primary care records to identify people likely to be living with frailty. In 2017/18, eFI recording was first introduced into the GP contract embedding its widespread application. The 2024/5 Direct Enhanced Service (DES) contract recommends its use as an "evidence-based risk prediction tool" p10 (NHS England – Network contract directed enhanced service – part A, 2024/5) for use alongside "clinical validation tools and local knowledge" p10 (Ibid) in adopting proactive care for frailty. As the eFI is intended for risk stratification and not a patient level diagnostic tool (NHS England - Identifying Frailty, date unknown), patient level diagnostic tools such as the Clinical Frailty Scale (CFS) (Rockwood and Theou, 2020) [Figure 2] and Edmonton Frail Scale (EFS) (Rolfson et al., 2000) [Figure 3] were also developed under the cumulative deficit model. Both tools are advocated in the NHS Skills for Health Frailty Toolkit (2018), endorsed by NICE and Age UK, with the CFS most widely used in clinical practice (Green et al., 2018; Britton, 2017).

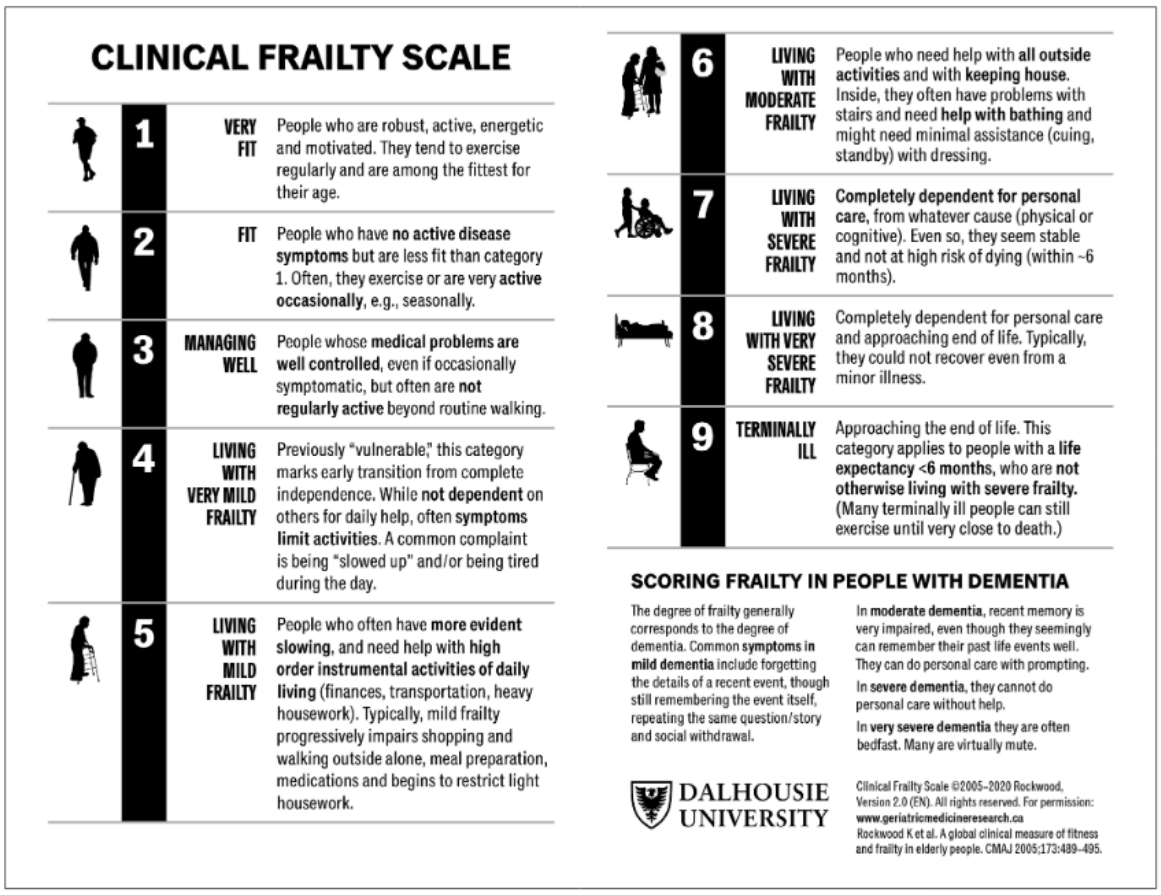


Figure 2: Clinical Frailty Scale version 2.0 (2005-2020) (Rockwood and Theou, 2020)

The Edmonton Frail Scale

NAME : _____

d.o.b. : _____ **DATE :** _____

Frailty domain	Item	0 point	1 point	2 points
Cognition	Please imagine that this pre-drawn circle is a clock. I would like you to place the numbers in the correct positions then place the hands to indicate a time of 'ten after eleven'	No errors	Minor spacing errors	Other errors
General health status	In the past year, how many times have you been admitted to a hospital?	0	1–2	≥2
	In general, how would you describe your health?	'Excellent', 'Very good', 'Good'	'Fair'	'Poor'
Functional independence	With how many of the following activities do you require help? (meal preparation, shopping, transportation, telephone, housekeeping, laundry, managing money, taking medications)	0–1	2–4	5–8
Social support	When you need help, can you count on someone who is willing and able to meet your needs?	Always	Sometimes	Never
Medication use	Do you use five or more different prescription medications on a regular basis?	No	Yes	
	At times, do you forget to take your prescription medications?	No	Yes	
Nutrition	Have you recently lost weight such that your clothing has become looser?	No	Yes	
Mood	Do you often feel sad or depressed?	No	Yes	
Continence	Do you have a problem with losing control of urine when you don't want to?	No	Yes	
Functional performance	I would like you to sit in this chair with your back and arms resting. Then, when I say 'GO', please stand up and walk at a safe and comfortable pace to the mark on the floor (approximately 3 m away), return to the chair and sit down'	0–10 s	11–20 s	One of : >20 s , or patient unwilling , or requires assistance
Totals	Final score is the sum of column totals			

Scoring :
0 - 5 = Not Frail
6 - 7 = Vulnerable
8 - 9 = Mild Frailty
10-11 = Moderate Frailty
12-17 = Severe Frailty

TOTAL /17

Administered by : _____

Figure 3: The Edmonton Frail Scale (1999)

Originally produced to summarise the findings of a Comprehensive Geriatric Assessment, the CFS - a 9-point scale with visual representations and simple descriptions - has since been adopted by clinicians as a judgement-based tool (Dalhousie University, date unknown). The Edmonton Frail Scale identifies a frailty score based on 11 questions covering a range of biopsychosocial domains, each scoring 0-2 points. Vulnerability or degree of frailty is confirmed where scores of 6 or above are recorded. Rolfson et al. have gone on to present the EFS favourably for use by non-specialist clinicians (Rolfson et al., 2006) positioning it as highly accessible and appropriate for a community setting where access to specialist frailty services may be more limited, however it is possible the

specificity of the 11 questions may restrict full completion and discourage patient-lead assessment. Similar positive attributes of accessibility are noted of the CFS; however, the simplicity of the scale perhaps belies the level of time and expertise needed to complete the first stage of the assessment process, the CGA. Criticism of the CFS has centred around its apparent focus on established functional deficit as the underpinning Cumulative Deficit model presents frailty as "the potential of a threatened future" (Tomkow, 2018, p701), with established deficit more typically considered as disability (Campbell and Buchner, 1997; Whitson et al., 2007)). Nonetheless, the CFS has been validated as an accurate predictor of adverse outcomes such as mortality and delirium (Ozsurekci C et al., 2020; Mudge, 2018).

As the cumulative deficit model encompasses psychosocial frailty as well as physical, when used to understand frailty levels among the general population its application tends to indicate higher overall levels of frailty amongst over 65s, by as much as 35% (Collard et al, 2012). The cumulative deficit model is more commonly adopted in the UK as it is thought to align more closely with clinical experience (British Geriatrics Society, 2014) suggesting a consensus amongst those working with people living with frailty in recognising the breadth and nuance in its contributing factors and favouring a biopsychosocial approach.

1.4 Frailty as an opportunity for Proactive Care

When viewed through a biopsychosocial lens frailty may present opportunities for proactive support beyond health and social care services. Proactive and preventative approaches to maximise older peoples' independence, health and wellbeing form part of the Ageing Well agenda (NHS long term plan, 2019) and are the broad aim of older peoples' health and social care services (Care Act, 2014).

Studies of frailty in acute settings have focussed on physiological contributors and health related outcomes as psychosocial factors are already artificially stabilised or altered by the context of the acute setting. Management of frailty within the community has been less well explored. Relationships between vulnerabilities and stressors in community settings are likely to be complex and warrant further research. Exploring the nature of these stressors from the perspective of lived experience may offer new insights to tackle the integration agenda between health, social care and the wider community (Department of Health and Social Care, 2021).

The challenge presented by frailty for Neighbourhood Teams is to prevent, reduce or delay disproportionate responses to a yet unknown stressor, often in the *absence* of a primary medical condition which might foretell patterns of deterioration. As an accepted definition of frailty appears to grow somewhat closer amongst healthcare professionals, it is nonetheless important

to consider integrating other potential wider Neighbourhood-based interpretations in unifying approaches.

Summary

This chapter has focused on current definitions and approaches to frailty identification within health and social care. Understanding frailty as a holistic state with multiple contributing domains, I have argued that separate but interrelated frailty domains can contribute to an overall balance of vulnerability or resilience. Chapter 2 further explores conceptualisation of frailty, and how differences in the conceptualisation of frailty by a wider range of stakeholders might be pertinent to engaging with frail older people.

Chapter 2: Mind the Gap

Building on definitions of frailty within health and social care and the notion of separate but interrelated frailty domains, in chapter 1, in this chapter, first I examine the cultural terms of frailty across history and how the medical and social concept of the covid pandemic shape meaning of frailty. I then use a concept analysis approach to describe lay and cultural understanding of frailty from 7 stakeholder groups, by analysing 39 papers from 1994-2020 using Delves-Yates et al.'s (2028) approach to concept analysis. Findings are reported which suggest differences in how stakeholder groups understand the role each frailty domain plays as 'antecedent to', 'consequence of' or 'potential mediator' to frailty trajectory. I conclude this chapter with recommendations for further research into the role of psychosocial factors on frailty trajectory

2.1 The language of frailty – what's in a name?

Efforts to define frailty in a way that may lead to its operational application within Neighbourhoods sit against a cultural backdrop of established lay understandings of the term. The first known use of the term "frailty" in English dates back to the 14th century (Merriam-Webster, 2020) when it was used to mean "morally weak" (Online Etymology Dictionary, 2020). Later used in Shakespeare's Hamlet c.1600 to proclaim the perceived physical and moral flaws of Hamlet's mother, a duality of meaning between physical weakness and flawed morality or character is presented - one which continues to be used colloquially in the United Kingdom (Cambridge Dictionary). This historic use within the English language paints a picture of frailty not simply as an objective disease state owned and defined by medical and academic commentators, but as a more complex concept shaped and defined through wider cultural narrative.

Bortz (2010) develops academic thinking beyond a focus on chronic illness and functional loss, presenting frailty as an emergent construct "…deriv(ing) its essence from the multiple synergies of the components" (p255). In doing so, he references Aristotle, describing frailty as 'more than the sum of its parts', implying intrinsic to frailty is not just which components are present, but how they interact (Richardson et al., 2014), thus frailty is seen as a dynamic if somewhat ambiguous state (Sharp et al., 2018). NHS England (2018) represents this interplay through the model of a frailty 'fulcrum' [figure 4], with each component on the fulcrum equally represented as a potential vulnerability or resilience.

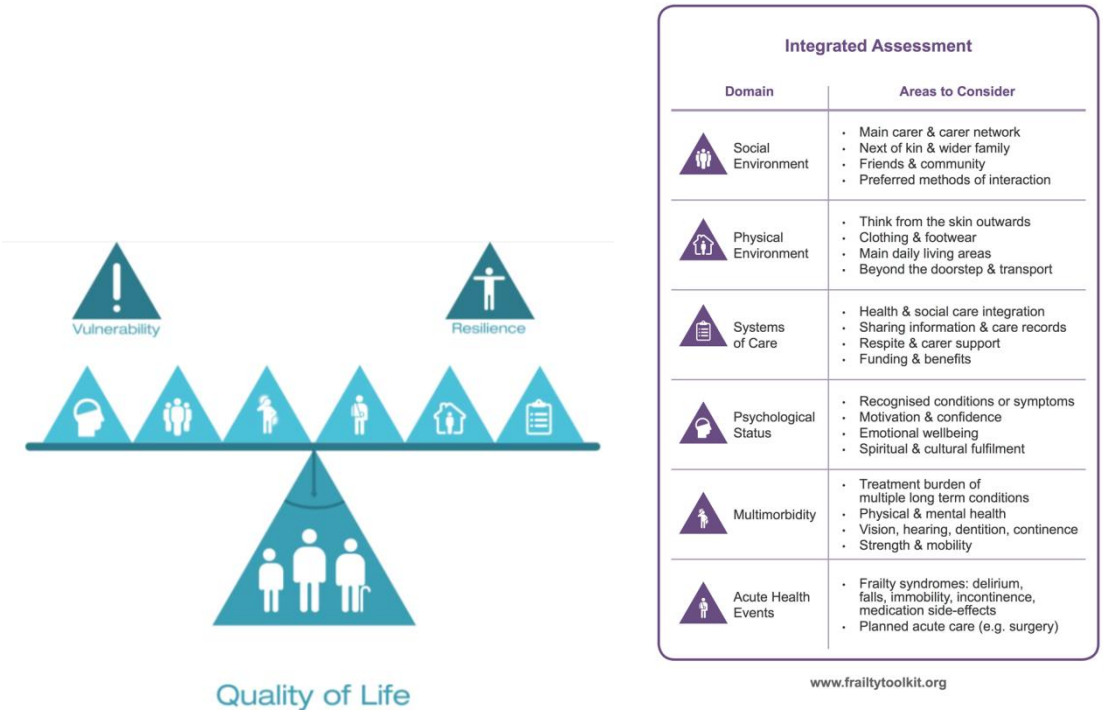


Figure 4: Frailty fulcrum and description of components. NHS England (2016)

"Frailty is theoretically defined as a clinically recognizable state of increased vulnerability resulting from aging-associated decline in reserve and function across multiple physiologic systems such that the ability to cope with every day or acute stressors is comprised" (Xue, 2011, p1). NICE (2015) add to this definition "a higher risk of a sudden deterioration" (p36) as distinction from simply living with comorbidities or disabilities, outlining not only what frailty *is*, but also what it is *not*.

In a study of older peoples' perceptions of frailty and their beliefs about its progression and outcomes (Warmoth et al. (2016)) older people support the notion that comorbidity did not equate to self-identifying as frail, supporting Bortz' perspective that the interactions between components may be as significant as the components themselves.

Alongside unresolved academic dissonance around the clinical definition and operationalisation of frailty (Nicholson et al., 2013), multiple key guidance papers also refer to the interpretative barrier between clinical and lay understandings of the term; absence of resonance which may hinder access to support (BGS, 2014; NHS Skills for Health, 2018; Vernon, 2017; Britain Thinks, 2015). Caroline Abrahams, Charity Director at AgeUK said: '"Frailty" is all at once a medical term, an adjective, and a noun, but as the research shows for many older people it feels like a

judgement" (Age UK, 2015). Mudge (2018) identified little "account of the consumer perspective" (p510) within frailty research however multiple studies report frailty is a term *actively* avoided by the older generation due to its negative connotations (Chao et al., 2019; D'Avanzo et al., 2017; Gilleard and Higgs, 2010; Manthorpe and Iliffe, 2015; Warmoth et al., 2016; Tomkow, 2018). Despite acknowledgement of this "discomfort" within core clinical competency frameworks (NHS Skills for Health, 2018, p5), a position is adopted within healthcare systems of continuing the use of the term but with recommendations to reframe frailty as "a passport to the kind of support that makes a real difference" (p5). To appear to disregard frail people's perspective and persevere with our own agenda is to directly contradict the principles of good person-centred care; to create services in partnership with citizens and in a way which aims to empower them (NHS Health Education England, no date). The 'top down' approach to tackling the interpretative barrier, seen in guidance at the start of this doctoral process was likely to compound engagement issues and result in poorer outcomes for the individual (D'Avanzo et al., 2017) raising concerns that frailty management at the time may actively *disempower* the individual (Mudge, 2018).

2.2 Frailty in a pandemic

The global COVID-19 pandemic drew greater conceptual scrutiny to frailty both in the public domain and within clinical practice. In the UK, people aged 70 or over were asked to isolate at home as an elevated risk of contraction was reported (NHS England, 2020). This national strategy was perceived by many as an ageist response, disregarding the recognised differences between biological and chronological ageing (Rockwood et al., 1994). For many it emphasised divisions between young and old, with a perception of the virus being an 'older peoples' problem' (Fraser et al., 2020), overlooking the complexity of vulnerability beyond age. Decision support tools were developed in clinical settings, such as 'NICE COVID critical care guidance' (2020) and the 'Clinical Triage Protocol for Major Surge in COVID Pandemic' (Ontario Health, 2020); both designed to support complex clinical decision making in anticipation of treatment becoming highly ethically charged. The Clinical Frailty Scale was used as a triage component, with the additional descriptor "due to progressive illness or condition" (NICE, 2020, p6) following outcry from disability rights groups.

Concerns were raised about the use of the tool by clinicians with limited training, amongst groups for whom the tool had not been validated (including against COVID as a novel disease), and that it was validated as a 'mid-term' indicator of life expectancy, not necessarily to predict short term outcomes (Lewis et al., 2020). In effect, there was a risk that the tool could be used to reflect subjective impressions of a person's likelihood of survival, based on the assessor's interpretation of what it means to be frail.

Miles et al. (2020) explored the relationship between COVID-19 and CFS score in predicting mortality rates and concluded poor predictability of mortality in hospitalised patients, however Hewitt et al. (2020) drew contradictorily that "disease outcomes were better predicted by frailty than either age or comorbidity (and) support(ing) the use of CFS to inform decision making" p1. In the absence of a clear evidence base to support these new decision-making tools, public scrutiny resulted in an outpouring of discontent on social media from individuals who felt their potential for treatment would be unreasonably affected by the use of the CFS (Kleinman, 2020).

Harwood (2020) warned that the intention to ration treatment based on perceived likelihood of survival would have caused lasting damage to public perceptions of the purpose of advanced care planning. It follows therefore that a similar effect may have followed within an already strained perception of frailty, which may potentially impact engagement with frailty services and adversely affect outcomes for the individual (Mudge and Hubbard, 2018). For frailty to be considered a positive or useful concept in emerging Neighbourhood models a preventative focus is needed using language chosen by the service user, with a view to rebuilding trust in an intention to protect the vulnerable, not identify them for rationed care (ibid). To achieve this, a detailed analysis of interpretations and perceptions of frailty, consciously recognising the uniqueness of various stakeholder groups appeared warranted.

2.3 Concept Analysis

Rationale

Concepts are important in healthcare, shaping the ways in which clinicians think about the individuals they support and their wider social contexts (Knafl and Deatrick, 2000). Walker and Avant (2005) described concepts as a mental image of a phenomenon, and as such can only ever exist within the mind of the individual (Beckwith et al., 2008), however some degree of shared understanding is necessary for a concept to be used in clinical practice (Cronin et al., 2013).

A detailed understanding of the antecedents and contributors to the development and progression of frailty is crucial in designing effective early intervention and management strategies. There is a consensus in the literature of an association between frailty and ageing however the two are not mutually dependent. Bortz (2010) described potential for malnutrition and inactivity causing frailty in younger people. Depletion of reserves is a common theme; however, the proposed nature of depleted reserves varies resulting in acknowledgement of unique individual responses to stressors (Whitson et al., 2018). Whilst some studies cite physical depletions in nutrition (ibid), endocrine function and body composition changes, insulin regulation (Pel-Little et al., 2009), immune and neuromuscular changes (Provencher et al., 2012),

ageing cardiovascular systems, metabolism and immune systems (Pel-Little et al., 2009), others focus upon socioeconomic antecedents such as lower education levels, household income (Rockwood et al., 1994) and social isolation (Pel-Little et al., 2009). Psychological antecedents have been acknowledged by both academic and non-medical groups, citing causal links between low self-perception of health and depression with developing frailty (ibid). Perceived antecedents prevalent amongst people living with frailty include a lack of "emotional resilience" (Grenier, 2007) and individual mind set (Sezgin et al., 2019; Britain Thinks, 2015), seen in the viewpoint; "thinking of yourself as frail then you gonna have some subsequent frail behaviour" (Sezgin et al., 2019, p20). A focus on health behaviours and lifestyle choices such as alcohol consumption, smoking and activity levels (ibid) also hint at the question of responsibility. Shaw's 2018 comparison of stakeholder perceptions of frailty highlighted greater emphasis placed on a perception of psychosocial antecedents by older people with frailty and by social care professionals than by health care professionals, who placed initial emphasis on physiological antecedents with psychosocial domains considered later.

"Health policy and biomedical discourses of frailty-prevention strategies largely centre on associations between frailty and individual health behaviours" (Tomkow, 2018, p705), however a social gradient is noted. Lower income, areas of deprivation and limited educational background have been associated with increased frailty incidence (Manthorpe et al., 2018), demonstrated by reduced balance, chair rise times and poor subjective wellbeing (Tomkow, 2018). Socio-economic antecedents of frailty correlate with associations of reduced productivity and social value, but challenge notions of frailty as a shameful blame-worthy state (Tomkow, 2020; Nicholson et al., 2013). Tomkow (2018) raises ethical concerns around encouraging self-management, placing the weight of responsibility solely with the individual, disregarding "…structural causes of health inequalities" (p696). Frailty is therefore "not just an individual problem, but a public health and political matter" (Manthorpe et al., 2018, p27). This discourse however creates a counterproductive representation of a disempowered individual at the mercy of social and political contexts, thus ironically reinforcing unhelpful power dynamics; perhaps an echo of the historic concept of the 'deserving poor'. Conscientious use of the term 'frail' not as a static binary term to represent who the person is, but rather in terms of a transient risk state of 'having frailty' (BGS, 2014) may go some way in mitigating disempowerment associated with the term, however high quality evidence derived from the experience of the person living with frailty is needed to inform effective services which engage and empower the individuals they support.

Approach

Concept analysis has been demonstrated to help clarify meaning when there is ambiguity and I used this approach to explore the term 'frail' or 'frailty' further. Delves-Yates et al's model of analysis was chosen due to its phased, cyclical approach, encouraging reflection and reflexivity within the process as new information emerges (Delves-Yates et al., 2018). Derived from Rodgers (1989) 'evolutionary' view, the model acknowledges the potential for a concept to modify dependent on context and user [figure 5].

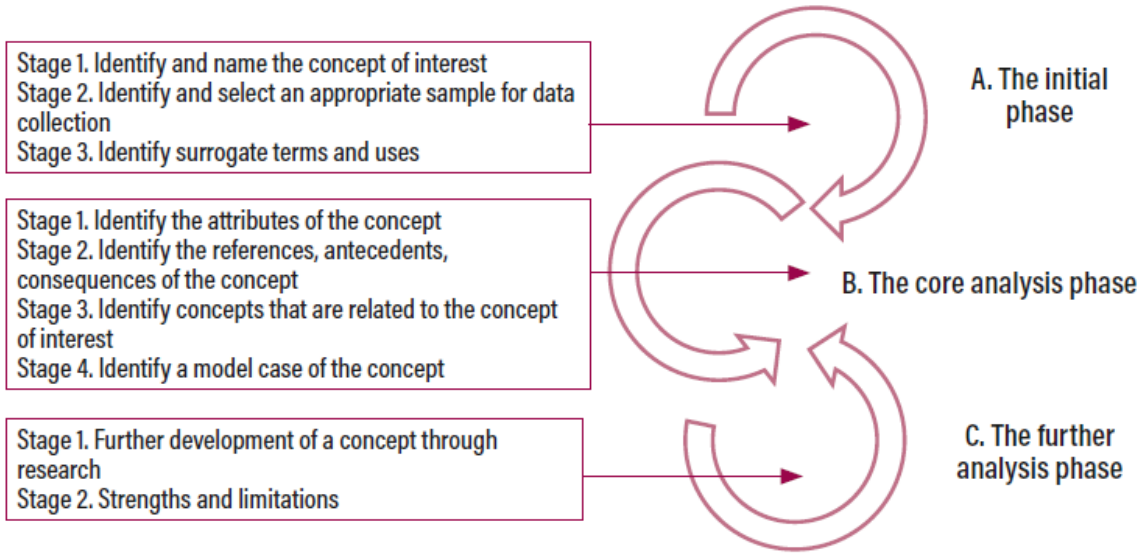


Figure 5: Delves-Yates model of concept analysis (2018)

The first cycle of the process was completed several times to refine the focus of the concept analysis. An initial database search in 2019 without filters using the terms "frail" or "frailty" produced 121,883 results. This was an unrealistic sample and refinement was needed. Initial search refinements were applied focussing on the methods or criteria used to identify or assess frailty, using search terms such as "assess", "gage", "evaluate", "tool", "approach" and "outcome". It quickly became apparent that results produced a representation of frailty as a risk identification tool (Tomkow, 2018) and did not capture the richer dispositional view more aligned to the area of interest. Search terms were refined to capture the fluidity of components; a second search was completed focussing on interpretation or meaning of the term frailty by various groups. This search was initially refined to peer reviewed key medical and social care databases only. However, these restrictions were removed to capture as broad and rich a sample as possible to minimise any preconceptions or biases regarding where one might expect the term frailty to be used [appendix 1].

This systematic approach to sampling "increases the likelihood that the items included are representative of the total population" (Rodgers, 1989). Similarly, the model advises selecting a date range based upon key papers (Delves-Yates et al., 2018), however removing this restriction captured what preceded seminal papers to understand how any dissonance may have evolved. For this reason, the search was not restricted by date, however the initial sample of 14 papers identified were almost exclusively from within the last 10 years. This suggests the significance of variations in the meaning and interpretation of the term frailty is a modern and developing consideration. Although the inclusion of additional papers identified through hand searches of reference lists broadened this date range to 1994-2020, again almost 75% of this total sample of 39 were from the past 10 years.

Inclusion/exclusion criteria were applied to the sample of 249 papers [appendix 2 and 3], initially via a title review for papers written in English and whose primary intent appeared to offer insight into frailty conceptualisation by any given group. A title review approach was necessary due to the practicalities of reviewing a larger sample size as a lone researcher. Potential to misunderstand the focus of some papers based on their title was mitigated where it was identified, using an additional review of the abstract for further detail. It is acknowledged however that this cannot guarantee all appropriate papers were identified. Reducing sample size down to 42, which was a manageable size to complete an abstract review on each paper to identify whether the study focussed on primary care, returning to a community setting (primary care) or no specific setting, and whether the cohort was primarily UK based. Rationale for these inclusion/exclusion criteria are provided in Appendix 4. From the 13 papers identified in the literature search, a hand search was completed of the reference lists, and a further 19 papers met the inclusion/exclusion criteria, a further 9 were also included which were identified during previous searches. The total included sample for concept analysis was 41 papers [figure 6] [table 1].

Codes covering concept attributes, references, antecedents, consequences, related concepts, and model cases were applied to each text based on Delves-Yates et al.'s model of the core analysis phase adapted from the coding system used in Waldon's (2018) principle-based concept analysis. Criteria for code application were defined to ensure consistency [Appendix 5]. Each paper was read once to gain an initial understanding and a second time to complete the coding process. Key phrases related to each code were transcribed onto data recording sheets [Appendix 6] recording whose 'voice' was being represented within each section. This was important because several papers represented more than one perspective. For example, in Skilbeck et al. (2018) the clinicians' perspective is of a "tendency to view frailty within a narrow biomedical and functional

framework" p2, whereas older and frail people, whilst acknowledging the accumulation of physical and functional deficit, described a more emotive and psychological representation of "Frailty as anxiety, fear and uncertainty… feeling frail… episodes of uncertainty challeng(ing) identity…" p4. "(T)hey focused on continuing to engage with daily living and in doing so they defined themselves in relation to what they could achieve" p9.

Codes for whose perspective was being presented were initially generated by the exact description provided in the text, then grouped into broader categories [Appendix7]. Thirty-four different descriptions were identified in the texts, from which seven broader categories were derived; those being described as frail (referred to henceforth by the abbreviation 'FP' – frail people/person), clinical experts, clinicians not specialising in geriatrics (referred to henceforth as 'NSCs' – non-specialist clinicians), informal carers/relatives, lay people/non-healthcare public, governing bodies/policy makers and academics. Comprehensive concept analysis is presented within each category. Concept mapping (Wilson et al., 2016) was then used to analyse the data and identify themes presented by each group [Figure 5]. In figure 7 I present this process in a visual flowchart for further clarity and provide a sample of my thematic analysis by stakeholder group in figure 8 and summarise my thematic analysis for each stakeholder group in the form of concept statements [Appendix 10].

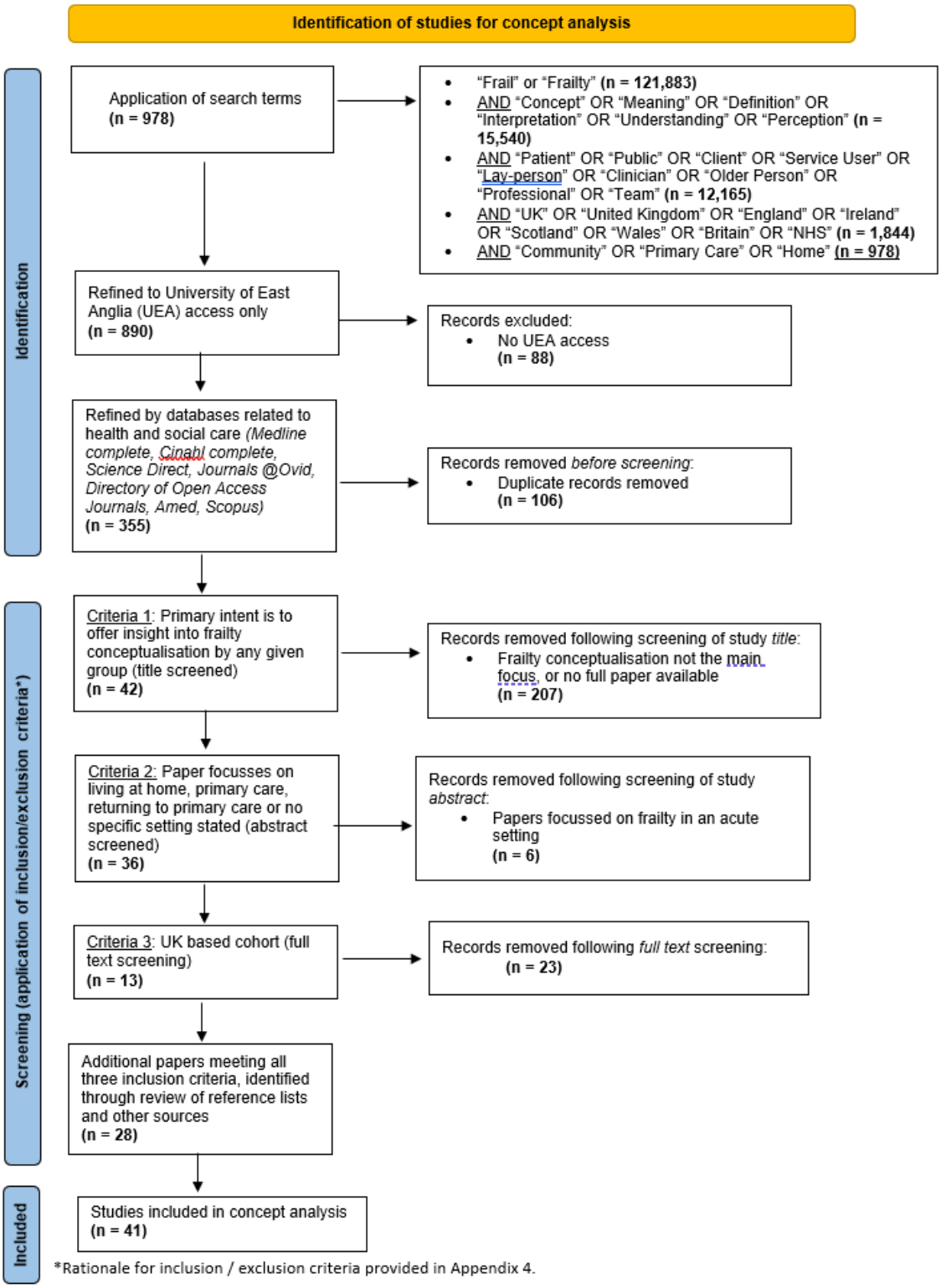


Figure 6: PRISMA diagram 1 – identification of studies for the concept analysis

Included papers

Table 1: Overview of papers included in concept analysis

	Author/ year	Title	Journal / Organisation	Description	Group/s represented [using coding from appendix 7]
1	*Bortz, W (2010)	Understanding frailty.	Journals of Gerontology	Editorial	• Academics (A)
2	*Britain Thinks (2015)	Frailty: Language and Perceptions. A report prepared by BritainThinks on behalf of Age UK and the British Geriatric Society	British Geriatrics Society and Age UK	Report	• Older peoples' specialists (OPS) • Non specialist Health Care Professionals (GPs, practice and district nurses, hospital ward managers, (NHCPs) • General Public (GP) • Older People age 69+ (OP) • Informal carers (IC)
3	Britton H (2017)	What are community nurses experiences of assessing frailty and assisting in planning subsequent interventions?	British Journal of Community Nursing	Qualitative (semi-structured interviews)	• Community nurses (CN) • Community Matron (CM)
4	*Campbell J and Buchner DM (1997)	Unstable disability and the fluctuations of frailty	Age and Ageing	Review	• Academics (A)
5	*Chao Y-S et al (2019)	A proposal for a self-rated frailty index for patient-	BMC Research Notes	Review	• Researchers and clinicians (RC) • Statisticians (S) • General Public/lay people (GP)

		orientated research			
6	Coker JF et al (2019)	Frailty: an in-depth qualitative study exploring the views of community care staff	BMC geriatrics	Qualitative (semi-structured interviews)	• Non specialist Health Care Professionals (GPs, practice and district nurses, hospital ward managers, OTs, PTs, TAs, psychiatric nurses, social workers (NHCPs) • General Public/lay people (GP)
7	*D'Avanzo B et al (2017)	Stakeholders' views and experiences of care and interventions for addressing frailty and pre-frailty: A meta-synthesis of qualitative evidence	PLoS One	Review (meta-synthesis of qualitative evidence)	• Non-specialist Healthcare Professionals (NHCPs) • Academics (A) • Older people (OP) • Non-frail participant (NFP) • Frail people (F) • Family of frail people (FF)
8	*Fried LP (2004)	Untangling the concepts of disability, frailty and comorbidity: Implications for improved targeting and care	Journal of Gerontology	Review (narrative review)	• Geriatricians (G) • Academics (A)
9	Frost R et al (2018)	Identifying acceptable components for home-based health promotion services for older people with mild frailty: A	Health and Social Care in the Community	Qualitative (semi-structured interviews and focus groups)	• Non specialist Health Care Professionals (GPs, practice and district nurses, hospital ward managers, OTs, PTs, TAs, psychiatric nurses, social workers (NHCPs) • Older People age 69+ (OP) • Informal carers (IC)

		qualitative study			
10	*Gilleard C and Higgs P (2010)	Frailty, disability and old age: A re-appraisal	Health	Review	• Academics (A) • Older people (OP) • Cultural representations (CR) • Policy makers (PM) • Frail people (F)
11	*Gobbens R (2010)	Toward a conceptual definition of frail community dwelling older people	Nursing Outlook	Review	
12	Green J et al (2018)	Ambulance clinicians' perceptions, assessment and management of frailty: thematic analysis of focus groups	British Paramedic Journal	Qualitative (focus groups)	• Paramedics (P)
13	*Grenier A (2006)	The distinction between being and feeling frail: Exploring emotional experiences in health and social care	Journal of Social Work Practice	Qualitative (narrative interviews)	• Academics (A) • Researchers (R) • Non-specialist Healthcare Professionals (NHCPs) • Researchers and clinicians (RC) • Dictionary (D) • Social Sciences (SS) • Older women (OW)
14	*Grenier AM (2019)	The conspicuous absence of the social, emotional and political	Ageing and Society	Review (critical discourse analysis)	

		aspects of frailty: the example of the White Book on Frailty			
15	*Gwyther H et al (2018)	Understanding frailty: a qualitative study of European healthcare policy-makers' approaches to frailty screening and management	BMJ Open	Qualitative (semi-structured interviews)	
16	Heath H and Phair L (2009)	The concept of frailty and its significance in the consequences of care or neglect for older people: an analysis	International Journal of Older People Nursing	Review (literature review and concept analysis)	• Academics (A) • Researchers (R) • Geriatricians (G)
17	*Junius-Walker U et al (2018)	The essence of frailty: A systematic review and qualitative synthesis on frailty concepts and definitions	European Journal of Internal Medicine	Review (systematic review)	• Academics (A) • Older people (OP) • Healthcare Systems (HS) • World Health Organisation (WHO)
18	*Manthorpe J and Iliffe S (2015)	Frailty – from bedside to buzzword?	Journal of Integrated Care	Review	• Cultural representation (CR) • Older people (OP) • Governments (GM) • Policy makers (PM) • British Geriatrics Society (BGS) • National Health Service (NHS)

19	*Manthorpe J et al (2018)	Frailty and social care: Over- or under- familiar terms	Social Policy and Society	Qualitative (semi-structured interviews)	
20	*Markle-Reid M and Browne G (2003)	Conceptualizations of frailty in relation to older adults	Journal of Advanced Nursing	Review (literature review)	• Academics (A) • Frail people (F)
21	*Mudge AM and Hubbard RE (2018)	Frailty: Mind the gap	Age and Ageing	Review/ Commentary	• Academics (A) • Older People age 69+ (OP)
22	Nettleton S et al (2018)	Envisioning bodies and architectures of care: Reflections on competition designs for older people	Journal of Ageing Studies	Review	• Architecture students (AS) • Cultural representation (CR) • Academics (A)
23	Nicholson C et al (2012)	Living on the margin: Understanding the experience of living and dying with frailty in old age	Social Science and Medicine	Qualitative (narrative interviews)	• Older people (OP) • Non specialist Health Care Professionals (GPs, practice and district nurses, hospital ward managers, OTs, PTs, TAs, psychiatric nurses, social workers) (NHCPS) • Older peoples' specialists (OPS)
24	Nicholson C et al (2013)	The experience of living at home with frailty in old age: A psychosocial	International Journal of Nursing Studies	Qualitative (narrative interviews)	• Academics (A) • Non specialist Health Care Professionals (GPs, practice and district nurses, hospital

		qualitative study			ward managers, OTs, PTs, TAs, psychiatric nurses, social workers) (NHCPs) • Frail people (F) • Family of frail people (FF)
25	*Nicholson C et al (2017)	Changing the way "we" view and talk about frailty…	Age and Ageing	Review/ Commentary	• Stakeholders (SH) • Policy Makers (PM) • Older People (OP) • Dictionary (D) • Frail people (F) • World Health Organisation (WHO)
26	*Pel-Little RE et al (2009)	Frailty: Defining and measuring of a concept	The Journal of Nutrition, Health and Ageing	Review (literature review)	• Academics (A) • Researchers (R)
27	*Provencher V et al (2012)	Frailty: A concept under-utilised by occupational therapists	Australian Occupational Therapy Journal	Review/ Opinion	• Academics (A) • Non specialist Health Care Professionals (GPs, practice and district nurses, hospital ward managers, OTs, PTs, TAs, psychiatric nurses, social workers) (NHCPs)
28	Richardson JC et al (2014)	'Keeping going': chronic joint pain in older people who describe their health as good	Ageing and Society	Qualitative (interview and diary sheets)	• Researchers (R) • Policy Makers (PM) • Academics (A) • Older people (OP)

29	*Richardson S et al (2011)	I may be frail but I ain't no failure	Canadian Geriatrics Journal	Review/ Commentary	• Academics (A) • Older people (OP) • Cultural representation (CR)
30	*Rockwood K et al (1994)	Frailty in elderly people: an evolving concept	Canadian Medical Association Journal	Review (literature review)	• Academics (A)
31	*Schoenborn NL et al (2018)	Older adults' perceptions and informational needs regarding frailty	BMC Geriatrics	Qualitative (focus groups)	
32	Schreuders LW et al (2019)	Understanding the perspectives of care home managers when managing care of residents living with frailty	Geriatric Nursing	Qualitative (semi-structured interviews)	• Care Home Managers (CHMs) • Older People (OP) • Non specialist Health Care Professionals (GPs, practice and district nurses, hospital ward managers, OTs, PTs, TAs, psychiatric nurses, social workers) (NHCPs) • Geriatricians (G) • Policy Makers (PM) • Social Care Professionals (SCPs) • British Geriatrics Society (BGS) • NHS England (NHS) • Professional Organisations (PO)
33	*Sezgin D et al (2019)	Defining frailty for healthcare practice and research: A qualitative systematic review with	International Journal of Nursing Studies	Review (qualitative systematic review)	• Older people (OP) • Academics (A) • Non specialist healthcare professionals (NHCPs) • Policy makers (PM)

		thematic analysis			
34	Sharp T et al (2018)	GPs' perceptions of advanced care planning with frail and older people: a qualitative study	British Journal of General Practice	Qualitative (focus groups)	• GPs (GPs) • NHS England (NHS)
35	*Shaw R (2018)	Understanding frailty: meanings and beliefs about screening and prevention across key stakeholder groups in Europe	Ageing and Society	Qualitative (focus groups and individual interviews)	
36	Skilbeck JK et al (2018)	Making sense of frailty: An ethnographic study of the experience of older people living with complex health problems	International Journal of Older People Nursing	Qualitative (semi-structured interviews)	• Academics (A) • Clinicians (CL) • Frail People (F) • Older People (OP) • British Geriatrics Society (BGS)
37	*Tomkow L (2020)	The emergence and utilisation of frailty in the United Kingdom: a contemporary biopolitical practice	Ageing and Society	Review/ Commentary	• Policy Makers (PM) • NHS England (NHS) • Academics (A) • Cultural representation (CR) • Governments (GM) • Medical experts (ME) • Researchers (R) • Non specialist Health Care Professionals (GPs, practice and district nurses, hospital

					ward managers, OTs, PTs, TAs, psychiatric nurses, social workers) (NHCPs) • General Public/lay people (GP) • Dictionary (D) • British Geriatrics Society (BGS)
38	Wallington S (2016)	Frailty: a term with many meanings and a growing priority for community nurses	British Journal of Community Nursing	Review/ Commentary	• British Geriatrics Society (BGS) • Academics (A) • NHS England (NHS) • Government (GM)
39	Warmouth K et al (2016)	'Thinking You're Old and Frail': A qualitative study of frailty in older adults	Ageing and Society	Qualitative (semi-structured interviews)	• Researchers (R) • Academics (A) • Older people 65+ (OP) • Older women (OW)
40	*Whitson HE et al (2007)	Frailty thy name is… Phrailty?	Journal of Gerontology	Review/ Commentary	• Non specialist healthcare professionals (NHPCs) • Researchers (R) • Patients (Pt)
41	*Whitson HE et al (2018)	Physical resilience: Not simply the opposite of frailty	Journal of the American Geriatrics Society	Review/ Commentary	• Academics (A)

Concept analysis process

Full text read: familiarisation with text
(n = 41)

Second full text read:
Deductive application of codes identifying concept components based on Delves-Yates' model
(n = 41)

I defined codes *prior to* my second full text read using Delves-Yates' (2018) Model of concept analysis – Phase B 'Core Analysis' and Phase C 'Further Analysis'

- **Attributes** of the concept
  - **Att1** – Has frailty been operationalised?
  - **Att2** Presents key characteristics or features inherent to frailty?
  - **Att3** – Clear positionality on the usefulness of frailty to support positive outcomes
- **References** of the concept
  - **Ref1** – Identifies situations, incidents or phenomena in which frailty can be considered
  - **Ref2** – Seeks to clarify the perception or perspective of a specific professional or population group
- **Identification** of the concept
  - A specific means to identify or assess frailty is recommended or commented on
- **Antecedents** of the concept
  - **Ant1** – Events of phenomena preceding frailty
- **Consequences** of the concept
  - **Con1** – Occurrences that follow frailty
- **Management** of the concept
  - **Man1** – A specific management approach or intervention is recommended
- **Related** concepts
  - **Rel1** – Identifies and/or discussed other concepts related to frailty
  - **Rel2** – Demonstrates or states how and/or why the secondary concept relates to frailty
- **Model case** of the concept
  - **Mod1** – provides a clear example of frailty
- **Philosophical view** of the concept
  - **Phi1** – Entity, dispositional or evolutionary view of frailty as a concept

Third full text read:
Inductive coding of perspectives represented in each text
(n = 41)

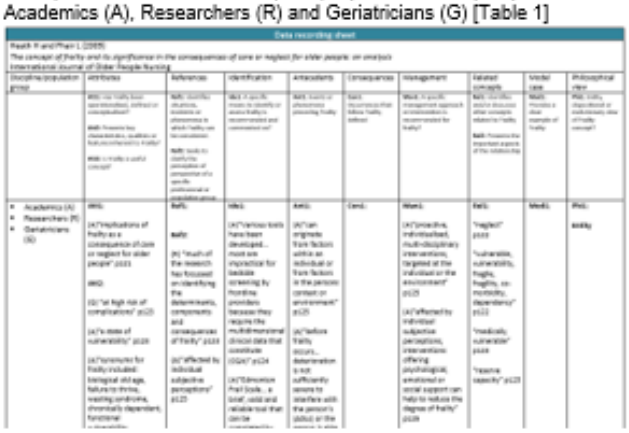
[Appendix 7] I identified codes inductively for each perspective represented, using the direct wording/description from each text

Code	Description in text
(A)	Academics
(R)	Researchers
(D)	Dictionary
(RC)	Researchers and Clinicians
(S)	Statisticians
(SS)	Social Science
(CHM)	Care Home Managers
(CM)	Community Matron
(CL)	Clinicians
(CN)	Community nurses
(NHCPs)	Non specialist Health Care Professionals (GPs, practice and district nurses, hospital ward managers, OTs, PTs, TAs, psychiatric nurses, social workers)
(GPs)	GPs
(P)	Paramedics
(SCPs)	Social Care Professionals
(OP)	Older People age 69+
(F)	Frail people
(OW)	Older women
(Pt)	Patients
(GP)	General Public/lay people
(CR)	Cultural representation
(AS)	Architecture students
(NFP)	Non-frail participant
(IC)	Informal carers
(FF)	Family of frail people
(OPS)	Older peoples' specialists
(G)	Geriatricians
(MT)	Medical Experts
(BGS)	British Geriatrics Society
(SH)	Stakeholders
(PM)	Policy Makers
(PO)	Professional Organisations
(GM)	Governments
(NHS)	NHS England
(WHO)	World Health Organisation
(HS)	Healthcare Systems

Continued on next 2 pages

Code recording sheet produced for each paper (n = 41)

[Appendix 34]
I collated excerpts of text related to each concept code into columns and coded each one according to the perspective represented.
Example: Heath H and Phair L (2009) represented the perspectives of Academics (A), Researchers (R) and Geriatricians (G) [Table 1]



Stakeholder categories: (n = 7)

[Appendix 7] 35 individual perspectives were coded, I then grouped into 7 broader categories
Example: Researcher (R) and Academic (A) perspectives in Heath H and Phair L (2009) formed part of the category 'Academia'



Code recording sheet for each stakeholder category: (n = 7)

[Appendix 8] I collated concept codes from all 41 code recording sheets to produce a separate code recording sheet for each of the 7 stakeholder categories. I thematically analysed each excerpt and applied themes using wording used in the original text.



Thematic analysis

Continued on next page

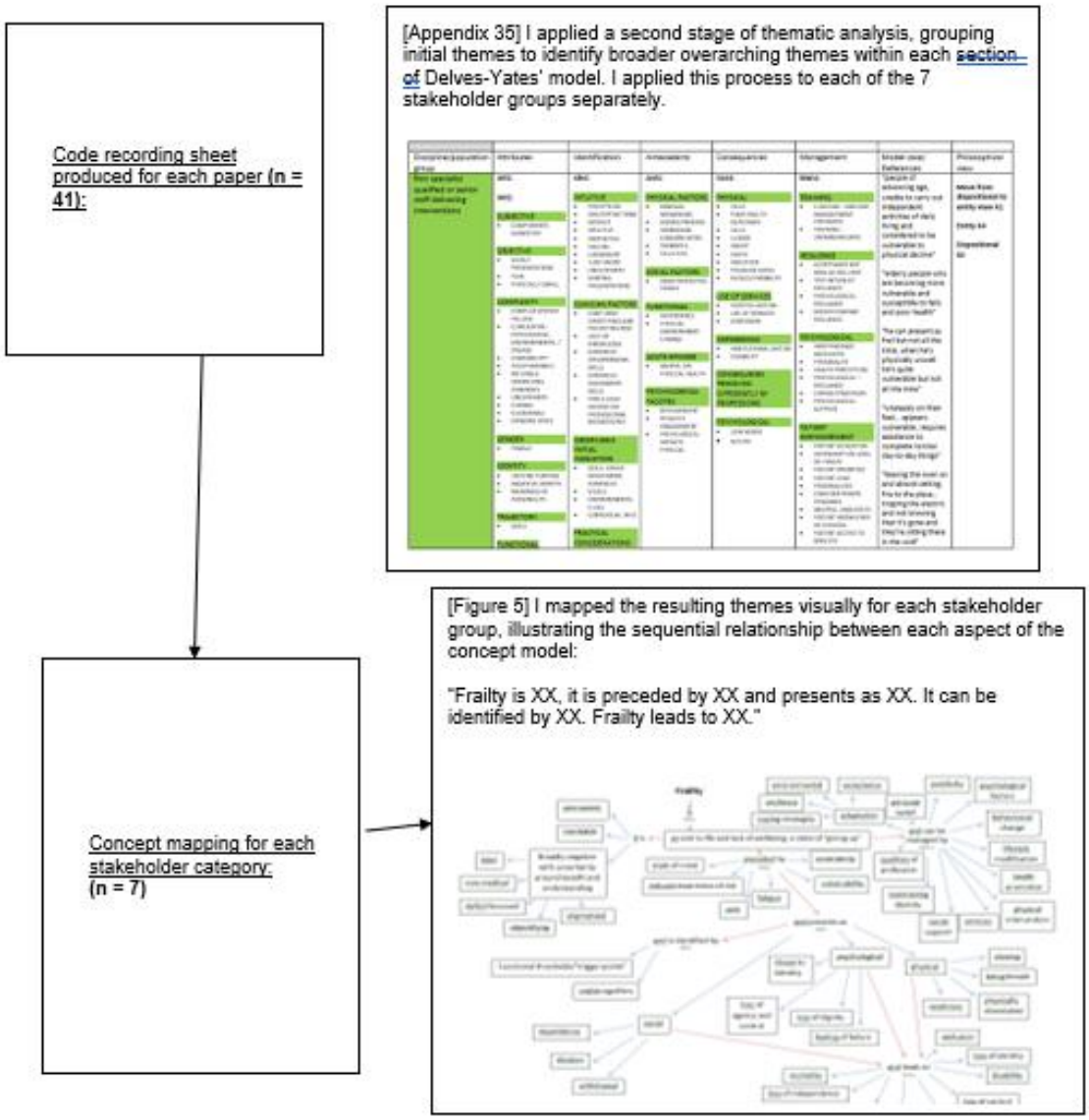


Figure 7: Process for the concept analysis

I produced visual concept maps for each stakeholder group using the codes derived through thematic analysis and presented these as concept statements for each group [Appendix 10]. I present a worked example of this for the stakeholder group 'people being described as frail' through table 2 [Sample of Thematic analysis by stakeholder category], Figure 9 [Sample of visual mapping of the relationship between concept attributes] and Table 3 [Sample of concept statement taken from Appendix 10].

Table 2: Concept analysis – Sample of Thematic analysis by stakeholder category – Coding for 'People being described as frail'

Concept analysis – Thematic analysis by stakeholder category							
Discipline/ population group	Attributes	Identification	Antecedents	Consequences	Management	Model case/ References	Philosophical view
	Att1: Has Frailty been operationalised, defined or conceptualised? **Att2:** Presents key characteristics, qualities or features inherent to Frailty? **Att3:** Is Frailty a useful concept?	**Ide1:** A specific means to identify or assess frailty is recommended and commented on?	**Ant1:** Events or phenomena preceding Frailty	**Con1:** Occurrences that follow Frailty defined	**Man1:** A specific management approach or intervention is recommended for frailty?	**Mod1:** Provides a clear example of Frailty **Ref1**: Identifies situations, incidents or phenomena in which Frailty can be considered.	**Phi1:** Entity, dispositional or evolutionary view of Frailty concept?
The people being described as frail	**Att1:** END OF LIFE "older people and their carers associated the term with end-of-life, cancer syndromes and high degrees of functional dependency" LACKING - WELLBEING "requiring the mobilisation of resources to create wellbeing" **Att2:** SENSE OF SELF • UNSUCCESSFUL • VALUE • FAILURE	**Ide1:** FUNCTIONAL THRESHOLD • TRIGGER POINT VISIBILITY • PHYSICALLY SMALL • OBJECTIVE • GESTALT	**Ant1:** POTENTIAL FOR CHANGE • VULNERABILITY • CHANGE • RISK • UNCERTAINTY PATTERNS • TRAJECTORY – GRADUAL • SPECTRUM • TRAJECTORY – CYCLE PSYCHOLOGICAL CONTRIBUTORS • STATE OF MIND KNOWLEDGE • REDUCED AWARENESS OF RISK	**Con1:** PHYSICAL CONSEQUENCES • MORTALITY • SLOWING • DEPENDENCY • HOSPITAL ADMISSION • DISABILITY PSYCHOLOGICAL CONSEQUENCE • SICK ROLE • NEGATIVE EMOTIONAL • LACK OF DIGNITY SOCIAL CONSEQUENCES • WITHDRAWN • DEPENDENCY • EXCLUSION LOSS • LOSS OF CONTROL • LOSS OF AUTONOMY	**Man1:** MODIFIABLE FACTORS • BEHAVIOURAL CONTRIBUTORS • PREVENTATIVE • LIFESTYLE MODIFICATION • OVERCOMING ATTIUDINAL BARRIERS • HEALTH PROMOTION PERMANENCE • PERMANENCE • INEVITABILITY MAINTAINING IDENTITY • CHOICE • ROUTINE • AUTONOMY • CONTROL • AGENCY	**Mod1:** "nothing wrong with my health but I have fallen five times and… I've broken everything" "for some a gradual decline and for others a sudden and shocking rupture which they related to	**Phi1:** Dispositional: 8 Entity: 1 Evolutionary: 1

	• AUTONOMY • MAINTENANCE OF IDENTITY • THREAT • DIMINISHED VERSION • ACCEPTANCE • IDENTITY • LOSS OF AGENCY **DEFICIT** • LACKING **LIVED EXPERIENCE** • EMOTIONAL EXPERIENCE • INDIVIDUAL EXPERIENCE • CONTEXTUAL • BALANCE • DEPENDENCE • MEANINGFUL ACTIVITY • HOME • PERSONAL **BIOLOGICAL** • MORTALITY • PHYSICAL CONSEQUENCES • PHYSICALLY DIMINISHED • SLOWING • GENDER **PSYCHOLOGICAL** • PSYCHOLOGCIAL CONDITION • PSYCHOLOGICAL CONTRIBUTORS • EMOTIONAL RESILIENCE • SICK ROLE		**PHYSICAL SYMPTOMS** • PAIN • FATIGUE	• LOSS OF IDENTITY • LOSS OF INDEPENDENCE • LOSS OF CONNECTIONS • LOSS OF MEANINGFUL ACTIVITY	• INDIVIDUAL EXPERIENCE • PERSONAL TRAJECTORY • ANCHORAGE • DOING TO V DOING WITH **COPING STRATEGIES** • RESISTANCE • LEVELS OF INTER-DEPENDENCE • PLANNING **BELIEFS** • REWARD/MOTIVATION • PERCEPTION **ADAPTATION** • ACCEPTANCE • ADJUSTMENT • DELEGATION • COMPENSATION • MANAGING CHANGE • ENVIRONMENTAL **POSITIVITY** • FOCUS ON ABILITY • FOCUS ON INDEPENDENCE **PSYCHOLOGICAL CONTRIBUTORS** • KEEPING GOING • INTERNAL DRIVE • EMOTIONAL EXPERIENCE • PERSONAL SENSE OF VALUE • INNER STRENGTH • KNOWLEDGE • RESILIENCE • RESPECT • ENGAGEMENT • MOTIVATION	a specific event, for example a fall” “a person that’s sitting in the armchair all the time” “losing independence, dignity and control” “isn’t strong… doesn’t have a lot of emotional resources… needs to be taken care of… they don’ have the resources themselves, they haven’t found the resources themselves… dependent… at risk… deteriorating.. more and more isolated”	

	• NEGATIVE EMOTIONAL • WILLPOWER SOCIAL • SOCIAL CONSEQUENCES • WITHDRAWAL • DIVIDING • SOCIAL CONSTRUCTION **Att3:** NEGATIVE • LINGUISTIC • LABELLING • DEFICIT FOCUS • IDENTITY • NON-MEDICAL • CONNOTATIONS • RESISTANCE • OBJECTIFICATION SKEPTICAL • WHOSE INTERESTS • RESONANCE • UNCLEAR BENEFITS • VARIOUS UNDERSTANDINGS				QUALITIES OF PROFESSIONAL • RESPECTFUL • RELATIONSHIP CENTRED • AGE • NON-SPECIALIST • COMMUNICATION SERVICE PROVISION • SPECIALIST INPUT • CONSIDERATION OF LINGUISTICS • TIMELY SUPPORT • INTENSITY OF SUPPORT • COMMUNITY BASED • NON-MEDICALISED PREFERRED • ACCESS • KNOWLEDGE • HOLISTIC • PERSONALISED • PRACTICAL • DURATION • CONTINUITY • FLEXIBLE • INFORMATION PROVISION SOCIAL SUPPORT • MAINTAIN CONNECTIONS PHYSICAL • MAINTAINING MOBILITY • EXERCISE		

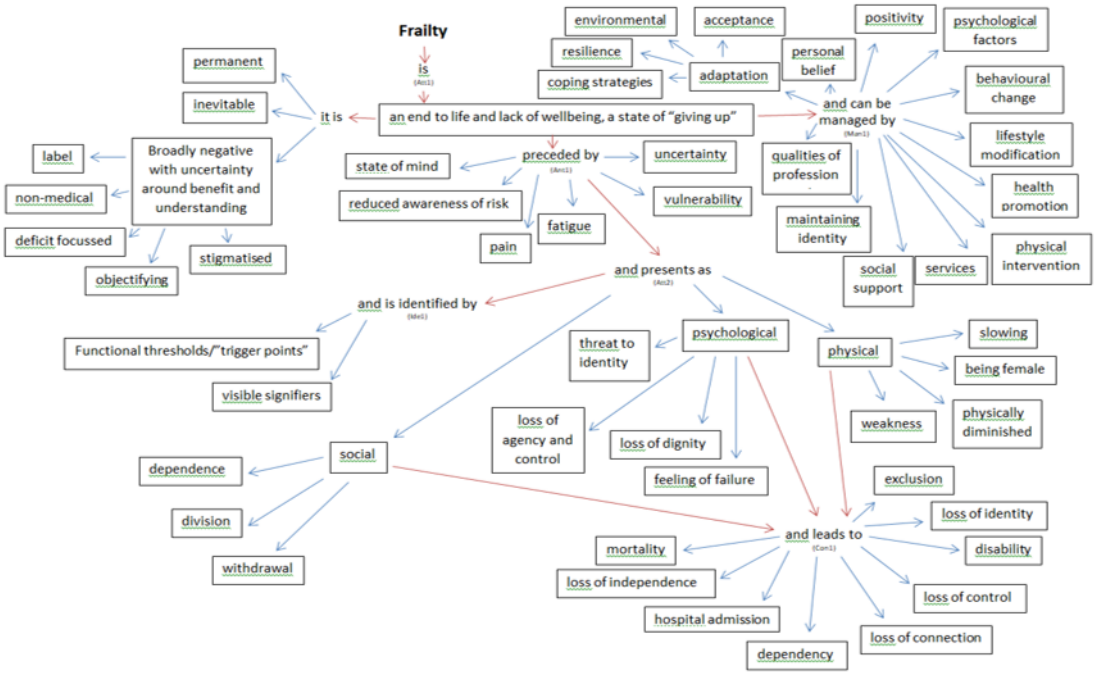


Figure 8: Sample of visual mapping of the relationship between concept attributes, using coding from 'People being described as frail

Table 3 Concept analysis – Sample of concept statement for the stakeholder group 'people being described as frail'

Concept attribute and code	**When the code was applied**	**Concept statement**	
Attribute (Att1) and Philosophical View (Phi 1)	Has Frailty been operationalised, defined or conceptualised? Entity, dispositional or evolutionary view of Frailty concept?	Frailty is…	…an end to life and absence of wellbeing…
Attribute (Att2) / References (Ref 1)	Presents key characteristics, qualities or features inherent to Frailty? Identifies situations, incidents or phenomena in which Frailty can be considered.	…it is…	…permanent and inevitable, broadly considered negative with uncertainty around the benefits and understandings (label, non-medical, deficit focus, objectified, stigma) …
Antecedent (Ant 1)	Events or phenomena preceding Frailty	…preceded by…	…state of mind, reduced awareness of risk, pain, fatigue, uncertainty and vulnerability…
Model case (Mod 1)	Provides a clear example of Frailty	…and presents as…	…social (division, withdrawal, dependence) …psychological (threat to identity, loss of agency and control, feeling of failure, loss of dignity) …biological (slowing down, being female, being physically diminished, weakness)

Identification (Ide 1)	A specific means to identify or assess frailty is recommended and commented on	…it is identified by…	…visible signifiers, and a functional threshold or “trigger point” …
Consequences (Con 1)	Occurrences that follow Frailty defined	…and results in…	…loss of independence, loss of control, loss of connection, loss of identity, acute admission, disability, dependency, exclusion, mortality…
Management (Man 1)	A specific management approach or intervention is recommended for frailty?	…and can be managed by…	…adaptation (resilience, acceptance, environmental) …positivity …psychological contributions …behavioural changes …lifestyle modifications …health promotion …physical intervention …maintaining identity

2.4 Concept Analysis Findings

In addition to observations on differences between stakeholder conceptualisations of frailty, I also identified themes which occurred across multiple stakeholder groups. I present and discuss these in the following sections.

Attitudes towards frailty

One unifying theme across all stakeholders was acknowledgement of differences between understanding and interpretation of the term across different groups. This variance may undermine proposals for shared clinical and social responsibility of frailty management [figure 9].



Figure 9: NHS Skills for Health Education England and NHS England (2018) Frailty Framework of Core Capabilities. Persons to whom the framework applies.

Although I acknowledge that the sample of 41 papers is somewhat limited in representing the views of 7 groups of stakeholders, sample size was sufficient to note key differences. In their investigation of language and perceptions in 2015, Britain Thinks found that frailty

conceptualisation by NSCs aligned more closely with that of the general public as a "descriptive term for a permanent state" (p12), rather than with the notion of a spectrum proposed within clinical guidelines. Although the views of specialist clinicians were minimally represented in this sample, tentative similar patterns were noted in the analysis. A comparison of professional bodies' conceptualisation and that of NSCs shows that although frailty is described similarly, as a complex state of vulnerability to both internal and external stressors, its perceived value as a concept is not shared. Governing bodies, experts and policy-makers present frailty as a broadly positive concept (Heath and Phair, 2009) enabling the clinician to provide a holistic personalised intervention to improve FPs outcomes (Britton, 2017; Gilleard and Higgs, 2010; Campbell and Buchner, 1997). The few clinical specialists represented also presented frailty as a broadly positive concept, a clinical tool used to support risk management in clinical decision making and care planning (Mudge and Hubbard, 2018; Britain Thinks, 2015).

NSCs presented an approximately equal mix of positivity and negativity towards the concept, acknowledging the potential of frailty as a unifying concept which could discourage silo working, but felt the term was unspecific and non-individual with the potential to do harm to dignity and identity (Nicholson et al., 2017; Schreuders et al., 2019). Outside of clinical contexts frailty was perceived as impersonal, stigmatising and broadly negative (Nicholson et al., 2017; Tomkow, 2018). Schreuders et al. (2019) noted "negative connotations of the colloquial understanding of frailty overshadowed the medical definition" (p3) amongst clinicians. NSCs appear positioned in the middle; a battle ground on which they must challenge the social stigma and rejection of frailty as a concept to implement the affirmative stance of the guidelines required by their professional roles.

Physicality

All stakeholder groups described physical aspects of frailty, the most common of which being weakening, slowing of movement and reduced mobility. Predominantly thought of as early indicators of a decline towards death, for most, frailty was associated with but not exclusive to the ageing process (Fried et al., 2004). Interventions to build muscle and bone density, counteract weight loss and improve aerobic fitness were widely discussed amongst academics and specialists (Campbell and Buchner, 1997). Whilst governing bodies and clinicians cited use of standardised assessment tools to quantify, measure and treat its physical presentation (Campbell and Buchner, 1997) such as grip strength and walking speed (Provencher et al., 2012), non-medical and FP perspectives tended to cite its physicality as visible features such as being underweight, stooped, pale or bruised (Coker et al., 2019), and considered these observable signifiers of a change in social role and autonomy (Nicholson et al., 2013). NSCs described how temporary changes to a

person's health or social circumstances could alter the 'appearance' of their frailty, confirming the observable nature of frailty (Coker et al., 2019).

The physicality of frailty took on more emotive and psychological meaning amongst those living with its daily reality, indicating how the components of the frailty fulcrum may be experienced differently by different people. FP frequently described resistance against visible identifiers such as mobility aids (Nicholson et al., 2012), and a preference for discrete environmental modifications (Nettleton et al., 2018). For FP, implications of the label reached far beyond simply using a walking stick in public. Visible frailty implied much more complex social ideas around retirement, loss of productivity and what it means to age successfully or in fact unsuccessfully (Nettleton et al., 2018; Richardson et al., 2011). As Gilleard and Higgs (2010) wrote; "…their frailty arises within the gaze of others, a gaze that sees in them the emergence of future dependency, decrepitude and death" p484. This was reflected amongst NSCs through a widespread perception that frailty could be identified by gestalt; that clinicians and society alike 'know it when they see it' (Nicholson et al., 2017; Whitson et al., 2007). Nurses in Britton (2017) described an accumulation of visible clues signifying frailty, such as environmental indicators of reduced coping and informal observations of mobility. They described recent frailty training which newly positioned frailty as a measurable state, not simply a general term. This indicates a spectrum in the theoretical approach to frailty as a concept; the quantifiable entity view adopted by governing bodies, through to the more individual dispositional stance adopted by the general public. Again, NSCs are currently on the middle ground.

Trajectory of change

Unlike with other medical conditions such as cancers, the concept analysis indicated that outside of healthcare frailty is not widely thought of in preventative terms. Professional and governing bodies align frailty management with the NHS long term plan (2019), focussing on prevention, pre-frailty and early intervention (Provencher et al., 2012). NSCs felt frailty is reversible only within earlier stages; consistent with evidence that transitions between lower levels of frailty occur less frequently, with "ample opportunities for prevention and remediation" (Gill et al., 2006, p1), and that individuals with fewer frailty characteristics or at the lower end of the frailty spectrum are more likely to regress to a lower frailty level than those with more advanced frailty (Espinoza et al., 2012). Conversely, more recent studies have been inconclusive around the delaying or reversal of frailty (Manthorpe and Iliffe, 2015; Tomkow, 2018).

Frailty is presented amongst academics as a continuous trajectory (Markle-Reid and Browne, 2003; Skilbeck et al., 2018); typically, a gradual decrease in independence and ability over time (Bortz, 2010). Representation of the trajectory of decline varied. Wallington (2016) cited Murray

et al. (2005a and 2005b) in reporting "…three potential trajectories of illness: short period of evident decline, long-term conditions with intermittent serious exacerbations, prolonged dwindling or frailty" (p387). She also suggests a "…continuum… robust and active – limiting activities… slowing down – needing help… recurrent episodes of illness… dependent… end of life" (Wallington, 2016, p386). Whilst academics consider long term frailty trajectories, the general public and FPs description of not only linear but also cyclical patterns of decline (Warmoth et al., 2016) echoes Wallington's notion of 'recurrent episodes of illness' later in the continuum, supporting the idea that FP focus on the later stages. In contrast to academic differentiation between frailty and disability, older people in Warmoth et al. (2016) used the two terms interchangeably to describe a current rather than potential state. FPs narratives focussed on the lived experience of established frailty, describing an inevitability of decline which must be accepted, not a reversible state they could control (ibid). This inevitability was echoed by social care managers using the phrase "just frail" (Manthorpe et al., 2018, p28) to imply non specialist care needs and an inevitable association with the ageing process, despite evidence that up to three quarters of people over the age of 85 may not be frail (Clegg et al., 2013). Social care managers also described frailty as a "spectrum, not in terms of pre-frailty but rather in its end stage" (Manthorpe et al., 2018, p30). This further serves to position NSCs concept interpretation in close alignment with the FP.

Several papers referenced a 'trigger point' at which an individual's reserve capacity is depleted such that they require support, perhaps even tipping into the 'dying phase' (Britain Thinks, 2015; Skilbeck et al., 2018; Nicholson et al., 2012). The individual contributors shape individual trajectory of decline. Objective and qualitative data shows most FP experience some degree of dependency a year prior to death, with steady deterioration leading to full dependency by the end of their lives (Skilbeck et al., 2018; Richardson et al., 2011).

Management strategies presented by FP were often based on resistance, coping and acceptance (D'Avanzo et al., 2017); avoiding association with the overall state of frailty and attributing their frailty to a specific physical limitation (Warmoth et al., 2016). Public perceptions related to humiliation, fear and helplessness (Gilleard and Higgs, 2010), and FP themselves described a feeling of personal failure (Mudge and Hubbard, 2018; Nicholson et al., 2017; Tomkow, 2018). Frailty was recurrently described as a term used to describe and objectify 'others' (Tomkow, 2018), but never a term one would use to describe themselves (Gilleard and Higgs, 2010), with clear associations between acceptance of frailty and 'giving up' (Britain Thinks, 2015). The extrinsic labelling of frailty was seen to cause social exclusion, which in turn accelerated deterioration (Warmoth et al., 2016).

Conceptually frailty journeys were characterised by FP as individual adaptability to deterioration, dependent upon one's inner resource and strength (Sezgin et al., 2019). Integral to this was individual understanding of the fluctuations within frailty trajectories (Richardson et al., 2014). At times judgement of 'other' was implied, in model case examples such as "a person that's sitting in the armchair all the time" (Frost et al., 2018). There was an impression of weakness of character as per the dictionary definition of frailty. Although one participant's account hinted at underlying complexity, when she talked about there being 'nothing wrong with her health but she kept falling over and breaking things' (D'Avanzo et al., 2017), there were few direct accounts amongst frail people of complexity, dynamic interplay of components or of a presentation resembling the fulcrum of contributory factors presented by NHS England.

Antecedents

There is a consensus in the literature of a presumed association between frailty and ageing however the two are not mutually dependent. Bortz (2010) described potential for malnutrition and inactivity causing frailty in younger people. Depletion of reserves is a common theme, however the nature of depleted reserves varied resulting in acknowledgement of unique individual responses to stressors (Whitson et al., 2018). Whilst many papers cited physical depletions in nutrition (ibid), endocrine function and body composition changes, insulin regulation (Pel-Little et al., 2009), immune and neuromuscular changes (Provencher et al., 2012), ageing cardiovascular systems, metabolism and immune systems (Pel-Little et al., 2009), others focused upon socioeconomic antecedents such as lower education levels, household income (Rockwood et al., 1994) and social isolation (Pel-Little et al., 2009). Psychological antecedents were acknowledged by both academic and non-medical groups, citing causal links between low self-perception of health, and depression with developing frailty (ibid). Perceived antecedents prevalent amongst FP included a lack of "emotional resilience" (Grenier, 2007) and the influence of individual mind set (Sezgin et al., 2019; Britain Thinks, 2015), seen in the viewpoint; "thinking of yourself as frail then you gonna have some subsequent frail behaviour" (Sezgin et al., 2019, p20). Lifestyle choices such as alcohol consumption, smoking and activity levels (ibid) also hinted at the question of responsibility, discussed later.

Resilience v threat

NHS England's Frailty Fulcrum depicts vulnerability and resilience as opposites. Within the concept analysis texts however, resilience was presented as a related term but with debate over whether it can reasonably be considered the opposite to frailty (Whitson et al., 2018). Resilience has been described as a measure of success in the transition between two points in time and frailty as a static measure of potential change (ibid), thus presenting the terms as integral to the

same trajectory but not opposites. Healthcare professionals may not consider acceptance of reduced function as a resilient response to deterioration (Richardson et al., 2014), preferring perhaps to see the individual resist the stressor. FP may disagree with this perspective, describing 'keeping going' as 'adaption to' and 'acceptance of' rather than rigid resistance (Nicholson et al., 2013; Richardson et al., 2014; Skilbeck et al., 2018). Richardson et al. (2014) describe "psychological success (as) an older person being able to adjust their goals when faced with the kinds of challenges that tend to occur in old age" p1381. Thus, to the individual, resilience, like frailty, could depict either a static or dynamic state. Whitson et al. (2018) suggest resilience is considered in the context of a lifespan, whereas frailty represents the limited end stage of a life; supporting linguistic differences in describing preventative early intervention versus late-stage management and cautioning against a deficit focus.

The notion of threat was common across all stakeholder groups, but its nature varied. Frailty was presented both as a 'threat of' (mortality, reduced independence, poor health outcomes) and a 'threat to' (services, budgets, social support systems). Frailty is thus problematized (Tomkow, 2018). For clinicians, frailty poses a threat to service capacity and cost alongside clinical outcomes for the patient. To the FP however threat came about via the use of the label itself, and the implied change to identity and social position (Nicholson et al., 2013). Frailty was associated with threat of unmet need and unfulfilled desires (Grenier, 2007). As with frailty, it is important to note that resilience is not a term commonly used by FP when describing themselves and should therefore be used with caution (Richardson et al., 2014). Tomkow (2018) wrote passionately about the threat of frailty becoming a biopolitical tool to exacerbate power inequalities between service and FP if its use progresses without the FPs perspective. All stakeholders shared a notion of frailty as an eventual threat to life and independence.

Whitson et al. (2018) describe resilience as the ability to utilise reserves in response to a stressor. Delay in deploying compensatory responses is linked to threat of neglect (Heath and Phair, 2009), thus strategies supporting the prompt use of resilient responses should be central to management plans (Skilbeck et al., 2018), with consideration given to autonomous implementation. Rather than being the most vulnerable, the oldest old are 'the survivors' (Nicholson et al., 2017); individuals with proven successful resilience which should be actively identified and supported. A clear differential was presented between physical, social and psychological frailty (Kuh, 2007); that one could be physically frail but maintain a "resilient sense of self" (Richardson et al.,2014, p1393), hinting at the psychological influence on responses to threat.

Identity and autonomy

Use of language amongst FP was frequently, although not solely, rooted in emotional lived experience (Sezgin et al., 2019), loss, loneliness (Skillbeck, 2018) and sense of self. Clearly linked to the ageing process, frailty was associated with transitioning from the "third-age (of) personal fulfilment" to the "fourth age (of) final dependence, decrepitude and death" (Laslett, 1994 p4), a "fluid space" (D'Avanzo et al., 2017, p2), where power and vulnerability can both be experienced. Gilleard and Higgs (2010) described "a state of becoming" (p476). Clear distinctions were made between being and feeling frail, with the former described as an externally imposed classification and the latter reflecting a temporary emotional state (Warmoth et al., 2016 citing Grenier, 2006). Older women in Grenier's later paper (2007) consistently associated feeling frail not with physical symptoms but with loss of control. Even those clinically classed as frail and fully acknowledging their physical decline did not self-identify as 'frail', evoking strong emotional reactions and even offense (Britain Thinks, 2015). The term implied a "…fading of personhood" (Mudge and Hubbard, 2018, p510), and a sense of detachment from citizenship (Gilleard and Higgs, 2010); a loss of identity at an individual level but also within social contexts. As the physical body declined, FP described a clear distinction between "…the body one is (self-identity) and the body one has – a physical, vulnerable and objectified social identity" (Nicholson et al., 2012, p1427).

FP attributed significance to the resistance or adoption of a 'frail identity'; reporting social and physical disengagement increasing the likelihood of adopting a frail identity, and that to self-identify as frail leads to further frailty manifestation (Warmoth et al., 2016). Emotional responses to frailty may be protective (Grenier (2006) (in Nicholson et al. (2012)) as they prompt resistant and perhaps self-affirming reactions. There was a sense amongst FP that identifying as frail acknowledged reduced self-worth (Warmoth et al., 2016), strength of will, and self-efficacy (Schreuders et al., 2019); a label which would overwhelm existing identity (Richardson et al., 2011; Gilleard and Higgs, 2010). FP maintained a continuous sense of self (D'Avanzo et al., 2017) to resist an identity imposed by others, and associated disempowerment and loss of autonomy (Gilleard and Higgs, 2010). Deficit focussed intervention was cited as contributing to perceived disempowerment, with "lived experience… reduced to a list of problems" (Richardson et al., 2011, p24). Nicholson et al. (2017) proposes the adoption of a "salutogenic approach" (p350). Personal narratives were key (Richardson et al., 2014), with maintenance of cognitive function (Frost et al., 2018), physical contexts and daily routines playing important roles (D'Avanzo et al., 2017).

Socioeconomic and political contexts

"Health policy and biomedical discourses of frailty-prevention strategies largely centre on associations between frailty and individual health behaviours" (Tomkow, 2018, p705), however a

social gradient is noted. Lower income, areas of deprivation and limited educational background were associated with increased frailty incidence (Manthorpe et al., 2018), demonstrated by reduced balance, chair rise times and poor subjective wellbeing (Tomkow, 2018). Socio-economic antecedents of frailty correlate with associations of reduced productivity and social value, but challenge notions of frailty as a shameful blame-worthy state (Tomkow, 2020; Nicholson et al., 2013). Tomkow (2018) raises ethical concerns around encouraging self-management, placing the weight of responsibility solely with the individual, disregarding "…structural causes of health inequalities" (p696). Frailty is therefore "not just an individual problem, but a public health and political matter" (Manthorpe et al., 2018, p27). This discourse however creates a counterproductive representation of a disempowered individual at the mercy of social and political contexts, thus ironically reinforcing unhelpful power dynamics; perhaps an echo of the historic concept of the 'deserving poor'.

Locations

All stakeholders agreed that preventative care at home was optimal for FP (Britton, 2017), consistent with current ambitions for 'left shift' and neighbourhood delivery models. Ambulance clinicians expressed anxiety around promptly identifying and responding to deterioration in the community, with a perceived risk of clinical failure (Green et al., 2018). Despite avoidable admissions in the short-term risking delayed recovery and persisting deficits known as 'post-hospital syndrome' (Mudge and Hubbard, 2018), they cited admission as an effective pathway to get 'into the system' (Green et al., 2018). Advance communication of FP treatment preferences was discussed by NSCs as person-centred practice (Green et al., 2018; Sharp et al., 2018) and supported by informal carers of FP in their desire for joined up services (Britain Thinks, 2015).

In Nettleton et al. (2018), young architects showed limited evidence of FP perspective, envisaging care homes within city centres for access to shops and social connection. Person-centred decisions were made within the homes however, with emphasis placed on the kitchen as "a significant space of 'ownership'" (p59) and on minimising visible features which 'overtly admit' a support need. They used possessions and memories within the home to create a sense of belonging, stability and security, whilst affirming identity (ibid). There was an uncomfortable acknowledgement of how physical deterioration impacts interactions between the physical self and the environment. Maintenance of daily routines was cited by FP as important in maintaining a sense of self, but also by academics in providing "anchorage" (Nicholson et al., 2013).

2.5 Concept analysis discussion

In contrast to emphasis on frailty evident in the guidance of governing bodies and professional frameworks, the term is used less frequently and less positively amongst the general public, FP and NSCs. Rodgers (1989) proposes that "a concept that is considered significant will be used often, ultimately facilitating the development of productive innovations and variations" (p332), thus implying lower perceived significance conceptually at the clinical front line as at a strategic level. However, care home managers (Schreuders et al., 2019) and NSCs (Britain Thinks, 2015) indicate 'frail' is not a term frequently documented, but is used as informal verbal 'shorthand' to "justify investigative or therapeutic nihilism" (Campbell and Buchner, 1997). This clinical use is difficult to evaluate but indicates contention not around the underlying concept of vulnerability, but the intention of its use (Grenier, 2007; Britain Thinks, 2015). Clinical records are accessible by their subject; therefore, the omission of the term 'frail' indicates it is not a term one would comfortably use in front of or with the individual. Mudge and Hubbard (2018) go further in questioning the value of frailty as a fundamental concept, challenging whether interventions shown to improve frailty such as physical activity are uniquely beneficial to frail or pre-frail individuals, or whether a broader public health approach should be adopted, evidencing the importance of control groups in studies evaluating targeted interventions.

The adoption of positive acronyms for frailty services in some areas of the UK such as 'FIT' (Frailty Intervention Team) and 'FAB' (Frailty Assessment Base) appear to disguise the term amid a more positive alternative, and evidence the role of clinicians in bridging the gap between policy makers' and FPs conceptualisations of frailty. Buta et al. (2016) systematically explored the characteristics and uses of existing frailty assessments. In total 67 assessment tools were identified, most used to assess risk of frailty but with scarce incidences of use to aid clinical decision making or to guide targeted intervention as per the positive attributes of frailty cited by clinicians (Green et al., 2018), experts and governing bodies. This demonstrates discrepancy between intention and practical application.

This concept analysis supports the widely recognised differences between clinical and social understandings of the term 'frailty', shown to be a barrier in FP engagement and outcomes [Appendix 10]. Social and individual definitions influence choices and behaviours, thus patient-centred practice is impeded (Richardson et al., 2014) and therapeutic opportunities missed (Skilbeck et al., 2018) without this understanding. In contrast to the predominant biomedical focus of the evidence base, FP place emphasis on the psychological and social domains as antecedents, management approaches and consequences of frailty. In the 1940s Abraham Maslow developed a model for considering human need, often presented in the form of a

pyramid, with more basic needs (e.g. food, water, warmth) at the base, moving up through safety needs (health and wellness, financial security, safety against injury), the need to belong and be loved (friendships, family, social and romantic connections), esteem needs (personal worth, self-esteem and respect), to self-actualisation at the top (personal growth and fulfilling of full potential). The original model proposed a hierarchical approach, suggesting needs higher up the pyramid cannot be met without first addressing the base levels, however academics have increasingly challenged this hierarchical thinking, with more recent studies suggesting belongingness and esteem needs may be greater influential predictors of life satisfaction (Mendez and Rojas, 2024). Mendez and Rojas' 2024 study found that "physiological and safety needs may have a limited impact on other needs, whereas gratification of higher needs such as belongingness, esteem, or self-actualisation could exert a more substantial influence on other needs" p6, supporting the perspective that personal and social factors may act as antecedents to poorer outcomes or offer opportunities for active management approaches. Having robust resources in place in these higher levels of Maslow's pyramid may not simply affect life satisfaction as a passive outcome but may actively affect more tangible outcomes across the other levels.

In 2016 the International Association of Gerontology and Geriatrics and Global Ageing Research Network published The White Book on Frailty, to "promote preventative interventions… highlight current knowledge on the identification and assessment of frailty… and the main frailty pathologies… preventing and/or delaying disability and dependence" (p4). The work however excludes the experience or voice of the frail individual, and as such "privileges biomedical and expert knowledge about function and decline over the emotional and embodied experiences of acquiring impairment" (Grenier, 2019, p10).

Despite the literary dominance of a medicalised focus on bodily impairment, recognition of the environmental, social and experiential domains of frailty is growing (Grenier, 2007; Schreuders et al., 2019). The social sciences argue that frailty is socially constructed (Kaufman, 1994), and reducing its conceptualisation to biomedical domains overlooks complex social and psychological contributors (Grenier, 2007; Gilleard and Higgs, 2010). The evolution of frailty as a holistic concept in the absence of a shared definition has generated independent frailty phenotypes including cognitive frailty (Royal College of Psychiatrists, 2020), nutritional frailty (Zupo et al., 2020) and social frailty (Bunt et al., 2017), with poverty and reduced access to medical care emerging as frailty indicators (Mudge and Hubbard, 2018). These definitions resonate with perceptions of NSCs, who perceived higher overall frailty in those without strong social support networks (Coker et al., 2019).

Higher depression incidence is cited amongst frail individuals (Lakey et al., 2012), and frailty is noted as a risk factor for cognitive decline (Avila-Funes et al. 2012). Links between depression and physical activity levels have been demonstrated, and loneliness has been associated with subsequent onset of frailty (Gale et al., 2018). Psychological wellbeing is known to be a protective factor in the prevention of developing frailty with control, autonomy, self-realisation and pleasure being more strongly correlated with a decreased risk of pre-frailty (Gale et al., 2014). This indicates a clear relationship between cognitive and psychological domains, and frailty. The BGS advocate multi-disciplinary CGA as the 'gold standard' for optimising outcomes, referring in their 2014 paper to the gradual deterioration of reserves across multiple body systems, however the 2020 position statement from the Royal College of Psychiatrists 'Frailty – ensuring the best outcomes for frail older people' highlights limitations in the CGAs assessment of cognitive and psychological aspects. A contemporary study of older institutionalised women in Portugal presents a potential new phenotype - psychological frailty, strongly associating emotional wellbeing and cognitive performance with physical frailty. Of note was "transition from the non-frailty to the pre-frailty condition (being) the most critical period for the development of negative outcomes in several (psychological wellbeing) domains" (Furtado et al., 2020, p8).

In the UK, the National Institute of Clinical Excellence (NICE) present frailty alongside dementia and disability (NICE, 2015), acknowledging both physical and psychological presentations and advocating individual behaviour change approaches as cost effective preventative strategies. Alongside health behaviour change, potentially controversial challenges to social norms are also promoted such as the expectation of 'slowing down' or 'taking a break' in older age. The prolonging of active lifestyle and promotion of 'ageing well' is well intentioned, however tackling this extrinsically via social expectations rather than promoting intrinsic factors such as patient empowerment and activation may further re-enforce an unhealthy power imbalance. An international systematic review conducted in 2012 noted that frailty levels amongst over 65s could be calculated as between 4% and 17% when using the phenotype model, however this increased to between 4.2% and 52% when using the cumulative deficit model which encompasses psychosocial frailty. NICE 2015 state however "…there is a lack of evidence on the most effective ways to address psychosocial factors and on their effect on the development of… frailty" (p30). Psychological and social frailty may be underreported and unaddressed, leading to much poorer outcomes.

NSCs in Coker et al. (2019) preferred profession specific assessment tools to build discipline specific understandings of frailty, for instance nurses discussed risk of infection and pressure injury, whereas therapists focussed their concerns on risk of reduced mobility as indicators and

consequences. Standardised measures were widely valued, however less so within frailty measurement (Campbell and Buchner, 1997; Green et al., 2018). In contrast to the benefits of an accessible standardised measure, community nurses felt the CFS was ambiguous, and open to subjective application (Britton, 2017), citing a preference for intuitive identification of frailty (Coker et al., 2019) until evidence of the value of an assessment tool is presented. Ambulance clinicians questioned the subjectivity and value of an "educated guess regarding usual levels of functioning" (Green et al., 2018, p27) regarding guidelines for CFS use in an acute episode (NHS Specialised Clinical Frailty Network, 2018). Clinical concern focusses on failure to fully capture the complex lived experience of frailty (Markle-Reid and Browne, 2003), or account for the context of assessment (Whitson et al., 2007; Nicholson et al., 2012). This consideration is supported by FP in Richardson et al. (2014), who reported the setting could influence individual experience of adversity. These examples represent the difficulties in operationalising frailty in the absence of shared conceptual clarity and the challenges of simplifying a complex concept. The frailty fulcrum exemplifies this, reducing complex biopsychosocial elements to a two-dimensional model, polarising them as either a positive or negative influence.

Occupational therapy (OT) is a profession which "empower(s) people to… overcome barriers preventing them from doing the activities (or occupations) that matter to them… (and) increases people's independence and satisfaction in all aspects of life" (Royal College of Occupational Therapists (RCOT), no date), thus their professional remit aligns strongly with the focus on functional outcomes of frailty such as those presented in Skilbeck et al.(2017). OT literature would argue that interactions between contributing factors are in fact three dimensional, as shown by the 'Person Environment Occupation' (PEO) model (Law et al., 1996), whereby biopsychosocial elements interact across domains of person, task and context [Appendix 33]. With this theoretical model underpinning practice, it is possible the involvement of OTs may show promise in moving discussions away from the binary success and failure balance of a fulcrum, towards reflecting the more complex dynamics of adaptation and coping cited by FP and clinicians dealing with frailty daily.

Since the completion of this concept analysis further research has been published adding to understanding of perceptions of frailty. Durepos et al's scoping review of older adults' perceptions of frailty language in 2022 included 8 studies from a range of Western countries including the UK. Using a narrative summary approach, the authors identified three key themes; 1. The inevitability of frailty as age-related biopsychosocial decline; 2. perception of frailty as a negative generalizable label, and 3. Perception that self-identifying as frail or being classified as frail by others has a direct causal relationship with negative health behaviours including health care utilisation (p198).

These themes support the findings of the concept analysis presented in this chapter which is perhaps unsurprising given the commonality in included papers, although the review added no further insights into the perceptions of other groups. There were no newer studies identified by the authors despite the date of publication being 3 years after the concept analysis was completed, which suggests slow growth in the evidence base around this subject in comparison to the growing body of research around frailty as an area of academic and clinical interest more broadly. Golbach et al. (2024) undertook a phenomenological qualitative study exploring the perspectives of Dutch community-dwelling older people regarding frailty and its opposing concepts. The findings affirmed the notion that older people recognise physical, psychological and social domains of frailty, but in addition also perceived financial and digital resources as significant but previously less considered domains; an indication of the role social deprivation and affluence may play. Additionally, "...older people perceived cognition as an essential aspect of frailty." (Golbach et al, 2024, p2) hinting that those living with frailty may perceive their own ability to rationalise, problem solve and plan as key to both lived experience and outcome.

2.6 Recommendations

Recognising frailty as a long-term condition has been proposed nationally; an idea supported by characteristics "such as episodic deteriorations, preventable or modifiable components and disease trajectories with defined phases" (Waldon, 2018). To do so, the influencers on trajectory and transition between phases must be better understood. Frailty is commonly measured using a scale which describes a static point in time, but not necessarily the pattern or trajectory of individual frailty, therefore providing limited indication of the risk of unmanaged deterioration. The pace of deterioration between frailty levels is a key concern for clinicians in community frailty management, a preferable location for care. FP cite a causal relationship between mindset and frailty trajectory, not necessarily an ability to resolve physical deterioration but to adapt effectively to associated changes. A strong sense of psychological wellbeing later in life may be a protective factor against developing physical frailty (Manthorpe and Iliffe, 2015), however NICE (2015) identified inadequate evidence related to this area, including the:

> *"relationship between psychosocial risk and protective factors in mid-life and the development (of frailty)*
>
> *effectiveness and cost-effectiveness of interventions for people in mid-life to address behavioural and psychosocial risk factors and their long-term impact on the delay or prevention (of frailty)*

relationships between the risk factors, compensatory behaviours when a risk factor is changed and which risk factors to address first" (p51).

These gaps suggest psychosocial contributors to frailty have been historically under-researched (Coker et al., 2019) yet resonate strongly with FPs conceptualisation of frailty. This presents an opportunity to remedy the absence of FP perspective in frailty research (Mudge and Hubbard, 2018). Despite promotion of early intervention, current evidence suggests medical professionals are not viewed by people in the early stages of frailty as a first port of call to seek help (Britain Thinks, 2015). Communication skills are valued but professional qualifications, although preferred by carers, could be detrimental to engagement as they connote medicalisation and dependency (Frost et al., 2018). To address challenges around engagement, co-production of service design may offer patient-lead solutions. Self-management approaches, when appropriately supported, allows autonomous informed decisions about individual choices and behaviours and empowers the individual to access and coordinate resources to support their wellbeing (Tomkow, 2020). The BGS toolkit for CGA in primary care (no date) provides practical tips to achieve this, however "self-management strategies are less readily utilised in poorer socio-economic groups" (Tomkow, 2018, p705). Further exploration of factors influencing self-management is warranted, to ensure patient-centred use.

A concept which echoes the notion of 'mindset' as a contributing factor and which may show promise in frailty management is patient activation, defined as; "a measure of a person's knowledge, skills and confidence to manage their own health and wellbeing, and is a core enabler for supporting self-management and personalising care" (NHS England, 2018, p3). It is "widely acknowledged that people who have knowledge, confidence and skills to manage their own health tend to have better health outcomes" (NHS England et al., 2018, p6). Patient activation is supported through personalised interventions such as health-coaching, condition specific education and access to peer support (ibid). Heath and Phair (2009) found "identifying coping styles, providing education regarding healthy lifestyles and the management of chronic illness using a participatory approach" (p128) to be effective in frailty management. The Patient Activation Measure (PAM) could add value in investigating the influence of mindset on frailty care planning and intervention, and in doing so progress a research area derived from the accounts of FP; however, cost implications associated with licencing present a barrier to use at this stage.

Summary

In this chapter I have presented an analysis of different understandings of frailty and how these differences may affect both clinical practice and frailty research. Perceptions of biopsychosocial

influences on frailty have been discussed, and I described how people living with frailty in the existing literature may perceive psychosocial factors as significant influences on frailty change and deterioration. In chapter 3 I present a review of existing literature pertinent to this subject area with a view to refining research questions and objectives.

Chapter 3: Scoping literature review

Building on concepts of frailty identified in chapter 2 this chapter reports on a scoping review of the literature and what is already known about the influence of psychosocial factors on living with frailty in the community. The initial literature search was completed in 2021 and updated in 2023. This chapter will conclude with the research questions and objectives identified as a result of this scoping review.

3.1 Literature review

A broad and systematic scoping review of the literature was completed in 2021 using the strategy and criteria detailed in Appendix 8, addressing the question 'What is known in the existing literature about the influence of psychological and social factors on changes in frailty status in UK community settings?'. Based upon the idea that psychological and personal factors can be an antecedent to frailty the review aimed to synthesise existing insights into this complex relationship. Tong et al.'s 2012 framework for enhancing transparency in qualitative synthesis was used to support this process. A scoping review approach allowed for the inclusion of a broader range of methodological approaches than a systematic review might encompass, and for a qualitative approach to synthesising evidence (Bunt et al, 2017).

Existing literature suggests language used to conceptualise frailty differs between stakeholder groups, for example in Skilbeck et al. (2018) the clinicians' perspective is of a "tendency to view frailty within a narrow biomedical and functional framework" p2, whereas older and frail people, whilst acknowledging the accumulation of physical and functional deficit, described a more emotive and psychological representation of "frailty as anxiety, fear and uncertainty… feeling frail… episodes of uncertainty challeng(ing) identity…" (Ibid. p4). To capture both lived experience and clinical perspectives, language for this scoping review was drawn from both the clinical guidance documents (NHS Rightcare, 2019) and from the language used by older people in existing studies (Grenier, 2007; Sezgin et al., 2019; Britain Thinks, 2015; Skilbeck et al., 2018). Search terms relevant to the proposed cultural setting were selected. Variation in cultural contexts and social norms which might alter use of terminology was limited by drawing upon only UK based studies as reference points for search terms. The sample was not restricted by language however no full studies required translation as available title and abstract translations were adequate to apply inclusion/exclusion criteria. The PRISMA flow diagram in figure 10 indicates the search and selection process applied in identifying the included sample of papers, whilst Appendix 9 provides further detail of the search terms used. The process was conducted solely by the researcher due to limited resources. Whilst it is acknowledged that the absence of additional

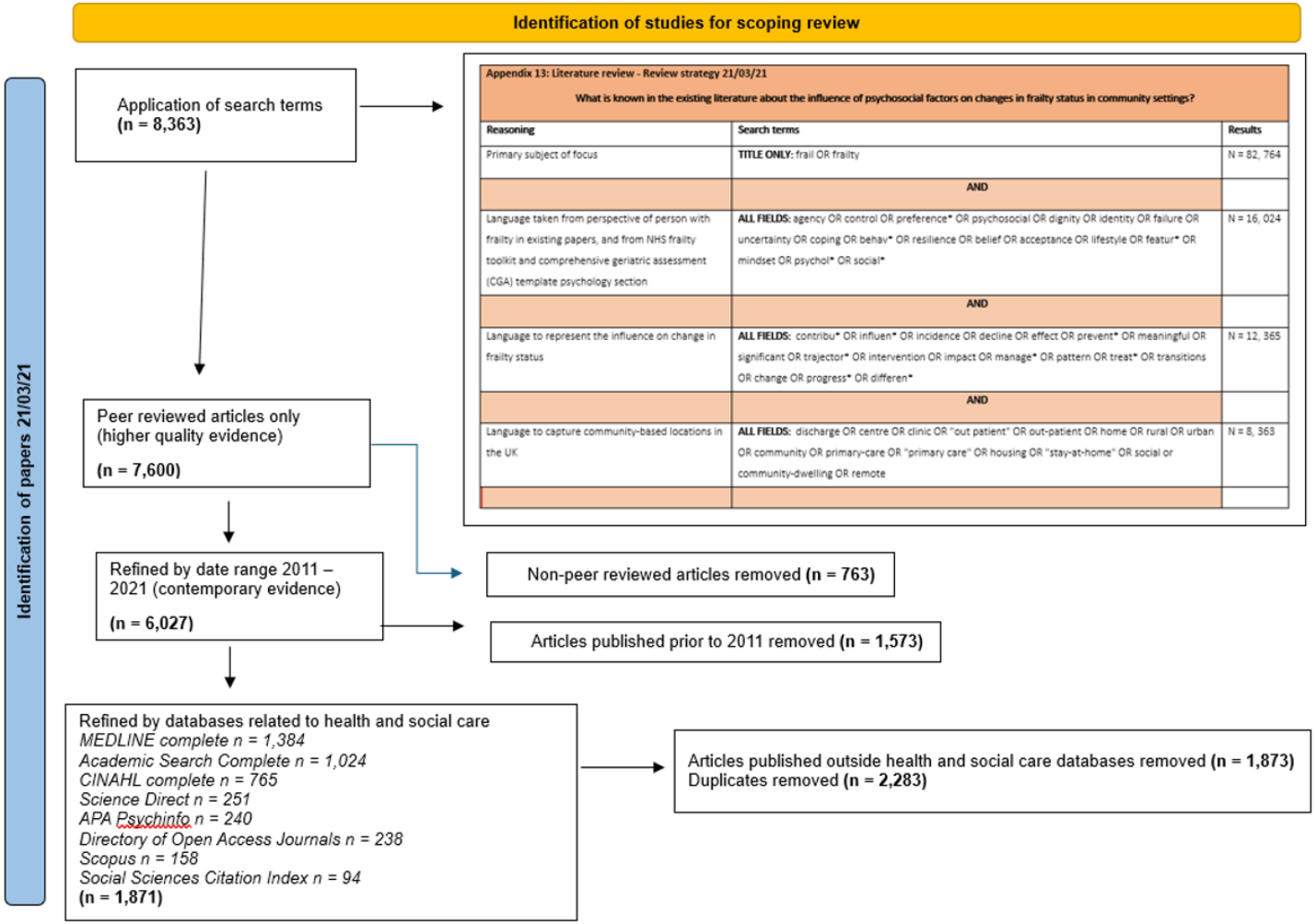
independent review limits perspectives on inclusion decisions, this was mitigated as far as possible by excluding papers only at the full text review phase if any uncertainty of focus was identified in the title and abstract review. A final sample of 21 papers were selected for more detailed analysis.

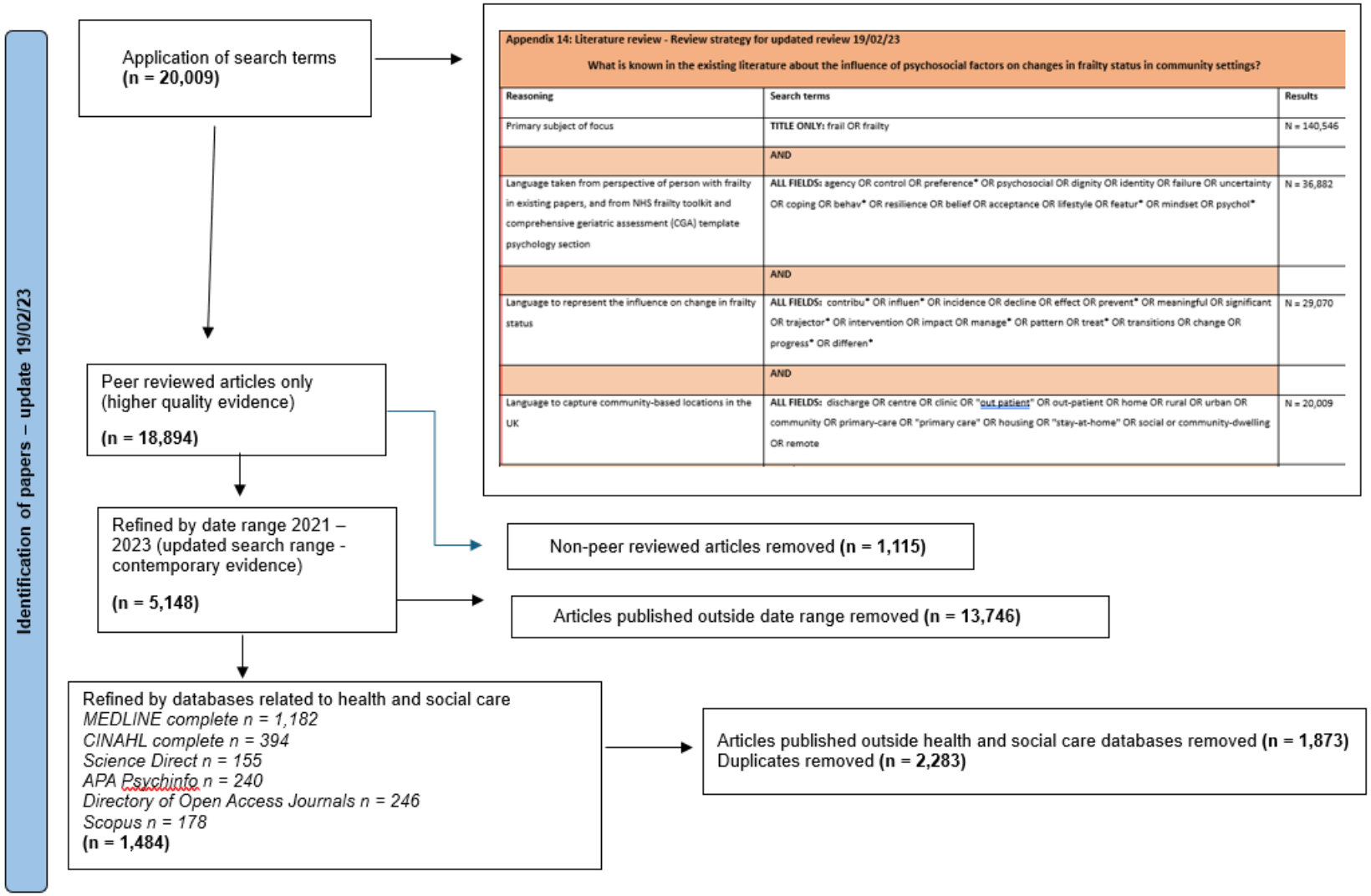
The 21 included texts were critically analysed by the researcher regarding their methodology and rigour, and to what extent their conclusions answered the review question [Table 4]. Critical appraisal skills programme (CASP, no date) checklists were utilised for more detailed analysis of the most pertinent papers. Key themes from each paper were identified as each text was thematically analysed, then compared manually. A summary account was then produced, with quotations from each paper selected and included to support each theme (Tong et al. 2012).

3.2 Data sources

Of the selected sample, several papers drew from the same datasets. Two papers used data from the Whitehall II study (Brunner Et al., 2018; Gil-Salcedo et al., 2020), and 6 used data from the English Longitudinal Study of Ageing (Rogers et al., 2020; Niederstrasser et al., 2019; Maltby et al., 2020; Gale, 2014; Gale et al., 2017; Gale et al., 2018; Hubbard et al., 2014). This lowered the overall picture of original data which had been produced to address this topic.

Figure 10 PRISMA diagram 2 – identification of studies for Scoping Review 2021 and updated Search Results 2023





Appendix 14: Literature review - Review strategy for updated review 19/02/23

What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in community settings?

Reasoning	Search terms	Results
Primary subject of focus	**TITLE ONLY:** frail OR frailty	N = 140,546
	AND	
Language taken from perspective of person with frailty in existing papers, and from NHS frailty toolkit and comprehensive geriatric assessment (CGA) template psychology section	**ALL FIELDS:** agency OR control OR preference* OR psychosocial OR dignity OR identity OR failure OR uncertainty OR coping OR behav* OR resilience OR belief OR acceptance OR lifestyle OR featur* OR mindset OR psychol*	N = 36,882
	AND	
Language to represent the influence on change in frailty status	**ALL FIELDS:** contribu* OR influen* OR incidence OR decline OR effect OR prevent* OR meaningful OR significant OR trajector* OR intervention OR impact OR manage* OR pattern OR treat* OR transitions OR change OR progress* OR differen*	N = 29,070
	AND	
Language to capture community-based locations in the UK	**ALL FIELDS:** discharge OR centre OR clinic OR "out patient" OR out-patient OR home OR rural OR urban OR community OR primary-care OR "primary care" OR housing OR "stay-at-home" OR social or community-dwelling OR remote	N = 20,009

Figure 11: Inclusion and exclusion criteria for Scoping Review

	Inclusion	Exclusion	Rationale
1	"Frail" or "Frailty" included in title	"Frail" or "Frailty" not included in title	Frailty to be primary focus of paper, to capture most significant evidence
2	Terminology used by people with frailty in existing literature or used by UK clinical guidelines, to refer to psychological aspects of frailty	Papers not using this terminology will not have been captured	Broad use of known clinical and lay perspectives to maximise breadth of sample
3	Terminology which describes a change in status or an active influence on the progression of frailty	Studies which do not refer to change in frailty *or* psychological status among people with frailty	Aiming to include all studies which offer insight into the relationship between changing frailty status and psychological or social factors, without limiting included methodologies or approaches
4	Studies of UK based cohorts, or predominantly UK based cohorts only	Studies predominantly or solely using participants outside the UK	To maximise transferability of known evidence to proposed study setting and identify gaps in current evidence base relevant to proposed setting
5	Peer reviewed articles only	Non peer reviewed	Capturing higher quality evidence

6	Articles published within the date range 2011-2021 (second search updated to 2021-2023)	Articles published prior to 2011	To reflect the most contemporary evidence base
7	Results refined to primary health and social care databases	Articles published in databases related to other disciplines	To capture the most relevant evidence to inform a health and social care study
8	Studies presenting empirical research	Opinion pieces, literature reviews and proposed studies	To identify and critique the existing evidence around frailty transitions and psychological or social influences
9	Frailty levels measured either objectively or subjectively	Frailty level not indicated at any time during the study	Extent and approach to frailty measurement is relevant to critical analysis of quality of evidence. Some indication of extent of frailty needed as basic requirement of subject area

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
1	**Brunner EJ et al (2018)**	*Midlife contributors to socioeconomic differences in frailty during later life: a prospective cohort study*	"...about a third of socioeconomic inequality in frailty at older ages was accounted for by health behaviours and cardiovascular risk factors measured at age 50 years" p321. "Depressive symptoms in this cohort did not	Depression is a risk factor for frailty. Depressive symptoms did not contribute to the social gradient in frailty.	Longitudinal cohort study – assessed factors contributing to frailty gradient.	Risk factors at age 45-55, then follow up 18 years later (mean age 69). Limited insight into frailty progression in older age. Limited inclusion of midlife psychosocial risk factors.	"Further research is needed to address other factors, including perceived control over health, that might explain social differences in this important measure of wellbeing in older people" p321.

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			contribute to the social gradient in frailty, and other midlife psychosocial risk factors such as job stress were not analysed" p321.				
2	**Etkind SL et al (2018)**	*Finding a 'new normal' following acute illness: A qualitative study of*	"Personal values were important as they influenced what participants considered normal was, and in turn	Satisfactory adjustment after fluctuations in health are influenced by previous experiences and personal values	Rich data from a 'difficult to reach' population. Theoretical sampling enabled	Single interview may be insufficient. All but one caregiver interviewed	Prospective longitudinal research needed to describe the stability and influences on preferences over time.

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
		influences on frail older people's care preferences	whether they felt they had achieved it" p306. "Participants experienced a cycle of illness and recovery, with preferences influenced by illness and care experiences, and by adaptation to	among people living with frailty	access to diverse experiences. Topic guide developed iteratively with input from PPI representatives. Random sample of transcripts double coded to mitigate bias.	jointly which may affect frank discussion. Single researcher so possible interpretation bias. Focus on acute illness severe enough to lead to admission – primary care management may	Future research should explore the concepts of getting back to normal and finding a new normal to better understand why, when and how this shift may occur.

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			ongoing health changes" p307. "... acute illness may represent the point when normality is lost and cannot be regained. Getting back to normal then becomes unachievable, and sometimes individuals must balance losses and			have had different results.	

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question							
	Author /year	**Title**	**Key findings**	**What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?**	**Strengths**	**Weaknesses**	**Recommendations made**
			continuity to find a new normal" p308. "... quality of life is the gap between actual experience and expectation. One can narrow this gap by improving health status (i.e. getting back to normal) ... (or) moderating expectations" p308.				

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			Crisis point represents a loss of normality that cannot be regained p308.				
3	**Gale C et al (2012)**	*Close relationships and risk of frailty: The Hertfordshire Cohort Study.*	No association between perceived social support and subsequent frailty No associations between confiding and emotional support or practical	Perception of negative close relationships may predispose women to frailty but not men.		"…duration of social isolation may provide a more accurate indicator of exposure to social support than this	"Future research needs to replicate these findings and investigate mechanisms whereby negative social interactions are linked with frailty in later life" p391.

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			support and risk of frailty p391. Link between exposure to negative interactions in close relationships and risk of frailty in women but not in men p391. "...provides support for the view that psychosocial factors may predispose an individual to frailty			single measure" p391. Limited baseline data son unable to exclude those who already had frailty. Mean age 64.8±. Uncertain whether findings apply to older people, or influence on	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			or precipitate its onset. The underlying mechanisms are uncertain but might involve high levels of stress hormones, impaired immune functioning, or chronic inflammation" p391.			established frailty.	
4	**Gale C (2014)**	*Psychological well-being and*	"Older people with a more positive	Hedonic and eudemonic aspects may both	Large sample size. Representative of	Possibility early onset physical	“Further follow up is needed for accurate

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
		incident frailty in men and women: The English Longitudinal Study of Ageing.	attitude to their own ageing report better functional health at subsequent follow-ups" p697. "…psychological wellbeing may be a protective factor. We also found an effect in the reverse direction, in that the incidence of either pre-frailty or frailty	protect against developing frailty	community-dwelling population in England aged ≥60. Prospective study including both frailty and psychological wellbeing measurements (CASP-19).	deficit might decrease wellbeing scores prior to being detectable on a frailty score. No insight into influence of psychological wellbeing on frailty trajectory. Number of chronic	determination of the trajectory of well-being in these frail older people" p703 "…mechanisms whereby psychological well-being might influence risk of frailty… are not fully understood" p703

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			in those initially not frail was associated with a relative decline in psychological well-being since baseline survey" p703. "The results of the present study show that it may be not only the hedonic aspects of well-being such as the			conditions based on participant recall.	

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			experience of happiness and pleasure but also the eudemonic aspects such as sense of autonomy, control, purpose and fulfilment that protect against the development of frailty. " p703.				
5	**Gale C et al (2017)**	*Personality and risk of frailty:*	Higher neuroticism and lower	Higher levels of neuroticism or lower	Prospective cohort study.	Perceptions of terminology used	"Further studies need to replicate our

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
		The English longitudinal study of ageing	extraversion and conscientiousness associated with greater frailty at follow up and two years later. Higher agreeableness associated with increased frailty but finding thought to be by chance.	conscientiousness or extraversion may predict onset or progression of frailty.	3-year period – 2 years was enough to see change. Large sample size, representative of population.	may change over time and influence self-rated responses.	observations in other populations and explore the mechanisms whereby these personality traits might increase the risk of frailty" p134.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			Conscientiousness presented as a key influencer. Discusses evidence for changes in personality in older years, particularly after big life events. Cites evidence for change in personality in old age, in response to critical				

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			events or chronic illness.				
6	**Gale C et al (2018)**	*Social isolation and loneliness as risk factors for the progression of frailty: the English Longitudinal Study of Ageing.*	Being more socially isolated or lonelier was associated with being older, less educated, less wealthy, having more depressive symptoms, more chronic physical disease, being a smoker, having more	(Same findings as Niederstrasser but used the same data source). Loneliness predicts physical frailty onset. Study does not explore rate or experience of progression.	Large sample size. Representative of community-dwelling English population aged ≥50.	Frailer, lonelier and more isolated people not fully represented, so may underestimate extent of relationships. May not have controlled adequately for	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			components of the frailty phenotype and having a higher frailty index score. Female associated with greater loneliness and social isolation. Findings suggest frailty may lead to social isolation but not vice versa.	Social isolation does not predict frailty.		depressive symptoms.	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			Relationship between loneliness and frailty is bidirectional.				
7	**Gil-Salcedo A et al. (2020)**	*Healthy behaviors at age 50 years and frailty at older ages in a 20-year follow-up of the UK Whitehall II cohort: A*	The risk of frailty decreased over a 20-year follow-up period as the number of healthy behaviours at 50 increased. Positive health-behaviours at age 50	Health behaviours may reflect underlying psychosocial circumstances and decrease risk of frailty onset.	Reverse causation bias minimised by measuring health behaviours earlier in life. 20 year follow up period. Large sample.	Sample included civil servants only therefore not representative of population demographic. Findings inform population level rather than frailty	Use of precise and objective measures rather than self-reporting in health behaviour research. Better assessment of sedentary behaviours as a predictor of frailty onset.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
		longitudinal study.	associated with cohabiting, fewer comorbidities and higher socioeconomic background.			specific intervention.	
8	**Hubbard RE et al. (2014)**	*Frailty, financial resources and subjective well-being in later life*	Financial resources only provide a partial buffer against detrimental psychological effects. "Higher levels of frailty were	"...wealth may be...a marker of an additional or alternative psychological safeguard" p367.	Frailty Index – broad range of domains. Validated measure of	Cross sectional design does not allow explorations of relationships or prognostic importance.	Further exploration of "how the psychological effects of frailty may be mitigated" p367.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			associated with poorer subjective well-being" p366. "...the capacity of older people to achieve certain functions (rather than health status itself) is critical to quality of life" p367 "The poorest participants in each frailty category had		subjective well-being (CASP-19)	No tracking of frailty changes at an individual level, only cross-sectional associations. Also, no subjective data on participant experience. Therefore, unable to confirm wealth	

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			similar well-being to the wealthiest with worse frailty status" p366.			as a psychological safeguard. Ages 65-79 only, and only those with complete data – older population and less engaged excluded.	
9	**Lloyd A et al. (2016)**	*Physical, social, psychological and existential*	Pattern 1 - coping narrative	Three trajectories in narratives.	Qualitative longitudinal approach	Frailty score for recruitment but no monitoring	There is a need to highlight positive ways of living with frailty and

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
		trajectories of loss and adaptation towards the end of life for older people living with frailty: a serial interview study.	Pattern 2 - struggling narrative Pattern 3 - overwhelmed narrative Absence of a clear cause obstructed capacity to adjust p9. Wellbeing related to ability to adapt. Sense of meaning and purpose only	Community and social support are vital to minimise alienation and maintain self-determination. Wellbeing associated with adaptation ability.	underpinned by constructivist theoretical perspective – build understanding of how meaning is constructed. Multipole perspectives to build rigour.	over the year of the study. Those without an informal carer or those with dementia not fully represented. Small scale study.	reduce focus on youthful old age as broadly achievable.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			steady in coping narrative p11. In the coping narrative, a hospital admission or event plus age was acceptable explanation for patient p12.				
10	**Lloyd A et al. (2020)**	*Stories from people living with frailty.*	Continuous work to construct identity and maintain control	For those living with frailty daily routines contribute to narratives about sense of self,	Narrative approach. Purposive sampling to	Small sample – 13 older people with frailty – limits	Support to reframe personal narratives may help build resilience.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			using everyday routines p2733. Construction of a cohesive narrative used to cope with chronic illness p2734. Focus on day to day living. Time to adjust to change of identity in long term illness p2737.	which are then used to cope with chronic illness. 'Giving up' occurs when sense of self is lost. 'Separation of disease from self is a powerful cultural resource'	reflect gender balance, cohabitation status and demographics of over 75s. Three interviews over 18 months, plus eight-weekly telephone contact – allows change to be	extrapolation to wider contexts. Older people with no informal carer or with dementia not included. Frailty scored for recruitment but not monitored throughout study, therefore no data around whether 'giving up'	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			Social connection crucial to wellbeing. Narratives of struggle and unbalancing. Erosion of sense of self p2738. Some resistance to changing identity - threat to identity as an external factor, not intrinsic within self p2739.		captured as it occurs. Perspectives of relatives and professions where possible to give broader context and rigour.	coincides with frailty change using current measures.	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			"A tipping point is reached where an important value that can bolster the older person's sense of self is lost, and the older person gives up" p2742. Conveying a sense of not coping compromises self-worth. Self-blame. Not dignified to				

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			resist frailty whereas fighting cancer is p2747. Those most physically fit had most difficulty adjusting to deterioration p2748.				
11	**Maltby J et al. (2020)**	*Frailty and Social Isolation: Comparing the Relationship between Frailty*	Loneliness is distinct from social isolation. Frailty is a syndrome of forced withdrawal.	Social isolation emerges over time with psychological contributors.	4-year period – adequate to detect change	The extent to which the findings are specific to this	Recommends starting a study before social isolation and frailty starts and examine the extent to which the emergence

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
		and Unidimensional and Multifactorial Models of Social Isolation.	Social isolation predicts higher risk of worsening of frailty when measuring with phenotype but not found to predict change in frailty over time. FP predicts higher social isolation after 2 years.	Isolation from wider social groups may indicate a critical threshold of physiologic decline. Social isolation does not predict frailty, but specific multidimensional contributors such as loneliness predict frailty using both FI and FP.		dataset are unknown. Established frailty and social isolation in wave point data limits the ability to detect sequences and causal relationships over time.	of one is associated with the emergence of the other p1306. Explore the effects of obligatory versus voluntary social isolation.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			FI predicts increased risk of social isolation after 4 years.				
12	**Martin CM (2014)**	*Self-rated health: patterns in the journeys of patients with multi-morbidity and frailty*	"SRH represents an individual's unique access to their own bodily sensations and their meanings... reflects important internal functioning such as inflammatory	'multi morbid frail patients intermittently experience reduced adaptability, with difficulty maintaining physiological, psychological and social stability'	2011-2013	Small study – 14 participants. Pragmatic cohort study. Those with high probability of repeat admission selected.	Further research is needed to untangle complicated dynamics of SRH, stress resilience and internal biomarkers in the patient journey.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			processes... correlates with changes in inflammatory markers in aging cohorts..." p1. "This case study findings support CAS theory that individual's at-risk journey due to frailty and multi-morbidity are volatile and non-	SRH is highly correlated with more urgent service use and hospitalisation.		Recruited via GP, admission follow-up and out of hours – may influence self-rated health.	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			linear in parallel with decline in internal resilience" p6. Need to monitor post discharge and after intense assessments as studies have shown instabilities can arise after these points p6. "The findings support the theory				

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	Author /year	**Title**	**Key findings**	**What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?**	**Strengths**	**Weaknesses**	**Recommendations made**
			that multi-morbid frail patients intermittently experience reduced adaptability, with difficulty maintaining physiological, psychological and social stability within an overall trend in their health. SRH appears to be very worthwhile as a				

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			single measure in monitoring people's daily status.				
13	**Nicholson C et al. (2012)**	*Living on the margin: Understanding the experience of living and dying with frailty in old age*	"...sense of change... for some was a gradual decline and for others a sudden and shocking rupture which they related to a specific event, for example a fall" p1428.	People with frailty work to regain balance through retaining anchorage.	17 participants – reasonable size sample for a qualitative study.	Micro level data may be less applicable at a system level than exploring larger cultural structures. Only included participants in contact with	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			"It is a state in which identity is continually negotiated through a prolonged dialectic between body and self" p1429. "Being at home was important to participants because it brought feelings of control and anchorage...			secondary care already. Frailty identified by clinical opinion, not measured. No ongoing frailty monitoring during study therefore unable to offer insight into the relationship between	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			participants needed to accommodate the physical and social changes necessary to continue to 'be' at home, but equally needed to work to regain or reconfigure what it meant for them to 'feel' at home" 1429. "Daily routines served to ground			anchorage and frailty score.	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			participants in the present and in a wider continuity of social relations" 1429. "Thus the emotional experience of frailty has a protective function" p1430.				
14	**Nicholson C et al. (2013)**	*The experience of living at home with frailty in old*	"...participants did all speak of loss over time, loss of physical capacity, social	People with frailty use anchorage to counteract imbalances of frailty.	Subjective data offers insight into lived experience.	Small sample size – not generalizable.	Explicit recognition of the interplay of biopsychosocial factors in

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
		age: A psychosocial qualitative study	status and friends and family" p1176. "Participants responded to the imbalance and loses of frailty by employing strategies that reconnected them to their bodies and created anchorage in their daily lives" p1177.		Researcher reflexivity used for confirmability and trustworthiness.	17 months insufficient to capture large change.	frailty needed in policy and practice.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			"Daily routine was an important anchorage, grounding people in the present and in a wider continuity of social relations" p1177. "The rituals of sustaining rhythm enable anchorage to wider social and cultural norms				

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			within the unsteady state of frailty... allowing services often disrupted these patterns. People struggled to accommodate carers who arrived to put them to bed too late or too early, or failed to appreciate the significance of the				

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			timings of the day" p1177.				
15	**Niederstrasser NG et al. (2019)**	*Determinants of frailty development and progression using a multidimensional frailty index: Evidence from the English Longitudinal Study of Ageing*	"In this study we found that higher baseline frailty score, increasing age, low wealth, low levels of education, obesity, high waist-hip ratio, being female, lower body strength, being a smoker or having a history of smoking,	Loneliness predicts frailty onset and progression. Study does not explore rate or experience of this progression. Social isolation does not predict frailty. Perceived social isolation may be a	Longitudinal study (8 years) so able to explore causal relationships. Multidisciplinary data representative of over 50 population in England.	Possible that older participants passed away or no longer able to contribute, therefore data may represent younger or less frail individuals.	Intervention studies aimed at reducing loneliness are warranted to confirm a causal link p9 Current FI does not include social isolation or loneliness – previous recommendations to include these domains.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			pain, low intensity of physical activity or sedentary behaviour, and loneliness were predictors of both frailty progression and development. Social isolation was not a predictor of frailty development and progression" p6 "FI does not contain deficits pertaining to	better indicator than an objective measure.			

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			social frailty such as perceived social isolation or loneliness... although these have previously been recommended for inclusion in a multidimensional frailty index" p8.				
16	**Ni Mhaolain AM et al. (2011)**	*Depression: a modifiable factor in fearful*	Fallers at a transitional level of frailty may represent	Fear may be a rational and protective	Moderately sized study.	Cross sectional design.	A longitudinal study is warranted to

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
		older fallers transitioning to frailty	a particularly vulnerable group psychologically who would benefit most from interventional strategies with specific intervention components addressing depressive symptoms p727. Fear of falls associated with	mechanism for people living with frailty. Offers no insight into whether fear levels influence frailty trajectory.		Focussed solely on fallers with frailty. Frailty measured using the Biological Syndrome Method – not a measure supported in the guidelines.	substantiate causal relationships. Further examination of the psychological factors underlying fear of falls in people with frailty versus robust fallers.

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	Author /year	**Title**	**Key findings**	**What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?**	**Strengths**	**Weaknesses**	**Recommendations made**
			objective measurements of balance, gait and falls - may reflect rational appraisal of reduced functional ability and increased risk, therefore strategies aimed at reducing fear may effectively reduce a natural protective				

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	Author /year	**Title**	**Key findings**	**What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?**	**Strengths**	**Weaknesses**	**Recommendations made**
			mechanism and increase falls p727. . "When compared with robust fallers, pre-frail and frail individuals displayed a greater fear of falling by a significantly lower mean MFES" p730.				

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
17	**Rogers NT et al. (2020)**	*Cultural engagement is a risk-reducing factory for frailty incidence and progression*	"Cultural engagement has psychological, social and behavioural components that in themselves are known to be protective for frailty" p572. "Compared with participants who never engaged in cultural activities,	Cultural engagement associated with reduced risk of frailty. 1.3 times higher risk of frailty by age 80 if not engaging in cultural activities at least every few months.	Large sample over 10 years.	Cultural engagement activities representative of a limited demographic/ perspective of 'culture'. Use of secondary data means no capacity to add qualitative data	Future behaviour change intervention studies to focus on increasing cultural engagement in those at risk of becoming frail.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			participants who engaged in cultural activities every few months or more were less likely to become frail over time" p574. "This study showed for the first time that cultural engagement in older age is associated with both reduced risk of			to aid understanding of why these activities might be significant. Possibility of many alternative aspects of activities in focus being the active ingredient.	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			incident frailty and a slower trajectory of frailty progression in older adults. These results were found independent of demographic, socioeconomic and social confounders" p574.				
18	**Shaw RL (2018)**	*Understanding frailty: meanings and*	"It's about attitude of mind... you wouldn't describe	Psychological factors such as loneliness can lead to frailty.	Recruitment asked for people who consider	Recruited via clinical judgement and	Further work in European countries to determine malleability of frailty, to

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
		beliefs about screening and prevention across key stakeholder groups in Europe (+corrigendum)	them as frail because of their kind of attitude of mind and they can be quite feisty" p1237. "...a lot of elderly peoples frailties begin with one thing and it might just be loneliness... with the death of a partner, or a divorce or whatever or that	Social care professionals and older people place greater emphasis on psychological contributors than health professionals.	themselves frail as well as those who regard themselves healthy and active. Semi-structured interviews to include pre-agreed frailty themes to guide a	self-identification due to data not being available in all participating countries – less comparable to other studies. Captures subjective beliefs but not	inform a cultural change in perceptions.

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			you've always been a single person but because you've got a disability you can't do things that you did so the loneliness sets in and then you become more frail in your mind and in your body" p1239. Protective factors are psychological resilience and social		participant-led discussion	Three European countries including UK – 5 in Italy and Poland, 6 in UK Dementia and terminal illness not included. Potential impact of translation on	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			connectedness p1239. "There was a clear awareness of the relationship between physical and psychological frailty and resilience in achievement of balance and maintenance of agency and identity, expressed by all			linguistic meanings.	

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			groups. Having said that, the significance of the psychological was more prominent in accounts from older adults and social care professionals. Health professionals turned first to the physical and only began to contemplate the impact of the				

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	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			psychological during the discussions" p1245.				
19	**Skilbeck JK et al. (2016)**	*Making sense of frailty: An ethnographic study of the experience of older people living with complex health problems*	."Upholding such routines... enabled the older participant to sustain their sense of self as an independent person and a degree of continuity with important aspects of	Continuity of personhood and the ability to make choices are	Included participants confined to home. Up to 6 encounters with each participant. 4-year period. Cards given out introducing study	Participants with communication difficulties excluded. No objective measurement for recruitment, therefore difficult to compare to other studies.	

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			life was maintained" p7. "...her attitude to risk taking appeared to change as she regained control of her body" p7. "Making choices in day to day living enabled these older people to continue to engage with life…" p9.		consistently once gatekeeper issue identified.	Already having community matron input at home – indicates higher need therefore limited cohort. Recruited by community matron, with matron present at first researcher visit – potential	

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
						for influence. Matron introduced researcher as 'a colleague'. Unclear whether recruitment criteria identified before or after purposive sampling based on matron's perception, as no	

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
						indication of how this criterion was confirmed Small study – 10 participants.	
20	**Stow D et al. (2018)**	*Frailty trajectories to identify end of life: a longitudinal population-based study*	"Individuals with rapidly rising frailty (average monthly rise in eFI of 0.01 or accrual of 0.4 deficits) are twice as likely to die within 12 months as	Rapid changes in frailty level predict mortality. Instability of frailty level may predict mortality more than the level itself.	Electronic Frailty Index – validated measure and widely available. Large population based longitudinal study.	Controls identified retrospectively to match participants who has died. eFI data dependent on	Trajectories of frailty progression can be used to identify people at higher risk.

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			individuals with stable frailty. Individuals in this class experience an initial monthly increase in eFI of 0.02, prior to slowing around 8-9 months prior to death" p5. "The association between severity of frailty measured at a single time point and	Population level data has not been shown to predict individual mortality risk based on measuring at a single time point.	Demographically and geographically representative of England's population.	quality of coding applied by clinicians but represents reality of using eFI in practice. eFI scores do no capture improvement in frailty. eFI data only captured via contacts with	

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			risk of mortality has been robustly demonstrated at the population level. However, our previous work found that this association did not translate into a useful measure for predicting individual risk of mortality when frailty is measured at a single			health services, therefore sample does not include those not on a health radar	

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			time point, even close to death... Our findings suggest that some individuals are resilient to higher but stable levels of frailty, and that changes in frailty status may be a more useful indicator of mortality risk... " p5.				

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
21	**Warmoth K et al. (2016)**	*'Thinking you're old and frail': a qualitative study of frailty in older adults*	"…perceptions regarding health can play an important role in determining the progression of illness" p1484. "...identity is negotiated in response to life experiences..." 1484. "...rejected the frailty label and distinguished	Internalisation of frailty as part of identity may lead to behavioural confirmation of the label. Identifying as frail may increase likelihood of accessing support.	29 participants – good sample size for qualitative study. Range of setting reflecting different experiences and levels of frailty. Grounded theory approach. Theoretical sampling used to	No severely frail participants. Cognitive impairment excluded. FI scores used to translate into CFS scores, however CFS not intended for use without CGA first.	Future work exploring the ways older people can be encouraged to employ resistance strategies is warranted p1497.

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			between 'being frail' and 'feeling frail'. 'Being frail' was viewed as an imposed medical or functioning classification, while 'feeling frail' reflected the emotional consequences of traumatic events,		develop emerging theory. Modified Frailty Index used to describe characteristics of sample and guide future sampling.		

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question							
	Author /year	**Title**	**Key findings**	**What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?**	**Strengths**	**Weaknesses**	**Recommendations made**
			disability or physical impairment" p1485. "The adoption of a frailty identity depended on resistance strategies and aspects of self-identifying" p1489. "According to them (participants), the key determinant of whether an individual adopted a				

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			frailty identity was disengagement - socially or physically - and not their physical impairments or poor health" p1492. "...disengagement accompanied (and possibly preceded) negative psychological affect" p1492.				

Table 4: Overview of papers included in the 2021 review, and findings relevant to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
			"...labelling people as frail, particularly against one's will, was seen as damaging to health, because it may lead to behavioural confirmation of the label p1497.				

Data analysis

I analysed each included paper line by line, applying codes that captured the explicit meaning of each line. I grouped these codes into related areas based on similarities and conceptual relationships, producing descriptive themes. I then reevaluated these descriptive themes within the context of my review questions, to produce cohesive, abstract theories that directly answered the review questions.

3.3 Scoping review themes

Social isolation and loneliness

The literature suggests loneliness, but not social isolation predict frailty onset, and increased social support is associated with lower frailty (Woo 2005, Labra 2018). This is noted with caution however as several of the studies reaching this conclusion used the same secondary data source, thus reducing the ability to consider these entirely separate pieces of evidence. Maltby et al. (2020) note that social isolation and loneliness, are related but separate and distinct concepts. Social isolation can be measured by the quantifiable number of contacts with others and can be explored both in terms of frequency and breadth of social contact (Maltby et al., 2020; Gale et al. 2018). Maltby's study found three dimensions of social connectedness; "nuclear family, other immediate family and a wider social network" (p1306), and proposed the gradual restriction of social contact down through these dimensions to be a possible early social indicator of the development of physical frailty, with social isolation "reflecting a syndrome of enforced withdrawal resulting from a cycle of energy dysregulation or lack of interest or capability in social engagement" (Maltby et al. 2020, p1297). This is consistent with previous proposals that social isolation is a consequence of frailty rather than an antecedent (Garre-Olmo, 2013). Social isolation in older people is a culturally loaded concept, related to social norms and cultural expectations of what 'ageing well' should look like. Maltby et al. suggest further research may be needed to explore obligatory versus voluntary isolation in relation to frailty progression.

Rogers et al. (2020) explored cultural engagement and frailty risk and found regular engagement in "cultural activities" (p574) was associated with lower likelihood of becoming physically frail and slowing the trajectory of frailty progression. Cultural engagement was however captured via self-reported frequency of visits to the theatre, concern or opera, the cinema or an art gallery, exhibition or museum. These signifiers of what constitutes cultural activity are unlikely to be representative of the cultural and socioeconomic diversity of populations either in urban or rural UK communities. Although the authors report the results were independent of demographic, social and

socioeconomic confounders, it is feasible that unreported behavioural, dietary and lifestyle factors associated with cohorts engaged in these activities may also contribute to the development of frailty aetiology (Bloom et al., 2017). Speculative connections between "hedonistic experiences, emotional expression and… sense of meaning and purpose" (Rogers et al., p575) are proposed by the authors in their discussion, however the quantitative methodology and absence of comparison to any other moderate activity (Song et al. 2015) as a control means these connections cannot be drawn from the study data and therefore undermine the conclusion that cultural activity is associated with slower frailty progression.

'Loneliness' reflects the subjective and qualitative dissatisfaction with either a disparity between desired and actual levels of social contact (Maltby et al., 2020, Gale et al., 2018), or with the quality and nature of existing connections. In their 2018 study Gale et al. reflect on existing evidence of associations between frailty and social isolation or loneliness and the absence of evidence for the direction of causal relationship and influence on frailty onset and progression. The study initially found both social isolation and loneliness were associated with an increased risk of developing physical frailty, however after adjustment for potential confounding factors only the results for loneliness remained statistically significant. This result was only found when using the phenotypical model of frailty, and not the cumulative deficit model which includes psychosocial domains. The two models of frailty are shown here not to have the same risk factors (Gale et al. 2018), which highlights the need in research and clinical practice to adopting a consistent approach to applying a frailty model throughout frailty pathways. Despite not being a risk factor for physical frailty, social isolation was found to be a consequence of frailty, and perhaps Maltby's (2020) three dimensions of social connectedness may offer some insight into how the transition into social isolation develops as frailty increases. It is also relevant to note that social connectedness here is a bidirectional relationship dependent equally upon the third party and the older person's ability to meet the demands of the relationship. In Lloyd et al. (2020) the final depletion of internal resources culminating in a 'tipping point' being reached was experienced by the older person's daughter, not the older person themselves but it was the older person experiencing the crisis event as a result. This would indicate that within community settings subtle changes to the nature and strength of supportive relationships may be predictors of frailty trajectories. In a longitudinal study in Japan, Makizako (2018) found baseline social frailty lead to a four-fold increased risk of incidents related to physical frailty over relatively short time periods, however in the UK NICE 2015 state "…there is a lack of evidence on the most effective ways to address psychosocial factors and on their effect on the development of… frailty" (p30). Psychological and social frailty may be underreported and unaddressed leading to much poorer outcomes.

Coping/ Mindset

Conceptually frailty journeys have been characterised by people living with frailty as individual adaptability to deterioration, dependent upon one's inner resource and strength (Sezgin et al., 2019). Healthcare professionals may not consider acceptance of reduced function as a resilient response to deterioration (Richardson et al., 2014), preferring perhaps to see the individual resist the stressor. People living with frailty may disagree with this perspective, describing 'keeping going' as 'adaption to' and 'acceptance of' rather than rigid resistance (Nicholson et al., 2013; Richardson et al., 2014; Skilbeck et al., 2018). Richardson et al. (2014) describe "psychological success (as) an older person being able to adjust their goals when faced with the kinds of challenges that tend to occur in old age" p1381. Thus, to the individual, resilience, like frailty, could depict either a static or dynamic state.

Response shift theory suggests that a health or social event can act as a catalyst that may change "internal standards, values, or conceptualization of QOL" (Schwartz et al. 2020, p1) and that response-shift effects are "influenced by stable characteristics of the individual (antecedents); as well as cognitive, behavioural, or affective processes (mechanisms)" (Ibid. p1). The term 'catalyst' is used here to reflect terminology used in the literature; however, it should be noted that a catalyst is characterised as something that precipitates an event but remains unchanged itself. It is debatable whether the 'catalyst' in this context truly remains unchanged. The theory proposes that self-perceived quality of life and overall wellbeing can remain relatively unaltered after a significant or even life altering health event, as such events can prompt a shift in priorities and life expectations (Ibid; Etkind et al. 2018). This phenomenon indicates change in functional independence may not be synonymous with overall perception of poorer quality of life. Ahmed et al. (2014) found minimal evidence of response shift in individuals with stable health conditions concluding that a catalyst is required to initiate the shift, however catalysts tracked were limited to health-care utilisation and co-morbidities The authors acknowledge the influence of psychosocial and sociodemographic factors may also be catalysts unmeasured in their study and may warrant further exploration. Earlier work in response shift used retrospective measures to appraise baseline statuses, however use of this approach has decreased over time as recall bias was found to affect validity (Rapkin and Schwartz, 2019). As a result, longitudinal rather than cross-sectional study designs are now typically used, however Ahmed et al. (2014) found one year insufficient to detect clinically meaningful response shift. Schwartz (2020) noted the nature of the 'catalyst' is directly associated with the individual's appraisal process trajectory. For instance, change in marital status was associated with greater focus on "legacy or generativity and independence" (Ibid, p12) and work change was associated with reduced focus on role maintenance in favour of greater emphasis on relationships.

People living with frailty cite a causal relationship between mindset and frailty trajectory, not necessarily an ability to resolve physical deterioration but to adapt effectively to associated changes. A strong sense of psychological wellbeing later in life may be a protective factor against developing physical frailty (Manthorpe and Iliffe, 2015), however NICE (2015) identified inadequate evidence related to this area. Viewed alongside understandings of response shift processes, further exploration of the nature of 'catalysts' experienced during the frailty trajectory and their influence on adaptation responses appears warranted.

Within the review papers, older people spoke of coping and adaptation as key factors in mitigating against sudden deterioration (Lloyd et al., 2016; Skilbeck et al., 2016), however frailty levels were not measured alongside these finding therefore these studies could not evidence this relationship objectively. Furthermore, reflection upon previous experiences of deterioration may have been subject to recall issues.

The existing evidence suggests older people perceive change in mindset, loss of self and routines, and changes to perceived control as playing significant roles in predicting frailty transitions, with 'giving up' frequently cited as an antecedent to deterioration rather than resulting from health changes (Lloyd et al. 2020, Britain Thinks, 2015). In their 2020 literature review, Alsadah A et al. reviewed definitions of 'treatment burden' in the literature and identified Boyd et al's 2014 definition as scoring highest within a quality appraisal. Treatment burden is defined as "…a patient's perception of the aggregate weight of the actions and resources they devote to their healthcare, including difficulty, time, and out-of-pocket costs dedicated to the healthcare tasks such as adhering to medicines, dietary recommendations, and self-monitoring" (Alsadah A et al, 2020, p4). A key identifier of the presence of frailty is comorbidity and therefore the perceived aggregate weight of resulting treatments warrants further exploration as a potential contributor to 'giving up'.

Control

Gale (2014) found "…sense of autonomy, control, purpose and fulfilment… protect against the development of frailty" p703, however frailty levels were not tracked therefore the study was unable to objectively demonstrate this relationship and the mechanisms through which these factors might affect change or stability within individual frailty trajectories. "Patient activation describes the knowledge, skills and confidence a person has in managing their own health and care" (Kings Fund, 2014). "Patients with high levels of activation understand their role in the care process and feel capable of fulfilling that role" (Patient Activation Measure quick guide, p6). In a series of studies by Hibbard et al., cross sectional designs have demonstrated a positive relationship between activation and health status (Hibbard et al. 2013, Hibbard et al. 2017), and longitudinal designs have

indicated activation may also predict future health outcomes (Hibbard 2003, Hibbard et al. 2018). In a 2018 study of activation levels in people with frailty conducted in the Netherlands, Overbeek et al. reference lower health literacy among older generations than younger generations (Cutner, 2006), and a tendency towards less active participation in health decisions (Legare, 2014), suggesting activation levels may be significant in planning for increased support need or even as a potential area to target preventative intervention. Overbeek's study found lower activation scores were associated with lower health related quality of life in both community care and residential care cohorts and concluded that "…frail older adults may not have the abilities, knowledge, skills and confidence to adequately engage to this level of self-management" p5. A biopsychosocial measure of frailty was used (Tilberg Frailty Index), and higher levels of frailty were found to be associated with lower levels of activation. The rigour of these findings is limited by the absence of a control group, meaning it is not possible to state whether this relationship between characteristics of frail participants and activation levels are unique to frail cohorts. The small scale of the study limited transferability, and the exclusive recruitment of participants already receiving care support at home or in a care home may also have restricted the sample to represent higher frailty levels and potentially lower activation. Considering older peoples' accounts of 'tipping points' of instability being related to 'giving up' (Lloyd et al. 2020, Britain Thinks, 2015), further exploration of the relationship between activation and frailty transitions appears warranted in a broader range of community UK settings.

Maltby et al.'s (2020) notion of "enforced withdrawal" from daily activities implies a transfer of control away from the older person. A recurrent theme in the literature is adaptation; to make sufficient changes to mindset, environment or lifestyle in response to imbalance and loss such that some continuity and sense of self is maintained (Nicholson et al. 2013; Nicholson et al., 2012; Skilbeck et al. 2016; Warmoth et al., 2016). The experience and outcome of a withdrawal from daily activities is likely to vary greatly and be influenced by the pace of the withdrawal (Nicholson et al. 2012; Stow et al. 2018) and the individual's response to it. As previously discussed, there is evidence that psychological adaptation to change may be affected by the presence or absence of a 'catalyst' (Schwartz et al. 2020; Ahmed et al. 2014). Accounts of older people in Nicholson et al's 2013 qualitative study reflected this concept, describing newly acquired deficits evoking an emotional response and "loss of certainty about how the world was" (p1176) which was thought to be either absent or less prevalent in deficits from birth. Frailty can be perceived from an outside perspective as a sudden deterioration due to a new stressor, however to the individual the diminishing of reserves over time is likely to have been a gradual process of multiple losses (Nicholson, 2013). Older people in Nicholson's (2013) study discuss strategies to anchor them into their daily lives. These

strategies included maintenance of routine, continuing social relations, and the integration of "…previous, present and future realities" (Ibid, p1178).

Contrary to belief that loss of independence equates to progression of frailty, some older people talked of creating new connections through "…allowing a level of inter-dependency on others" (Ibid, p1177). Others talked of the challenges of accepting carer support not due to the loss of independence with the activity, but in terms of the failure of carers to "appreciate the significance of the timings of the day" (p1177). The perception of handing over control of anchorage to 'previous realities' represented by the rhythm of the day was for some more significant a loss than independence in the task itself. Participants in Nicholson's study were recruited by an older person's intermediate care team and were purposefully selected based upon being regarded as frail by clinicians in the team. No frailty screening or assessment tool was used for recruitment or as an outcome measure and no further subjective assessment of frailty level was undertaken either by the clinicians or participants. As such the study does not evidence the frailty fluctuations cited in the study objectives and therefore offers little insight into the relationship between the psychosocial domains discussed and frailty transitions. Further research using a more rigorous methodology is warranted to expand upon these findings.

Self-rated health

Self-rated health measurement is thought to represent the unique access of the individual to "their own bodily sensations and their meanings" (Martin, 2014, p1) and has been correlated with "changes in inflammatory markers in aging cohorts" (Ibid, p1). Amongst cohorts of older people experiencing falls, those with frailty or pre-frailty in comparison to robust fallers were found by Ni Mhaolain et al (2011) to demonstrate greater fear of falls. The authors propose this is a rational appraisal of reduced functional ability and provides a natural protective mechanism to reduce falls risk, which would suggest self-reported health insights may alter health-related or day to day behaviours. The synthesis of past, present and future realities presented in Nicholson (2013) would suggest however that individual responses to current health status will be influenced by previous experiences and insight into future possibilities (Etkind et al. 2018). Individual sense of identity is built upon previous life experiences and events (Warmoth, 2016), and as such previous experiences of successful adaptation may influence perceptions of self as adaptable. Previous experiences of not being able to adapt may create a mindset of helplessness and a passive recipient of support, therefore emphasising the need to challenge existing negative beliefs about the self. Although Ni Mhaolain et al.'s (2011) finding that individuals transitioning to frailty and fearful of falling may be more likely to experience depression is of note, the cross-sectional design of this study does not

allow for causal relationships to be explored, and as such the ability to implement this finding within early intervention strategies is limited.

Stability

Consistent with the nature of frailty and with previous discussion around change and adaptation, periods of destabilisation were a common theme in the literature. Stow et al. (2018) found rapid increase in frailty measured using the Electronic Frailty Index (eFI) was associated with a two-fold increase in mortality within 12 months. It was noted that baseline eFI for this group could be lower than populations averages meaning these individuals may not be recognised as at risk. It should be noted however that the eFI is calculated using 36 deficits measured using some 2000 SNOMED-CT codes taken from GP records [Figure 12]. These include social vulnerabilities but the detection of these would be dependent on interactions with primary care. Early indicators of functional decline such as informal support arrangements below the threshold for formal care provision, or a self-referral made directly to social care for assessment for example for minor home adaptations would not necessarily be captured by the eFI due to the separate nature of health and social care record keeping, making it a limited tool for detecting some of the early signs of frailty risk. The below average baseline eFI score in high-risk individuals highlighted by Stow et al. (2018) may in fact reflect needs not captured via health services and supports further research into the potential benefits of integrating health and social care insights.

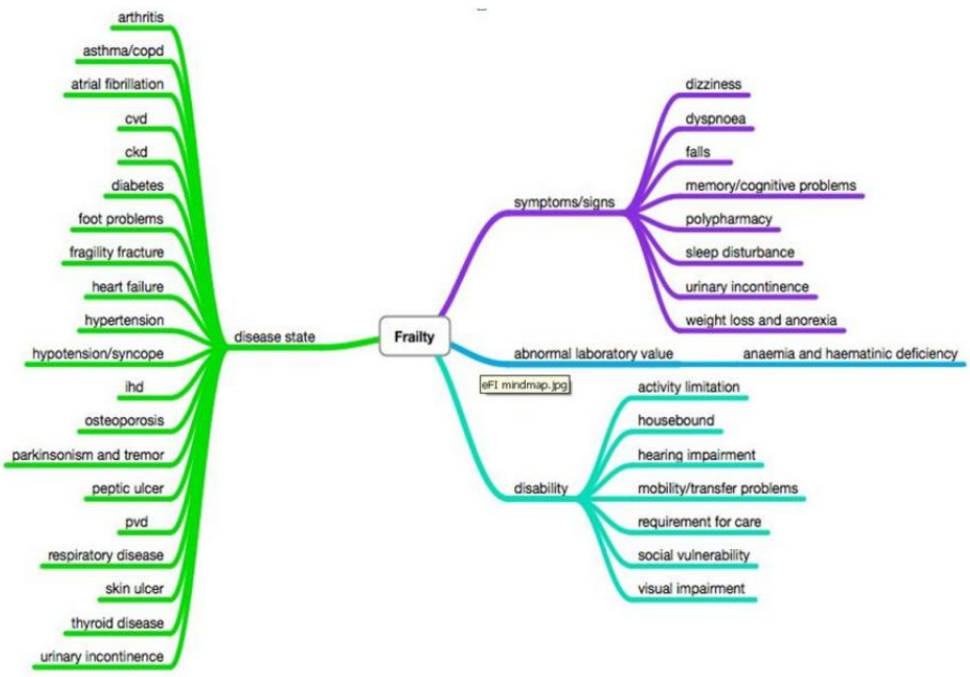


Figure 12: The 36 deficits measured by the eFI (Improvement Academy - Yorkshire and Humber AHSN (no date)

Martin (2014) explored self-rated health patterns within frailty trajectories and noted an expectation of deterioration but not for the timing or severity of the event itself, even when attributed to a chronic condition. Periods of time after acute admission or after intense assessments were identified as posing greater risk of physiological, psychological and social instability, with self-rated health fluctuations showing potential to guide prompt interventions (Martin, 2014). The study found associations between the outcome of the destabilisation and access to timely personal, social care and medical support. Due to the complexity of potential contributory factors in physiological, psychological and social destabilisation, further research is warranted to explore and understand these factors to plan responsive and appropriate support strategies. This review indicates social factors as key contributors reaching a psychological 'tipping point' and 'giving up'. To expand understanding of psychosocial influences on frailty transitions, broader contexts must be considered.

3.4 Review Summary

All papers included in this review explored the relationship between psychosocial factors and frailty. Some studies adopting a cross-sectional approach to a single point in time, offering insights into psychosocial factors amongst a cohort deemed frail, or a snapshot comparison of frail versus non frail groups. Other studies utilised secondary data from previous studies or surveys, conducting multiple cross-sectional reviews of population level data to explore trends. This allowed for relationships and trends to be observed between characteristics and make comparisons between different time points; however, the cross-sectional design did not offer insights into cause-and-effect relationships. In studies such as Gale et al. 2017 secondary data from the English Longitudinal Study of Ageing was used, however rather than adopt a population level approach the analytic sample was selected based on participants who had complete data on personality, frailty index (using the same items to derive score each time) and covariates at baseline and follow ups, thus adopting a prospective study design. This methodology provided the most relevant data to respond to the review question as it allowed cause and affect relationships to be derived from the data which could be applied to clinical practice.

Lloyd (2016, 2020) and Nicholson (2012) used narrative review to explore the experience of living with frailty. This approach offered in depth insight into lived experience through analysis of the linguistic choices made by participants and the order in which stories were told. Although these were longitudinal studies, frailty was not monitored or reviewed beyond recruitment phase and

therefore frailty transitions associated with these narrative insights were not captured. There is an absence of research exploring the relationship between these detailed participant accounts and the ability of routinely used frailty measurement tools to detect key aspects of the lived experience as potential antecedents of frailty, not simply consequences as per the frail persons perspective in my concept analysis.

Of the included studies only 10 studies completed a follow up which included a frailty measure, 5 using the Fried criteria, 3 using a measure derived from the cumulative deficit model, 1 using a combination and 1 using the eFI. By omitting a follow up frailty measure, frailty status is no longer the dependent variable in the study. No studies used the PRISMA-7 or Edmonton Frail Scale despite both being advocated in the NHS Frailty Toolkit as appropriate for community use and self-assessment. Despite the focus of this review being derived from the perceptions of people with frailty in the existing literature, only one of the included studies gave any indication of patient participation or co-production in the research design, and there was minimal evidence that findings had been triangulated with the participants.

To refresh and update the dataset and inform study design in response to the findings of the scoping review, the literature search was repeated in 2023 with a particular focus on gaps in study design and methodological approaches in the existing evidence base. Inclusion and exclusion criteria remained unchanged [appendix 8] however date range was limited to 2021-2023 to update the existing search results. Screening was applied in the same way as the initial search [figure 10] and details of the search terms used are presented in Appendix 11. A separate additional search was completed in 2023 to include the term 'social*' which had been unintentionally omitted from the updated search. A further 6 papers were identified in addition to the 21 included in the initial review, bringing the total number of papers reviewed to 27. Details of study design and key themes for the additional 6 papers were added to the original sample [table 6].

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
Brunner EJ et al (2018) *Midlife contributors to socioeconomic differences in frailty during later life: a prospective cohort study*	To examine the contribution of modifiable behavioural and biomedical risk factors and disease status at age 50 years to the occurrence of later life frailty and its	Fried phenotype.	Whitehall II study of British Civil Servants. 6223 middle aged adults measured for frailty between 2007 and 2016.	Whitehall II study of British Civil Servants.	Multi-wave longitudinal cohort study. Occupational class based on current or most recent employment grade at age 45-55. GHQ-30 (general health questionnaire) used to assess depressive	Assessed socioeconomic status, behavioural and biomedical risk, and disease status at 45-55 years and frailty status (fried criteria) at one or more of three clinic visits about 18 years later (mean age 69).	No	Health behaviours Socioeconomic inequality

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	socioeconomic gradient.				symptoms. ADL questionnaire to gage disability.			
Calvey B et al (2022) * *Expecting the best or fearing the worst: Discrepancies between self-rated health and frailty in an ageing Irish population*	To create a new metric for the identification of inaccurate health ratings in ageing populations, based on discrepancies between self-	Frailty Index.	The Irish Longitudinal Study of Ageing (TILDA) – wave 1 (2009-2010). 6907 participants included.	The Irish Longitudinal Study of Ageing (TILDA) – wave 1 (2009-2010).	Cross sectional study drawing on wave 1 TILDA data. Self-rated health measured on a 5-point scale. Frailty Index calculated using	Cross-sectional study, but observed trends across different age groups, exploring self-rated health compared to Frailty Index, indicating	No	Loneliness Anxiety Health pessimism/ optimism Health behaviours

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	rated health and frailty index scores.				measures collated during TILDA.	change over time.		
Davies K et al (2021) * *The longitudinal relationship between loneliness, social isolation, and frailty in older adults in England: a prospective analysis*	To assess the relationship between loneliness, social isolation, and frailty across 14 years.	Frailty Index.	Community dwelling older people (50+), living in private households in England. 9171 participants.	Data from the English Longitudinal Study of Ageing (ELSA) waves 2-8 (2004 – 2017)	ELSA used face to face interviews, self-completed questionnaires and a nurse visit every 4 years for a subset of participants.	Data taken from a 14-year period.	No	Loneliness Social isolation Quantity and quality of relationships

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
Dugravot A et al (2020) * *Social inequalities in multimorbidity, frailty, disability, and transitions to mortality: a 24-year follow-up of the Whitehall II*	To examine whether social inequalities were present before or after the onset of adverse health conditions (multimorbidity, frailty and disability).	Fried frailty scale.	Whitehall II study of British Civil Servants. Data taken from 2002-04, 2007-09, 2012-13 and 2015-16.	Participants aged 35-55 at time of enrolment in 1985-1988.	Multi-wave longitudinal cohort study. Occupational position and literacy at age 50. Minimum of 2 frailty criteria.	Compares risk of frailty onset and risk of mortality after frailty onset.	No	Social inequality
Etkind SL et al (2018) *Finding a 'new normal' following acute illness: A*	To explore influences on the care preferences of frail older	Scoring 5 or more on the Clinical Frailty Scale. Median frailty score 6.	Age over 65. Median patient age 84. 53% female. 18 patients and 7	Two acute care admissions/contacts in the last 6 months. Two acute hospitals,	Qualitative in-depth interviews. Thematic analysis.	**Frailty measured to identify sample but no second**	No	Acute illness Personal values Normality Care experiences Adaptation

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
qualitative study of influences on frail older people's care preferences	people with recent acute illness.		family carers purposefully sampled from the population of an ongoing mixed-methods study of frail older people with recent hospitalisation. Excluded: palliative care, lacking capacity. 351 patients and carers	one sub-acute hospital and one acute community service in London.	Prospective cohort study. Feb 2017 - Feb 2018.	**measurement to track change.**		Health changes Balance Quality of life Expectations

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
			screened, 192 eligible.					
Freer K (2020) * *Falling through the cracks: a case study of how a timely integrated approach can reverse frailty*	To discuss how timely integrated care helped address problems within a case study example.	Clinical Frailty Scale. Case study scored at 5.	Single case example. 76-year-old male.	Living alone in the suburbs of a northern English town.	Case study.	**Observations of support needs post-intervention. Reversal of frailty reported but not formally assessed.**	No	Engagement with services Environmental improvement Wellbeing Independence Integrated services
Gale C et al (2012) *Close relationships and risk of frailty: The*	To investigate whether social support and negative interactions	Fried criteria.	482 people. Mean age 64.8.	Hertfordshire Cohort Study.	Close Persons Questionnaire. HADs. BMI. Grip strength. Medical	Mentions follow up although later cites a single measurement.	No	Social support Relationships Social isolation Emotional support

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Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
Hertfordshire Cohort Study.	were associated with risk of frailty				Outcome Study. Waling speed.			Confiding Negative interactions
Gale C (2014) *Psychological well-being and incident frailty in men and women: The English Longitudinal Study of Ageing.*	To investigate whether psychological wellbeing was associated with incidence of physical frailty.	Fried criteria calculation.	2557 participants. Aged 50+.	Sample based on people who participated in the Health Survey for England.	Interview. Measurements of anthropology, physical function and blood sampling. Standardised assessment of depression.	**1998, 1999, 2001.**	No	Attitude Psychological wellbeing Protective factors Autonomy Control Purpose Happiness Pleasure

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
					Cognitive tests. Socio-economic data. Psychological wellbeing via CASP-19. Maximum hand grip. BMI. Gait speed. Frequency of vigorous exercise. Centre for Epidemiologic			

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
					Studies Depression Scale (CES-D).			
Gale C et al (2017) *Personality and risk of frailty: The English longitudinal study of ageing*	To investigate the relationship between the five major personality traits and frailty in people aged 60 to over 90 years. Hypothesised that people	Rockwood cumulative deficit model/ frailty index.	5314 men and women aged 60 to over 90.	Participants from the Health Survey for England, waves 5 (2010-2011) and 6 (2012-2013).	Data from the English Longitudinal Study of Ageing (ELSA). Midlife Development Inventory used to measure levels of personality traits.	Frailty index calculated at both waves with same data areas included.	No	Personality Risk

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	who are lower in conscientiousness or extraversion or higher in neuroticism may be at greater risk of frailty in later life.							
Gale C et al (2018) *Social isolation and loneliness as risk factors for the*	To investigate whether social isolation and loneliness were	Fried phenotype at waves 2 and 4, and frailty	2817 participants aged 60 or more.	Health Survey for England.	Loneliness assessed using revised UCLA score. Social isolation	**2002-3. 2 yearly intervals. Waves 2-5.**	No	Social isolation Loneliness Socioeconomic factors

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
progression of frailty: the English Longitudinal Study of Ageing.	independent risk factors for change in frailty status, and also to investigate whether greater frailty increased the likelihood of high levels of loneliness or social isolation in the future.	index at waves 2-5.			derived from data on living alone, frequency of social contacts and participation in social organisations.			
Gil-Salcedo A et al. (2020)	To examine the	Fried frailty phenotype.	6357 participants.	Data from Whitehall II		1985, 1991, 1997 and 2002.	No	Health behaviours

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
Healthy behaviors at age 50 years and frailty at older ages in a 20-year follow-up of the UK Whitehall II cohort: A longitudinal study.	association between health behaviours at age 50 and subsequent risk of frailty over a mean follow-up of 20 years. Additional post-hoc objective to examine the association of change in the		Aged 50 at time of recruitment.	study. Health behaviours at 50 measured, mortality data and covariates.		Phenotype model.		Self-reporting Cohabitation Sedentary behaviour

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	number of healthy behaviours over midlife and subsequent risk of frailty							
Hubbard RE et al. (2014) *Frailty, financial resources and subjective well-being in later life*	First, to investigate the association between frailty and subjective wellbeing in older people; second, to	Frailty Index.	3225 people. Over 50 - age 65-79.	Data from a population-based panel study, the English Longitudinal Study of Ageing	CASP-19 to measure subjective wellbeing. Cross-sectional association between	No tracking of frailty trajectory. Cross sectional design at each follow-up – population level data. 1998, 1999, 2001.	No	Finances Psychological safeguards Functional outcomes v health outcomes

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	explore the impact of household wealth and income on this relationship.				frailty and wellbeing.			
Lloyd A et al. (2016) *Physical, social, psychological and existential trajectories of loss and adaptation towards the end of life for older*	To understand the experiences, needs and priorities of frail people living at home and their lay carers towards the end of life	Clinical Frailty Scale (CFS).	CFS mod or severe. Aged over 75. 13 patients. 13 informal carers. 8 case-linked professionals. Average age 86.	Medical day hospital. Outpatient unit, inpatient unit, home.	2010 – 2011. Qualitative longitudinal approach. Underpinned by a constructivist theoretical perspective, which	**Interviewed up to three times over an average of 18 months. Every 6 months, plus 8-weekly telephone calls. CFS used for recruitment but not repeated.**	No	Coping Balance Adaptation Normality Sense of self Social connections. Struggling Narrative Loneliness

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
people living with frailty: a serial interview study.	to inform effective models of supportive and palliative care desirable to frail people.				emphasises that meaning and understanding is achieved socially rather than in isolation from the world around us. MMSE. Narrative approach. Open questions. Voice Centred			Hope Uncertainty Futility Fear Burden Overwhelmed Meaning Purpose Anchorage Belonging Infantilising Depersonalising Failure

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
					Relational Method (VCRM). Professional interviews alongside. Longitudinal case studies.			
Lloyd A et al. (2020) *Stories from people living with frailty.*	To explore the role that narrative may have for people living with frailty.	Clinical Frailty Scale (CFS).	Aged over 75. Moderate or severe frailty on CFS. 13 frail older people. 13 linked carers, 8 professional carers.	Recruited from a medical day hospital.	Individual or joint interviews. 54 patient and carer interviews 14 of which were	**Three times over 18 months. Eight-weekly telephone contacts. No tracking of frailty changes.**	No	Identity Routines Narrative Coping Adjusting Change Social connection Wellbeing

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
					joint with a carer.			Balance Struggle Control Fear Self-worth Self-blame.
Maltby J et al. (2020) *Frailty and Social Isolation: Comparing the Relationship between Frailty and Unidimensional and*	To examine whether 1. a multidimensional structure existed among the social isolation indicators in a large cohort dataset, and 2.	FP and FI used. All 52 indices suggested were used for FI.	Aged 60 and over. Private households in England.	English Longitudinal Study of Ageing dataset - wave 1, 2 and 4.	Gap of four years between waves to examine longitudinal effects of social isolation on frailty. Five indicators of social frailty	Four yearly follow up.	No	Loneliness Social isolation Forced withdrawal Social relationships Critical threshold

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
Multifactorial Models of Social Isolation.	a multidimensional, rather than a unidimensional, model of social isolation would improve the specificity of the relationship between social isolation and frailty longitudinally.				used as per previous studies, all objective measures. Two frailty assessments to reflect both frailty models.			

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
Martin CM (2014) *Self-rated health: patterns in the journeys of patients with multi-morbidity and frailty*	To explore patterns of SRH in calls to older patients with multi-morbidity and frailty and their variable hospital utilisation events over 6 months or longer… to test the theory that SRH is unpredictable	Rockwood	14 patients randomly selected. Ambulatory care setting in Ireland. Adults aged 50+. High probability of repeated admission in accordance with screening tool, and high risk of destabilisation. One or more hospitalisations	Three primary care settings – out of hours, post-hospital discharge and GP practices.	Pragmatic cohort study. 2011-2013. Conducted via regular telephone contacts. For 90% of calls same Care Guide called the same patient each time. Descriptive case study triangulating	**Monitored over at least one winter. SRH scored 0-6. GP visits, ED use or admissions tracked. Brief explanatory narratives about how patient felt, why, and consequences.**	No	Self-rated health Health trajectory Destabilisations Adaptability Physiological stability Psychological stability Social stability

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Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	in a cohort of patients identified as being at high risk of (re) hospitalisation but is a useful barometer of illness severity p2.		and more than 7 doctor visits in past 12 months. Frailty score 4 or more. At least one major chronic disease. Exclusion: nursing home residence, dementia, non-English speaking.		quantitative autoregressive techniques and qualitative case analysis. Quantitative autoregressive techniques and qualitative case analysis on SRH time series.			
Nicholson C et al. (2012) *Living on the margin:*	To understand the experience of home-	Frailty defined by the team as "people of	19 older people purposefully selected. 5 men.	Identified through	Qualitative psychosocial method.	**Interviewed up to 4 times.**	No	Change Trajectory Loss

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
Understanding the experience of living and dying with frailty in old age	dwelling older people living with frailty over time in order to develop the empirical evidence base for this group and to consider more fully how narratives of frailty can shape person-	advancing age, unable to carry out independent ADLs and considered to be vulnerable to physical decline"	12 women. 86-102 years old. 9 lived alone. Dementia excluded. All had contact with HASC services	intermediate care teams	Interviewed up to 4 times in their homes. Close attention to the ordering and phrasing of narrative. Two psychosocial approaches - BNIM and FANIM. Three cases chosen which represented	**Frailty changes not tracked.**		Psychosocial imbalance Identity Control Anchorage Daily routines Emotion

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	centred care provision				three points of gradations of physical frailty - intermittent dependency and independence, continuing stable housebound dependence and highly escalating morbidity.			
Nicholson C et al. (2013) *The*	To understand the experience	Regarded as frail by a	At home. 15 people (5 men,	Via an older persons'	A combined qualitative	**Repeated interviews over**	No	Loss

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
experience of living at home with frailty in old age: A psychosocial qualitative study	of home-dwelling older people with changing states of frailty… to enhance the evidence base around person-centred nursing care for this group.	clinical multi-disciplinary intermediate care team.	10 women). Majority widowed and lived alone. Socio-economically diverse area of inner London. Excluded: dementia.	multidisciplinary intermediate care team. Purposively selected.	psychosocial method. Two stages of face-to-face interview: one - the question is asked, and the interviewer does not interrupt answer, 2-interviewer goes back and asks questions about the	**17 months (up to 4 times). No tracking of frailty level?**		Emotional response Uncertainty Imbalance Anchorage Connection Routine Rhythms of the day Social and cultural norms Rituals Adaptation

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
					detail of what was said but only in the order in which it was originally raised, using the language of the participant.			
Niederstrasser NG et al. (2019) *Determinants of frailty development and progression*	To identify modifiable risk factors for development and progression of	Frailty index.	Aged 50+. Living in England.	Data from the English Longitudinal Study of Ageing.	Cox proportional hazards regression model. 8 waves with	12-year follow-up.	No	Socioeconomic inequality Sedentary behaviours Loneliness Social isolation

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
using a multidimensional frailty index: Evidence from the English Longitudinal Study of Ageing	frailty in older adults living in England, as conceptualised by a multidimensional frailty index (FI).				two-year intervals between 2004/2005-2016/2017.			
Ni Mhaolain AM et al. (2011) *Depression: a modifiable factor in fearful older fallers transitioning to frailty*	To evaluate the psychological factors associated with fear of falling in a group of	Biological Syndrome Model (Fried's 5 criteria) but with objective measurement of BMI rather than	Convenient sample. 301 fallers assessed. Minimum of 1 self-reported fall in 12m. 60+ years. Community	Technology Research for Independent Living Clinic in Dublin. 2007-2009.	Modified Falls Efficacy Scale. Assessment of anxiety, depression, loneliness, personal	Cross-sectional design.	No	Transition Rational appraisal Protective mechanism

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	fallers transitioning to frailty when compared with robust or non-frail fallers	subjective reporting.	dwelling. Able to mobilise independently. Able to consent.		factors and cognition.			
Ragusa F et al. (2022) * *Social frailty increases the risk of all-cause mortality: A longitudinal analysis of the English*	To investigate the possible association between social frailty and its components at baseline and all-cause mortality over	Chi-square/Fisher exact tests for categorical variables. Social frailty using Bunt et al. 2017 definition.	4149 participants.	Data from the English Longitudinal Study of Ageing (ELSA) between wave 2 (2004-2005) and wave 7 (2014-2015).	Social frailty and all-cause mortality calculated. Cox proportional hazard models.	Longitudinal cohort study.	No	Social frailty Risk of death Social support Contact with other people Social activity

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
Longitudinal Study of Ageing	ten years of follow-up							
Rogers NT et al. (2020) *Cultural engagement is a risk-reducing factory for frailty incidence and progression*	As studies have demonstrated the beneficial effects of cultural engagement (including visiting museums/theatre/cinema) for many of the components	Rockwood criteria. Frailty denoted as a FI score of .25 or higher, which is equivalent to at least 14 of the 56 indicators that comprise the Rockwood FI.	Analytic sample of 4575 participants. Aged 50+. Living in England.	Used data from the English Longitudinal Study of Ageing (ELSA). Wave 2 and wave 7.	Multilevel growth curve models were used to calculate trajectory of frailty. Measured cultural engagement via frequency of visits to theatre/concert/opera,	Frailty measured biennially over a duration of 10 years.	No	Cultural engagement Health behaviours Frailty trajectory

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	of frailty, this study sought to explore whether wider community cultural engagement is associated both with a reduced risk of becoming frail and a slower trajectory of frailty progression in older adults				cinema, art gallery/exhibition/museum.			

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
Shaw RL (2018) *Understanding frailty: meanings and beliefs about screening and prevention across key stakeholder groups in Europe (+corrigendum)*	To explore and better understand how frailty prevention and screening for frailty would be accepted and adopted by frail and non-frail older adults, by family caregivers, and health and	Frailty measure	Key stakeholders from frail, non-frail, family caregiver, health and social care professional groups.	UK participants identified using accumulation of deficits. "We are interested in hearing from people who consider themselves frail or infirm as well as people who regard themselves as healthy and active. This enabled older	Semi-structured focus groups and individual interviews in three EU countries (Italy, Poland and UK). Significant UK involvement indicated but specific breakdown not provided. Designed to	None	No	Isolation Shock Attitude Psychological resilience Positive mental outlook Self-confidence Protective factors Loneliness Clinically meaningful change Social connectedness Self-advocacy Balance

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	social care professionals. P1225			adults to self-identify as frail or not frail." p1227	guide a participant-lead discussion, to reduce interviewer bias, and improve consistency and comparability.			Agency Identity Flexibility Change
Skilbeck JK et al. (2016) *Making sense of frailty: An ethnographic*	To contribute to an understanding of the personal	Perceived as frail by Community Matron.	Age 75 and over. Living at home alone. Two or more LT conditions.	Access to older people gained via a community matron.	Semi-structured interviews. Ethnography.	Up to 6 encounters with each older person and CM were observed	No	Loss Stability Disruption Routine Self

Table 5: Initial 21 papers included in the 2021 review - Overview of study designs and key themes of papers in review								
Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
study of the experience of older people living with complex health problems	experience of frailty in the context of fluctuating health		Polypharmacy. Risk of falls. In receipt or eligible for social services input. Receiving Community Matron service.	Purposive sampling technique.	Credibility, dependability and transferability considered using the COREQ checklist.	at monthly intervals. 4-11 months		Continuity Coping Support networks Attitude Control Risk Expectations Transitions Adjusting Balance Adaptation Choice Agency Emotion
Stow D et al. (2022) * *The*	To investigate how	eFI	13149 people at the end of life	Electronic health record	Longitudinal case-	In EEOL cases information was	No	Deprivation

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Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
relationship between deprivation and frailty trajectories over 1 year and at the end of life: a case–control study	deprivation influences short-term trajectories at the end of life and if these differences could be used to inform care planning and provision at the end of life. Whether any patterns observed were unique to the		and 13149 age, sex and practice-matched individuals not at end of life.	data from primary care practices in the UK.	controlled study, with risk information collected retrospectively over 1 year.	collated 1 year before date of death. In control cases information was collated between Jan 2015 and Jan 2016.		Morbidity compression Time to accrue deficits Midlife Disadvantaged areas

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Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	last year of life or were present in non-end-of-life populations too.							
Stow D et al. (2018) *Frailty trajectories to identify end of life: a longitudinal population-based study*	To determine if changes in frailty measured by the eFI could be useful in primary care to indicate increased risk	EFI.	13,149 adults. Records of individuals aged 75 and over who died between Jan 2015 and Jan 2016.	Control group constructed by matching records by age, sex, and location but with no recorded death. External causes	1 year 2015-2016. Longitudinal study.	Monthly intervals.	No	Stabile frailty Frailty trajectory

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Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	of dying and the need to consider palliative care.			of death excluded. No eFI score excluded. Records of less than 6 months excluded. Monthly frailty scores for 1 year prior to death.				
Warmoth K et al. (2016) *'Thinking you're old and frail': a qualitative study of frailty in older adults*	To gain a more detailed understanding of older adults' perceptions of frailty and	Modified version of an established frailty index after interview. Frailty Index	29 participants aged 66-98. Own homes or institutional settings.	Open purposive sampling through a network of research contacts and community	Semi structured interviews in own homes or private meeting room on campus.	No follow up.	No	Identity Response Being Feeling Imposed Emotion Wellbeing

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Author/ year / Title	**Objective of the study**	**Frailty measurement**	**Participants**	**Recruitment/ setting**	**Study design**	**Follow up**	**Patient participation/ Co-production**	**Key themes**
	their beliefs concerning its progression and consequences	very fit to moderately frail and previously frail.		organisations. Excluded if unable to consent independently. Recruitment posters. Information pack for informed consent. Theoretical sampling later in interviews.	Topic guide for interviews. Grounded theory approach.			Resistance Fear Vulnerable Control Transition Disengagement

Table 6: Additional 6 papers identified through the 2023 update - Overview of findings which respond to the review question

	Author /year	Title	Key findings	What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in UK community settings?	Strengths	Weaknesses	Recommendations made
2	**Calvey B et al (2022)**	Expecting the best or fearing the worst: Discrepancies between self-rated health and frailty in an ageing Irish population	"…very advanced ageing can lead to the overestimation of healthiness" p9 "…sociodemographic and health behaviour variables were relatively useful in predicting membership of the health pessimistic group" p9 "…educational attainment can often act as a proxy for socioeconomic status and wealth, and can be influenced by an individual's ability to access healthcare" p10 "…psychosocial factors – including loneliness, anxiety, and social connectedness – were also useful in	Psychosocial factors (anxiety, loneliness and decreased social connectedness) significantly predicted being health pessimistic.	Large sample size (6907 participants)	Cross-sectional design	Assess longitudinal associations between sociodemographic, psychosocial and health behaviour variables with health asymmetry

Table 6: Additional 6 papers identified through the 2023 update - Overview of findings which respond to the review question							
			predicting health pessimistic individuals" p12 "…being more socially connected also decreases the probability of being health pessimistic" p12 "…no psychosocial variable was found to significantly predict membership of the health optimistic category" p12				
3	**Davies K et al (2021)**	The longitudinal relationship between loneliness, social isolation, and frailty in older adults in England: a prospective analysis	"Both loneliness and social isolation increase the risk of developing frailty" p1 "… both the quantity and perceived quality of social interactions and relationships can adversely affect functioning" p6	"Using ELSA, Gale and colleagues showed that although loneliness predicted higher frailty on the Fried frailty phenotype, it did not predict a higher frailty index, and social isolation did not predict frailty on either measure" p2" p1	Large sample size over 14 years (multiple waves) (more than Gale et al), nationally representative dataset for people aged 50+	Low representation of ethnicity, missing data for the social isolation scale. Use of partial records in dataset (unlike Gale).	Understanding the mechanisms through which loneliness and social isolation increase risk of developing frailty might offer opportunities to attenuate the risk

Table 6: Additional 6 papers identified through the 2023 update - Overview of findings which respond to the review question							
4	**Dugravot A et al (2020)**	Social inequalities in multimorbidity, frailty, disability, and transitions to mortality: a 24-year follow-up of the Whitehall II	"Socioeconomic status affects the risk of multimorbidity, frailty, and disability, but does not affect the risk of mortality after the onset of these adverse health conditions" p1	"…social inequalities exist in multimorbidity, frailty, disability and mortality" p1 "…we did not find any studies that examined whether socioeconomic factors play a role in the incidence of adverse health conditions (multimorbidity, frailty or disability) and their progression to mortality" p1	Large sample size with multiple measures of socioeconomic status Long follow-up period.	Frailty measured using phenotype at clinical examinations No access to emergency care records	"Social inequalities exist in the transition from health state to adverse health condition, but not in the transition from adverse health condition to mortality. Therefore, primary prevention… will be important in reducing social inequalities in mortality" p1
6	**Freer K (2020)**	Falling through the cracks: a case study of how a	"… frailty can have multiple contributors, including physical, psychological, social and environmental elements" p4	Follow-up to a previous paper, which discussed the "interplay between social and	Case study – personalised approach	No second frailty score reported to evidence change. Social isolation and environmental factors not measured.	"Further research would be beneficial to establish a stronger evidence base in the UK for standardised assessments and

Table 6: Additional 6 papers identified through the 2023 update - Overview of findings which respond to the review question							
		timely integrated approach can reverse frailty		environmental factors" (p1) in frailty			interventions in the community" p386. "Emphasises the value of joined up care" p4
21	**Ragusa F et al. (2022)**	Social frailty increases the risk of all-cause mortality: A longitudinal analysis of the English Longitudinal Study of Ageing	"Social frailty was significantly associated with all-cause mortality… highlighting the importance of identifying this phenomenon in older adults! P1	Relationship between social frailty and negative outcomes. But not explored in the community.	Large cohort (n=4149)	Social frailty scoring used, no frailty score. Data regarding medical conditions was self-reported. Limited ethnic diversity in sample.	Research on social frailty may prevent the onset of pathologies that can lead to death and allow better use of health resources.
25	**Stow D et al. (2022)**	The relationship between deprivation	Greater area-level deprivation is associated with higher levels of frailty, but people who survive to 75 or over have similar 1 year	"Differences in frailty trajectories associated with socioeconomic	Frailty measured at monthly intervals (eFI).	Few people from areas of greater deprivation.	Interventions to address health inequality in frailty should target younger age groups.

Table 6: Additional 6 papers identified through the 2023 update - Overview of findings which respond to the review question				
	and frailty trajectories over 1 year and at the end of life: a case–control study	frailty trajectories, regardless of area-level deprivation.	factors e.g. wealth in later life" p844	Nationally representative primary care dataset.

3.5 Gaps in knowledge

There are indications in the current evidence base that psychosocial factors such as positive attitude to ageing (Gale, 2017), health literacy (Huang, 2018), anxiety (Bernal-Lopez, 2012), and loneliness (Kojima, 2022) may influence the onset or trajectory of frailty, however little is known about the mechanisms of these relationships (Kojima, 2022; Archibald, 2020; Gale, 2017; Majnaric, 2021; Murray 2014; Warmoth, 2018). Studies to date which have explored these relationships over time have typically compared quantitative data from larger longitudinal ageing studies, which are unable to provide the detailed qualitative data required to understand how or why these quantitative measures changed or remained the same. Without the 'how' and 'why' the development of effective prevention or intervention strategies is limited.

Both academic and non-medical groups acknowledge psychological antecedents, linking low self-perceptions of health and depression with developing frailty (Whitson et al., 2018). Low self-rated health has also been shown to be directly related to decreased resilience (Abu et al., 2020). Antecedents of frailty perceived by those living with it include lacking "emotional resilience" (Grenier, 2007) and the nature of an individual's mind set (Sezgin et al., 2019; Britain Thinks, 2015), as expressed by an older research participant in Sezkin et al. (2019, p20) who said, "thinking of yourself as frail then you gonna have some subsequent frail behaviour". Additionally, there is a focus in the literature on the contribution of health behaviours and lifestyle choices such as alcohol consumption, smoking and activity levels (ibid) on frailty. The socioeconomic implications of such lifestyle factors suggest complex problematic issues may be at play around personal choice and responsibility, which may influence perceptions of the role of psychosocial factors as causes of frailty.

A 2018 comparison of stakeholder perceptions of frailty (Shaw, et al.) suggested older people with frailty and social care professionals have stronger perceptions of psychosocial antecedents than health care professionals, who emphasised physiological antecedents ahead of psychosocial domains. Studies of frailty historically focussed on the acute setting and focussed on physiological contributors and health related outcomes, as considerations within the medical management of needs. Psychosocial factors have not featured highly in this research, perhaps in part because the temporary accessibility of support in the acute setting and the unfamiliar environment alter how the person might normally respond or behave. Psycho-social factors are better explored in a community setting, however community-based frailty management has been less well researched. It is possible that differences between perceptions of frailty through health and social care lenses may be linked to differences in the timing or nature of contact with each service during the frailty trajectory however this has not been explored within the current literature. Exploring frailty through a social lens may offer new insights into responses to change

which better represent the role of the individual in managing frailty in the community and help move the narrative around frailty away from being a problem to solve and towards creating genuinely person-lead services.

The concept analysis and comparison of perspectives presented in Chapter 2 indicated that although there is broad consensus about biopsychosocial elements to frailty, there may be significant differences in perspectives as to whether these elements act as antecedents to the possibility of frailty, attributes of frailty itself once established, or the consequence or outcome of the condition. Understanding how these elements contribute to or present in relation to frailty may offer key insights into how frailty trajectories might be experienced or influenced. People living with frailty and the wider public in the concept analysis sample suggested frailty may be preceded by features of the individual's state of mind, reduced awareness of risk, inactive lifestyle choices and a sense of uncertainty. For healthcare professionals, psychological aspects of frailty were represented more frequently as aspects of an established frailty presentation as opposed to as an antecedent, whereas perceptions of risk within the immediate social or family network were thought to influence physical activity and therefore the onset of frailty.

There is limited understanding in the evidence base of the strategies or responses used by the person living with frailty to anticipate or respond to change and how this relates to current approaches to frailty measurement. Social psychologist Robert Cialdini identified 7 universal psychosocial principles of influence on thinking and decision making (Cialdini, 2021): reciprocation, liking, social proof, authority, scarcity, commitment& consistency, and unity. Drawing on Cialdini's principles can help identify implications for support, better understand the active role of the person living with frailty in managing their needs, and identify further areas of research into how best to engage with and support people living with frailty.

This further literature review completed in 2021 and updated in 2023 highlighted some evidence that psychosocial factors may predict or even contribute to the onset of frailty, and supporting the notion from the concept analysis that people with frailty perceive a causal relationship between psychosocial domains and frailty transitions. Changes in support systems were shown to influence psychological factors although the mechanisms and direction of this relationship and the relationship with frailty status were poorly understood. Limited evidence was found within UK cohorts exploring the relationship between psychosocial factors and frailty indicators over time. No studies in the review used self-reported frailty indicators despite evidence that self-reported health can predict morbidity and urgent healthcare utilisation. A gap in the evidence base is therefore identified in understanding the role of psychosocial factors over time in relation to changes in frailty status for people living in the UK, and therefore implications for operationalising these factors in Neighbourhood approaches to frailty. A qualitative longitudinal

study exploring the role of psychosocial factors in relation to frailty status from the person's perspective would address a gap in the existing evidence base and offer novel insights into prevention and supporting self-management.

3.6 Research questions

The overarching aim of this study was to understand the role of psychosocial influences on frailty trajectory and implications for self-management decisions and personal responses to change, by addressing the following questions:

a. How do people living with frailty in the community use psychosocial factors to maintain physical, psychological and social stability?
b. How do people living with frailty in the community anticipate, experience and respond to physical, psychological or social change?
c. Is there a relationship between the role of psychosocial factors during periods of instability and frailty levels calculated using self-reported support needs?

3.7 Research objectives

1. To increase understanding of the mechanisms which lead to transitions between frailty levels for people living with frailty in the community and how people with frailty or risk of frailty experience those transitions.
2. To understand what people living with frailty see as relevant psychosocial influences on frailty trajectory.
3. To understand which factors influence help-seeking and self-management decisions, and personal responses to change.

Summary

In this chapter I have presented a scoping review of existing research into the influence of psychosocial influences on frailty. The current evidence supports the notion that psychosocial factors may influence frailty onset and trajectory, however the scoping review identified gaps in the current evidence base. The review indicated the interaction between psychosocial factors and frailty levels over time is not well understood. These gaps in the evidence base may be adequately explored through an in-depth qualitative methodology. In the following chapter I describe the methodology and methods chosen for this study in response to the findings of this review.

Chapter 4: Methodology and Methods

This chapter draws upon findings from the concept analysis and scoping literature review presented in Chapters 2 and 3 and presents the methodological stance underpinning this study. I provide a rationale for the ontological and epistemological standpoint, and for the approach taken in addressing the research questions and objectives set out at the end of the previous chapter. Research ethics and rigour are discussed towards the end of this chapter.

4.1 Methodology

Findings from the concept analysis and literature review presented in the previous chapters, foreground the role of psychosocial factors and how the change in frailty over time is not well understood. This chapter describes how concepts from the literature were used to inform the study design, ontological and epistemological standpoint and the methodological approach to addressing the research aim; **to understand the role of psychosocial influences on frailty trajectory, and implications for self-management decisions and personal responses to change**. Considerations around credibility and trustworthiness in relation to researcher reflexivity are covered in recognition of the potential dissonance in conceptual understanding presented in earlier chapters.

Qualitative methodology

The literature review in Chapter 2 found that studies across several years of frailty have frequently drawn upon quantitative data from larger longitudinal ageing studies, which are unable to provide detailed insight into the complexities and nuances of psychosocial influences, whether past or present. Using qualitative approaches had potential to provide a greater depth of understanding of individual lives and experiences (Braun and Clarke, 2013). However, there are multiple research paradigms in qualitative research, so I now provide a detailed account of the methodology approaches used.

Ontological and Epistemological standpoint

Ontology is the 'study of being' and is concerned with what exists in the human world that can be considered 'truth'. It is often represented through a spectrum from realist ontology: one single reality, through to relativist ontology; reality constructed and experienced differently from one individual to the next (Moon and Blackman, 2014). The concept analysis suggested frailty may not be a single reality which can be understood through a single scientific theory, but may be constructed individually through cultural, moral and psychosocial domains. Ontologically, this study takes a relativist standpoint to explore this further.

Epistemology is concerned with the creation of new knowledge. As with Ontology, epistemology is also considered through a spectrum of objectivism: an objective reality or meaning that exists

separately to the individual, through to subjectivism; reality or meaning imposed onto the object by the individual. Between the two extremes is constructivism, which conceptualises meaning as created through an interplay between the objective and subjective (Moon and Blackman, 2014). Through models such as the frailty fulcrum, and representations of older people's perspectives in the literature there is evidence that frailty has not only objective physical domains, but also more nuanced and complex psychological and social domains (Golbach et al, 2024). The interplay between these domains forms the primary area of focus for this study. In addition, there are powerful indications that cultural meaning and belief around frailty may be explored through hermeneutics. Hermeneutics is a branch of knowledge and methodological principle that focusses on interpretation and how meaning is formed. This study adopted a constructivist epistemology, which takes the stance that 'truth' emerges from individual engagement with the world (Moon and Blackman, 2014) and therefore supports a more contextual understanding of frailty trajectory.

Constructivist grounded theory

Grounded theory aims to build specific 'substantive theory' which may be more directly applied to clinical practice than theoretical outcomes and has particular strengths in exploring how things change over time (Merriam, 2015). With its philosophical roots linked to pragmatism and symbolic interactionism, grounded theory seeks to prioritise the 'useful' over the theoretical and seeks new knowledge inductively such that the "understanding of human experience is dynamic, evolving, situated within context, and value laden" (Burns et al., 2022:3). Symbolic interactionism is a lens through which to understand how meanings are created dynamically through social interactions and contexts.

Whereas traditional grounded theory focusses on the development of theories grounded in data rather than from existing evidence, constructivist grounded theory takes a more active stance, discarding the notion of the researcher as an impartial observer in favour of encouraging a more reflexive analysis of the researcher's role in constructing meaning and theory with the participant. In this way this methodological approach is closely aligned to the rationale for this study; the need for evidence which acknowledges and responds to different understandings of frailty, and in doing so aims to build a shared understanding (Mudge, 2018). Constructivist grounded theory encourages simultaneous data gathering and analysis to explore emergent leads as they arise, allowing for an open-ended, inductive, and comparative approach (Charmaz, 2014).

Interpretive influences

In their 2022 paper, Burns et al. draw comparisons between constructivist grounded theory and interpretative phenomenology as both methodologies share the same ontological and epistemological paradigms. Although constructivist grounded theory was selected as best suited

to this study due to its focus on social processes here in responding to living with frailty, interpretive research takes the approach that there is no single, observable reality but instead there are multiple socially constructed realities (Merriam, 2015). Whereas interpretative phenomenology focusses on lived experience and narratives of 'being', constructivist grounded theory allows constant comparison of data in order to more actively develop substantive theory. I chose constructivist grounded theory as wanted to be able to acknowledge my own observations as clinician-researcher alongside the participant's account, as I felt this approach reflected the multiple perspectives interacting within clinical practice. This is consistent with evidence of conceptual disagreement about the antecedents and contributors to frailty. Interpretive influences, particularly the role of individual narratives, supported the data collection and analysis process to offer insight into how and why people with frailty construct understandings of instability.

4.2 Methods

Overview of design

This qualitative study aimed to increase understanding of psychosocial influences and personal responses to change associated with living with frailty in community settings within an Eastern Coastal region of the UK, by interviewing people living with frailty over up to a 12-month period. Potential participants were identified through community health and social care teams, with study recruitment processes completed by the researcher. Up to three interviews were conducted with each participant during the study period, exploring in real time the experience of living with frailty. Participants were asked to diarise life events between interviews whether new or mundane, alongside the use of visual analogue scales within the participant diary to reflect on perceived ability to make decisions or seek support. A semi-structured interview approach aimed to explore diary contents and personal responses with the participant.

In grounded theory, the delaying of any literature reviewing is advocated, such that new theories and understandings can truly be derived purely from the data. Through the doctorate process literature reviewing was a necessary and appropriate precursor to designing this study and informing initial recruitment decisions. Charmaz (2014) suggests in her book 'Constructing Grounded Theory' that theoretical sampling can be used during the study process to inform ongoing recruitment decisions, such that the researcher uses contemporaneous data to decide what data to collect next and where to find it, (Glaser & Strauss, 1967). As such it was intended that purposeful sampling within this longitudinal study could be used to explore the experiences of different demographics or patient groups, should recruitment volume allow for this. Four waves of recruitment were originally proposed, with participants from each wave interviewed up to three times.

Duration of the study

To explore the role of psychosocial influences on frailty trajectory over time, a longitudinal study design was adopted. Change can be best understood through the contemporaneous observations on a series of occasions over time (Mason, 2018). There is some disagreement in the literature regarding duration required to observe meaningful changes. Ahmed et al. 2020 noting one year to be insufficient to detect clinically meaningful response shift, and Nicholson et al. (2013) found 17 months insufficient to detect large changes in frailty status, however participants in Nicholson's study were already known to intermediate care services and already receiving support with reduced independence. Nicholson's participants were interviewed at 6-month intervals which was an appropriate interval to illuminate changes and stability, however as two participants dropped out due to acute admissions these longer intervals may have reduced likelihood of capturing change immediately prior to these crisis events. Conversely, Stow et al. (2018) note that for a small but high-risk proportion of people living with frailty, 12 months was adequate for significant changes in frailty to occur despite baseline frailty scores calculated using healthcare data being low. These are arguably the individuals who may benefit most from greater understanding of why this phenomenon occurs, therefore a period of 12 months was identified as appropriate to this high-risk group of interest.

Interviews were offered no more than three times with each participant over the 12-month period in recognition that the interview process may deplete energy reserves for this already vulnerable cohort; however actual frequency was participant-lead. In grounded theory the intention of reflexivity is to acknowledge the effect of these factors and their role on the coproduction of meaning. By taking time to recognise my own thoughts and assumptions prior to each interview, the influence of these factors on my own questions and responses during the interview became if not minimised, more intentional. Therefore prior to each interview i completed a reflexive diary entry designed to explore my own personal "experiences… prejudices, viewpoints, and assumptions" (Moustakas, 1994, p. 33).

New knowledge and improving practice

Through the study design it is anticipated that new understanding of the experience of transitions between frailty states can be greater understood. Within the broader national context of integration of health and social care services it is imperative that services begin to view frailty through a combined health and social care lens, and this study design aims to contribute new learning to the integration agenda. For frailty to be considered a positive or useful concept in community-based services a preventative, strengths focussed approach is needed using language chosen by the service user, with a view to rebuilding trust in an intention to protect the vulnerable, not identify them for rationed care (Mudge and Hubbard, 2018). The Care Act section

1 sites the importance "…of beginning with the assumption that the individual is best placed to judge the individual's well-being" and this study design adheres to that principle.

4.3 Recruitment

Cohort scoping

In Stow et al.'s 2018 study identifying a small proportion of people at risk of rapid deterioration despite low frailty levels at baseline it was suggested this high-risk group may not be easily identified using data from medical records (eFI). Despite being recognised as a complex holistic state, frailty is traditionally identified via contact with a healthcare organisation following a change in health status. Suggestions that loneliness may precede frailty and subtle reductions in social connectedness may be early warning signs of onset (Maltby et al. 2020), alongside notions that financial resources may offer a 'psychological safeguard' against frailty progression (Hubbard et al., 2014) indicate social care may hold promising opportunities to identify early warning signs not currently detected by healthcare records. With this in mind study participants were to be recruited via the Integrated Neighbourhood Teams (INTs) which include both health and social care referral systems, thus moving the focus away from the medicalisation of frailty. The proposed recruitment criteria was shared with service leads within the INTs who confirmed a high number of people meeting the criteria had been referred to the INTs over the previous six months, thus providing reasonable assurance that the criteria was appropriate to the proposed recruitment approach.

Participant Identification Centres (PICs)

Given older peoples' increased likelihood of perceiving psycho-social causes of frailty it is possible that social care might provide the first point of contact when reaching a 'tipping point', particularly when no specific medical diagnosis has been given. Equally the exact nature of the tipping point within a holistic condition like frailty may result in health services as a first point of contact. Despite a shared identity as an Integrated Neighbourhood Team, health and social care are currently two separate organisations therefore separate PIC agreements were needed to recruit via the two front door referral pathways. It is not currently known whether this first point of contact provides any insight into the person's perceptions or personal responses to frailty, or what role coordination between health and social care support might play in offering support along the way, however by including both front doors as PICs this study offered potential to explore this subject further.

Indication of social or functional fluctuation or change was identified through new requests to the INT related to, community access, minor home modification or equipment provision, domestic home support enquiries, or housing needs assessments. These enquiries might indicate

changes in instrumental activities of daily living (IADL)[2], shown to be the first steps in a distinct progression of functional decline (Morris et al., 2013) prior to the development of difficulty with activities of daily living (ADL)[3]. Functional decline within IADL has been associated with elevated informal support need (Ibid), which might be detected via requests for carer support assessments. Requests for new financial support for social care needs also formed part of the inclusion criteria as the literature review indicated low financial resource may be a risk factor for frailty. Fluctuation or change in physical health was identified through new requests to the INT related to any of the frailty phenotypes (unintentional weight loss, exhaustion, weakness, slowness or low physical activity), or a change in the person's ability to manage their physical health needs.

Gatekeepers

To ensure my access to participant information remained within the boundaries set out in the consent process, triage professionals within the INTs (PICs) acted as gatekeepers for recruitment to the study. Gatekeepers had access to clinical records as part of their professional role and were therefore able to identify people meeting the study criteria. I selected set dates for recruitment in advance to identify the therapy, social work and nursing triage professionals on duty. I then completed a short training session with each triage professional on the inclusion/exclusion criteria and recruitment process. To support this I also provided a screening guide and brief script to ensure consistency and that approved terminology was used [Appendix 18 and 19]. I produced a detailed flowchart of the steps involved in the recruitment process and associated documentation for further clarity [Appendix 17].

Sampling in grounded theory is aimed towards constructing a theory rather than population representation (Charmaz, 2014), and as such in the initial recruitment process I focussed on indicators of new instability rather than attempting to represent the full demographic of those thought to be living with frailty. Triage professionals were asked to seek verbal permission for follow up contact regarding the study once the initial referral processing has been completed and outcome shared so as not to disrupt or delay the usual process or conflate the study with access to services. This mitigated against any potential for coercion to join the study. As I had a professional connection to one of the INTs, this INT was excluded from the recruitment process to further reduce any potential for bias in the recruitment process.

Recruitment took place over agreed dates and triage professionals were asked to identify potential participants based on the criteria provided and seek verbal consent for further contact

[2] IADLs are more complex tasks which support overall wellbeing and independence, beyond basic physical need. Examples might include managing money, transportation or preparing meals

[3] ADLs are day to day tasks related to essential survival and wellbeing. Examples might include toileting, eating or moving/transferring

to discuss the study. A name and either a telephone number or address was obtained by the triage professional dependent on the individual's contact preference. Any specific communication support needs were identified to ensure contact was made in an accessible format when appropriate. Names and contact details were shared with the researcher via a secure email address and deleted if not recruited.

Sample size

Sample size for this study was limited by only having one part time researcher to conduct interviews. The small scale made a fully representative sample of the demographic of people living with frailty in this Eastern Coastal region unrealistic. However, the depth of description made available by the longitudinal qualitative methods and efforts to be selective in recruitment decisions to explore different lived experiences was designed to strengthen the usefulness of findings to inform clinical practice and prompt reflection for those involved in shaping the wider integration and 'Neighbourhood' agendas. Findings based on lived experience can inform person-centred use of public services and local delivery of the health and social care integration agenda.

Due to researcher resources a conservative estimate of two interviews per month in the first quarter, and four interviews per month in the subsequent two was applied to calculate a maximum total of 38 interviews over 12 months, or the equivalent maximum sample of 13 participants completing 3 interviews each. This was rounded up to 14 to allow equal recruitment from health and social care parts of the INT. For a longitudinal in-depth study, a sample of 14 would be sufficient to generate meaningful data.

Inclusion/exclusion criteria

Around 10% of people aged over 65 live with frailty. This figure rises to between 25% and a 50% for those aged over 85 (Age UK, 2015). To increase likelihood of identifying individuals with frailty gatekeepers were asked to identify individuals/referrals for individuals aged 75 or over requesting support for the *second time or more*, or where this recurrent need could be identified through clinical judgement [Appendices 18 and 19]. This purposeful sampling strategy was intended to detect the pattern of deterioration outlined by Clegg et al (2013) [figure 1], to produce a sample of people reaching a new "tipping point", either self-initiating contact or being referred by a third party. The combination of the older age group and recurrent contact with services may also be an indication that a person could be reaching the 'last 1000 days' of life (Dolan and Holt, no date) and therefore increasing the possibility that during the 12 months duration of this study participants may experience some type of health or care need changes relevant to the research question.

Individuals whose capacity to consent was in doubt at this stage were not recruited. Capacity was presumed for all other potential participants as per the Mental and Capacity Act [DoH, 2005] and

assessed more formally by the researcher in person at subsequent stages prior to recruitment onto the study [Appendix 25]. Triage professionals were asked not to put forward individuals with any type of safety alert recorded on the home screen of their care record.
Recruitment of self-referring individuals took place via the telephone referral system to identify a more diverse sample group than other routes such as online referrals which require a level of IT access and literacy for example. Purposeful sampling using existing web referral systems was confirmed as feasible in subsequent recruitment waves if specifically relevant to emerging themes.

4.4 Engaging with participants

Supporting engagement

An existing body of literature has documented many challenges engaging frail cohorts in research previously (Dismore et al, 2023) and in recognition steps were taken within the study design to support and encourage engagement with the study where possible. Communication preferences including language were identified by the triage professional as part of existing organisational processes. A telephone interpreter or translated version of any written information would be provided to aid communication. Large print texts would also be available on request, as would the use of a virtual face to face conversation with subtitles to aid independent communication where possible. Any other communication methods requested by participants would be considered and implemented wherever feasible and practicable to do so.

Confirmation phone calls were made a week prior to each interview and again on the day of the interview to mitigate against any potential cognitive difficulties as well as providing opportunities to reschedule in response to any fluctuations in ability to partake. Multiple communication methods were considered to minimise the potential influence of variable literacy levels. On the day of each interview, I wore conventional modest clothing to strive for neutral perceptions of my own character. Participants were also offered the choice of having a spouse or carer present during interviews, for instance to help overcome communication challenges, memory or anxiety challenges or cultural expectations.

Consent

Triage professionals obtained verbal consent from potential participants to share their contact details with the researcher for the purposes of communication regarding the study only. The Participant Information Sheet (PIS) was posted by the researcher to all potential participants and made clear that participation was voluntary, as well as information about the process to withdraw from the study. After provision of the PIS, Expression of Interest form including self-assessment questions and return envelope, the potential participant was asked to return their completed documents within 14 days if they wished to participate. The researcher called each

person one week after posting the PIS to ensure it has arrived and offer an opportunity to ask any questions. The person could opt out of this phone call at their discretion. If a response was not received within 2 weeks the researcher would telephone the potential participant to confirm their decision not to participate or offer any support needed with the forms. If the researcher was unable to contact the individual by phone a second letter would be sent stating non-contact had been interpreted as a decision not to participate, and reiterating researcher contact details should the individual change their mind or have further questions. The participants details were be deleted by the researcher one week after posting this final letter if no further contact is received.

It stated to all participants that they would be free to withdraw from the study at any time, however four weeks after each interview the transcript would be thematically analysed and anonymised. At this stage data may be combined with data from other participants and it would no longer be possible to withdraw an individual's data. Individuals not consenting to participate or wishing to withdraw consent would be excluded, however no participants withdrew consent.

At each interview the PIS was revisited with the participant. Capacity was presumed as per the Mental Capacity Act (MCA) (DoH, 2005) and assessed more formally at each face-to-face contact using the 'Capacity to give informed consent decision tool' developed for this study [Appendix 25]. Individuals whose capacity to consent was in doubt would not have been recruited. No vulnerable groups were intentionally included within this study.

As an experienced clinician, the researcher has undertaken mental capacity training and is skilled in identifying non-verbal indications that a participant may wish to withdraw. In one instance a participant stated that they would like to participate but were unable to return the postal form (or access emails). Eligibility criteria questions were completed over the phone and met, therefore a date for initial interview was agreed and written consent received by the researcher in person.

The study aims and participant requirements were discussed at the start of each subsequent contact. Written consent for continued participation was sought at the start of each contact. Any additional persons present such as a spouse or carer were also asked to sign a consent form if they participated in the conversation such that their transcript might be included to analyse the data fully. Interviews only went ahead if written consent was collected but was also implied during the interview by continued engagement in the interview process. Should withdrawal of consent have been implied through a lack of engagement or expressly stated, the interview would be terminated immediately. The Participant Information Sheet detailed the protocol for use of data should consent be withdrawn during the study or should an individual's capacity to consent change during the study.

Participant Information Sheets

During my initial contact with potential participants, I outlined the focus and duration of the study with the individual and sought consent to provide more detailed information sheets in the individual's preferred format and in plain English (HRA, no date). Large print and accessible format versions would be made available as required. Participant Information Sheets (PISs) [Appendix 20] made clear that participation is voluntary, outlined the nature and aims of the study, explained what participation meant in real terms, the inclusion and exclusion criteria, any reasonable risks to be expected, benefits to the participant, how privacy and confidentiality would be maintained, contact details of the research team and host organisations, data storage intentions consistent with data protection and GDPR requirements, and protocol for withdrawing from the study and for raising any concerns (HRA, no date). I produced a Decision Tool to support evaluation of capacity to give informed consent [Appendix 25].

Terminology used in participant documents

The concept analysis undertaken to inform this research study indicated that a shared understanding of frailty as a concept was necessary (Cronin et al., 2013) for clinical practice or to at least approach a phenomenon collaboratively. People's understanding of frailty could not be assumed as clinical, academic and public understandings may differ. There was also evidence that older people may not perceive frailty in terms of its potential to lead to improvement, that the term may be perceived as impersonal, stigmatising and broadly negative (Nicholson et al., 2017; Tomkow, 2018). These associations may be off putting for potential participants who may not wish to associate themselves with the term. For these reasons use of the term 'frailty' was included in the full study title for transparency but embedded within an acronym in participants to keep further repetition to a minimum. ('MYSELF: (M)echanisms of destabilisation in older people living with frailt(y): understanding social influences on frailty trajectory, (self)-management and personal responses to change') - thus adhering to BGS (2014) recommendations to present frailty as a transient state, not a part of who one is. The study protocol and participant information sheet was shared via a local PPI network, facilitated by the local ICB in November 2022. Feedback predominantly focussed on the length of the pack being somewhat long with no comments shared regarding terminology.

4.5 Data collection

Setting

This study took place in a community setting within an Eastern Coastal region of the UK. Participants were interviewed in their own homes. The rationale for this was multifaceted. Participants homes were intended to offer a confidential and non-medicalised environment, where the individual might be most likely to feel connected to the realities being discussed.

Seeing participants "…lives from the inside… gives the researcher otherwise unobtainable views" (Charmaz, 2014, p47). Although not as immersive as an ethnographic study, intermittent observations and reflections of the individual within the context of their homes over time can enrich data and were used to enrich transparency of data, and to form part of the reflexive process associated with interpretive constructivist grounded theory. Interviews focused on the personal experience of participants lives, therefore discussing this within this context also had the potential benefit of prompting more accurate recall.

Conducting interviews within people's own homes reduced the likelihood that health or socioeconomic factors commonly experienced by the older demographic might impact on ability to engage e.g. Fatigue, mobility or access to transport. Alternatives to face-to-face interviews at home were provided, including use of online platforms which comply with UEAs data-protection policy (Zoom, Microsoft Teams) and confidential community spaces outside the person's own home. No participants expressed a wish to meet outside their home.

Iterative topic guide

An iterative topic guide was produced prior to the first interview [Appendix 27], which outlined indicative topics designed to support a breadth of conversation. Indicative topics included connection with local context and community, going out, managing at home, recent health/social care need leading to contact with services, and decision making within any experiences raised. Interpretive constructivist grounded theory enables interview questions to evolve throughout the study, led by themes emerging from each wave of interview data. As such, additional follow-up questions were introduced at second and third interviews, which were bespoke to individual interview content.

Interview style

Interviews were conducted using a semi-structured approach, to guide the direction of the conversation towards the study objectives but allow for participants to lead the content. Interviews were intended to produce high levels of detail about the experience of the participants. Open ended questions were utilised to encourage participants to speak freely, and summary statements mirroring the terminology used by the participant were used during the interview to encourage participants to talk without the researcher leading the focus of the conversation (Charmaz, 2014). Interview questions were developed iteratively [Appendix 27] in response to the emerging themes and through reflection with research supervisors. As a novice researcher transitioning from a clinical role, my interview approach evolved from the more familiar therapeutic interview style which aims to produce a positive change for the interviewee, into research interview style aimed at collecting and probing participant accounts (Targum, 2011). A reflexive diary was used to document and reflect on this transition.

A combination of informational and intensive interviewing was used to gain accurate information about events and chronologies, but also to focus on how participants described experiences and their meanings. These were used sequentially, to start with less emotive subjects and build gradually towards the potentially emotive. In her 2002 paper on illness narratives, Annika Lillrank discusses the concept of 'splitting' in which events eliciting 'good' and 'bad' emotions are separated internally and the 'bad' is distanced from the sense of self as a strategy to avoid anxiety. Lillrank refers to both participant and interviewer as "defended subjects" (p115) in that negative highly emotive subjects although integral to the reality of daily life may not be freely approached. This identifies a tension between overt discussion and covert emotion (Ibid), which poses a challenge for myself as the researcher to explore the wholeness of lived experience without challenging or compromising what may be protective coping strategies for the participant. Direct questions about emotional or psychological states may be perceived by participants as confronting, therefore a focus on pragmatic or less emotionally vulnerable lines of questioning such as how an individual responded to an event and why they believe they responded as they did may offer insights indirectly. The coding process and interval of time between interviews may also add a protective layer of distance between the participant and the data such that when themes are revisited, they become a 'safer' version of the original discussion.

Home visit procedure

Within two weeks of the provision of the PIS an additional contact was made with each potential participant using their preferred contact method. Where individuals responded positively a home visit was arranged to complete recruitment processes and consent form (HRA, no date). A buddy system was arranged with a member of the supervisory team including details of the location and time of the planned visit for safe lone working practice.

Participant diaries

In addition to qualitative interviews, participants were asked to complete participant diaries [Appendix 29] between interviews to collate discussion points for subsequent interviews in 'real time', thus reducing the influence of response shift (Schwartz et al. 2020). Diaries contained three questions per entry related to activity that period - whether routine or unplanned - and three visual analogue scales related to self-management, support seeking, and feeling able to manage health needs. One entry per week was proposed, with space included for up to 20 entries however no minimum diary use was required between interviews as variation between participant ability was expected. Findings from Chapters 2 and 3 suggested loss of self and routines may predict frailty transitions (Lloyd et al. 2020), therefore questions were included focussing on continuity or change in day-to-day activity.

Participants were asked to place a cross on a visual analogue scale (VAS) to state how much they agree with three given statements - placing a cross somewhere along a straight line, somewhere between the two ends marked 'strongly agree' and 'strongly disagree'. The lines were always the same length to achieve a high degree of sensitivity to change. A numeric scale was avoided to reduce any temptation to consciously compare current feelings to a previous point in time. The statements chosen were derived from the Patient Activation Measure (PAM). Access to the full PAM tool was not possible due to lack of funding and the anticipated cohort size for this study falling below the minimal required under licencing terms. These areas of enquiry were derived from the perceptions of psychosocial influences on frailty trajectory in the concept analysis; specifically, the perception of older people that individual response and adaptiveness to change may play a key role in mitigating against sudden deterioration (Lloyd et al., 2016; Skilbeck et al., 2018) and therefore potentially influencing frailty trajectory and outcome. Used alongside the more pragmatic questions about activity on the first diary page, this combination of questioning was designed to explore the relationship between types of change and personal responses.

Frailty scoring

Qualitative longitudinal studies reviewed during the concept analysis or literature reviews presented in Chapters 2 and 3 did not include frailty measurement, so to provide new insights and the rigor of a repeatable and auditable approach, a frailty measurement tool was included in this study design. The PRISMA-7 frailty screening tool was chosen for the recruitment phase of the study as it is supported in current guidelines for use in clinical practice. It can be completed as a self-assessment (supported or independently) and completed remotely without the need for clinical assessment, therefore ensuring the person's own perceptions were used to identify frailty, alongside frailty characteristics included in this study's recruitment criteria such as recognition of the typical trajectory outlined in Chapter 1 [see Figure 1]. In a 2018 systematic review of frailty assessment tools with social components, Bessa et al. found that of the 27 instruments reviewed, the PRISMA-7 contained the highest proportion of social components (43%) excluding tools designed to assess *only* social frailty, suggesting the tool is an appropriate fit for this study's conceptualisation of frailty as a biopsychosocial construct. The PRISMA-7 tool is a valid and reliable tool with high level accuracy in the identification of frailty (Yaman & Unal, 2018) and is recommended in the NHS Rightcare Frailty Toolkit.

The Clinical Frailty Scale, also advocated for use in the community in the NHS Frailty Toolkit (NHS Rightcare, 2019), formed part of the constant analysis and comparison process. I recorded a Clinical Frailty Score after each interview by combining the qualitative interview content with my own observations and experience from my professional clinical background, reflecting on my own reflexive contribution to this process at each stage. A convergent approach was planned, with the

integration of the qualitative themes, and CFS scoring taking place during the analysis phase, therefore strengthening inferences made (Guetterman, 2019). Conducted longitudinally, this approach allowed contemporaneous analysis of 'incidents' (described by Charmanz in a 2015 interview with G. Gibbs as 'actions which lead to outcomes' irrespective of scale) grounded in data from participants, alongside changes in frailty score. From a reflexive standpoint as an inexperienced researcher, a methodological approach which actively encouraged a continuous process of analysis and exploration supported my own professional development during this process.

4.6 Research ethics

Participant rights, dignity and welfare

Participant rights, dignity and welfare were considered and planned for in advance by using 'Researcher Safety Checklist' and 'Risk and Mitigation table' templates provided by the UEA, and through drawing upon my experience of working with older adults living with frailty to anticipate potential dignity and welfare issues that may arise. Perceptions of myself and my role as researcher, distinct from the role of the PIC site teams, were purposefully managed through both my physical presentation and wording used in the participant information. Given the limitations in health information available I called ahead of each interview to confirm each participant was well and able to participate and took PPE to each face-to-face interview as a precaution. As a registered health professional, I had all mandatory vaccinations required for a clinical role, which served to protect both myself and the research participants. Participant wellbeing was further supported through providing the option for an advocate to
be present during interviews, and my own wellbeing and reflexivity process was supported via regular supervision.

It was possible that participants might experience emotional or psychological distress through discussing life experiences. Details of appropriate support organisations such as counselling services were identified in advance as a contingency should this situation arise. Interview questions were open ended to allow participants to disclose at an emotional depth they were comfortable with.

Inclusivity of participants with communication, or significant mobility issues was accounted for to maximise accessibility, including the availability of adapted formats of information to be accessible to the individual. The Mental Capacity Act (MCA) (DoH, 2005) guidelines were adhered to as a regulatory framework, and capacity to consent to participate reviewed at each interview. I had undertaken Mental Capacity Act (MCA) (DoH, 2005) training through my clinical role and was able to conduct a capacity assessment specific to the decisions related to taking part in the study. A protocol was put in place should any participant lose capacity during the study.

REC approval

This study (IRAS ID 312260) received favourable ethical opinion from the East of England – Hertfordshire Research Ethics Committee on 21/12/22. REC reference number 22/EE/0265.

Data integrity and storage

Data management followed the Data Protection Act (gov.uk, 2018), UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's Research Data Management and Lone Working Policies. As researcher I hold professional indemnity insurance through my membership to the Royal College of Occupational Therapists. The University of East Anglia acted as sponsors and as such were accountable for insurances and/or indemnity related to the management and design of this study. Regular supervision meetings took place throughout this study to monitor ethical compliance.

Audio recording took place in an open and transparent way, with the Dictaphone being visible to the participant throughout the interview and both verbal and written consent to record gained at each interview. Capacity to consent was checked at each contact. Third parties also present at the participant's request and contributing to the interview in any way were also asked to provide written consent to audio recording.

Interview audio recordings were transported in a locked bag and the files moved onto an encrypted laptop and deleted from the Dictaphone immediately following each interview. To manage the disclosure of potentially sensitive information interview recordings, transcripts or subsequent coded data was not stored alongside identifiable information. A pseudonym was assigned to each participant and corresponding identifiable data was stored in a separate password protected file on an encrypted laptop owned by the researcher's employing organisation. It was explained to each participant that should any disclosure indicating that the participant or others around them may be at risk of harm, confidentiality would need to be broken to appropriately safeguard those individuals. Recordings were transcribed by the researcher. Transcripts were anonymised with any identifiable details removed.

4.7 Rigour

To demonstrate rigour in this study design, credibility, dependability and transferability need to be considered (Holloway and Wheeler, 2010). Daniel's 2019 TACT framework is used here to demonstrate and evaluate rigour in the study design. The framework has four dimensions; "Trustworthiness, Auditability, Credibility and Transferability (TACT)" (Daniel, 2019, p1) [Figure 13] and is intended to support new researchers in incorporating these concepts into study design and evaluation.

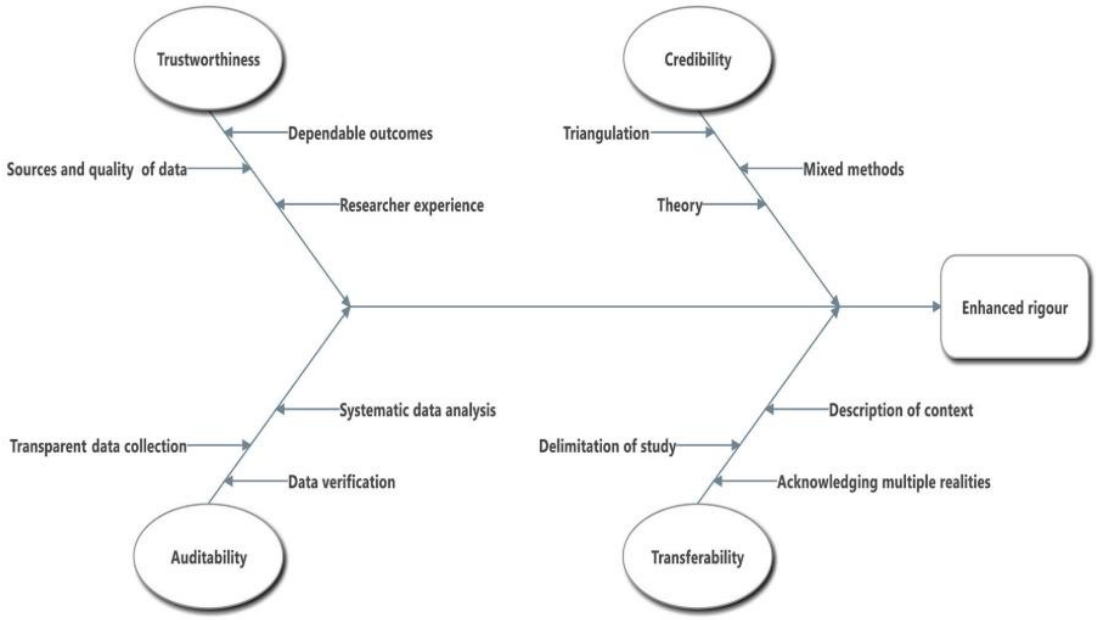


Figure 5: TACT Model for assessing rigor in qualitative research (Daniel, 2018)

Trustworthiness

Trust involves "demonstrating relevance and confidence in research findings and establishing the authenticity of the results" and is achieved through "…a systematic and methodical approach, demonstrating data analysis and interpretation consistency" (Daniel et al. 2024, p2). This dimension of rigour has been applied by describing influences on the study design and the study planning process in detail, including approvals received through the REC and flowcharts detailing consistency in the study process. Participants were identified through REC sites using a script and recruitment criteria for consistency. A separate nhs.net email account was used for triage professionals to securely share the contact details of potential participants and part one of the eligibility and recruitment checklist [Appendix 19]. I identified levels of frailty using nationally recognised screening and assessment tools, and although calculating frailty scoring based on self-reported information rather than full clinical records access as a clinician, this was an intentional aspect of the study design, consistent throughout the study and is recognised in this paper. As part of the interpretative constructivist grounded theory methodology, a researcher diary was used for reflexivity around the influence of my own personal and professional background on the study design and development [Appendix 32]. Instead of attempting to remove this influence, I actively recognise and engage with it and to take into account is interpretating results, the interplay of differing perspectives shown in the concept analysis (Chapter 2). Additionally, full interview transcripts are provided to display thematic analysis applied consistently to all transcripts. A framework was used to present the outcomes consistently for both participants (Chapter 6).

Auditability

Auditability is a "systematic recording of the research process" (Daniel et al. 2024, p2), evidenced by displaying a "clear pathway of decisions made during research, facilitating reflection on the process" (ibid). Documents detailing the study pathway and any decision points along the way such as applying inclusion/exclusion criteria and establishing capacity to participate were submitted to the Research Ethics Committee in advance and have been included in the appendices of this document for transparency. Copies of these documents containing participant information will be submitted to the UEA data repository. External auditability has been adhered to in accordance with PIC agreements. As such names and dates of potential participants identified and contacted as well as the recruitment outcome has been shared with the Research and Development Office of the relevant PIC organisation. Original interview recordings were destroyed after transcription as per the study protocol however, interview full interview transcripts have been submitted. A 'Declaration of the end of study' has been made to the Health Records Authority (HRA), and a Final Report will be submitted within 12 months of the end of the study as required by HRA processes. I demonstrated Internal auditability through supervision records, including conversations about methodological integrity on the topic guide content, study design, approach to data analysis and drawing conclusions.

Credibility

Conveying research credibility validates the authenticity and reliability of findings and so supports the truth of conclusions (Daniel et al. 2024). To manage expectations from the outset it was stated that the study was unrelated to waiting lists or clinical interventions. This was also reiterated upon first contact from myself, alongside confirmation that information collated by the triage professional accurately reflected inclusion criteria being met.

A longitudinal design has the benefit of reducing recall bias in participant accounts of their own recent life events by recording responses over time rather than asking people to retrospective recall events retrospectively. As "interpretation of the past though the lens of the present" may alter analysis (Mason, 2018, p33). Participations were not offered the opportunity to review full transcripts of each interview as this may lead to a more conscious choice of wording in subsequent interviews or may lead to self-conscious behaviours detrimental to the interview process. Instead, a summary of subjects discussed was compiled and key themes drawn from the transcripts by the researcher. Sections of transcripts were also analysed by research supervisors for quality checking and to apply a range of perspectives. I relayed these summaries back to the participant at the start of the subsequent interview by way of triangulation. The purpose of reflecting on the themes of previous conversations with the participant was two-fold. Firstly, this served to validate my interpretation of data provided and address any misunderstandings or

what the participant had intended to say or insider-researcher influence early, thus ensuring a more robust study. Secondly this helped compare two points in time and prompted reflection on any change that may have occurred. There were no instances whereby either participant expressed a different recollection of the discussion points I relayed from previous interviews; however, I used the opportunity to raise additional points of clarity with both participants where details from the previous interviews had been unclear during the transcription process.

I collated research data through multiple methods (qualitative interviews, researcher observation, clinical frailty scoring and participant diaries) which provided multiple datasets over the same period. This was consistent with Daniel's (2018) model in Figure 13, which states that credibility and dependability of findings is strengthened by the use of multiple methods, as the participant's experience is viewed and analysed through multiple different lenses. By analysing these data sources alongside each other I was supported to take a reflexive approach in recognising how my own observations might differ or align with participants' own accounts. Credibility of findings is also supported through the researcher and participant being consistently and repeatedly involved in interactions over time (Holloway and Wheeler, 2010), and through continual reaffirming of a shared understanding of what has been discussed. This was achieved by reflecting on previous themes and key discussion points at the start of each new visit. All recruited participants had adequate recall to reflect on the previous 3-6 months in response to these prompts.

Transferability

Transferability is the extent to which findings can be applied to other similar groups or settings. This study does not set out to identify a single truth that may be applied to all people living with frailty, but to detail commonalities and differences in experiences of the study participants related to social and interpersonal influences. To contribute to transferability, I have provided a detailed description of the setting in which these interviews took place and of participants' broader circumstances and worldviews (Daniel et al. 2024, p3) to contextualise the accounts provided.

Summary

In this chapter I have described the ontological and epistemological standpoint and relevant theories used to inform my study design. A longitudinal qualitative design underpinned by a constructivist epistemology is well suited to the research questions and overall aim to explore individual perspectives of frailty change over time. Key features of the research design have been presented, including steps taken to ensure research quality and ethics. In Chapter 5 I describe the process of study recruitment including decisions arising around inclusion and exclusion of participants. I will provide an overview of the two participants recruited to the study and describe the process used to analyse data from the two illustrative cases.

Chapter 5: Susan, Margaret, and analysing the interviews

This chapter provides an overview of the recruitment process and additional recruitment decisions made. The two recruited participants are introduced including basic demographics, household composition, ability to go out, health conditions disclosed, and key support sources in place. The Clinical Frailty Score calculated at each interview is provided as a reflection of frailty trajectory for each participant during the study period. I describe how I analysed interview transcripts in relation to experiences of change and stability, and to consider indicative domain specific frailty levels.

5.1 Study participants

Following a 3-month recruitment period, the PIC sites had identified 7 potential participants. Of these 7, 4 initially consented to receiving information about the study but later declined to participate. Reasons given included insufficient communication ability and energy to be able to engage for a full interview (reported by a spouse/power of attorney), and a disinterest in the study focus. 3 people consented to participate. Of these, 1 repeatedly described diary commitments and periods of illness that prevented scheduling of the first visit. After two attempts to schedule I suggested the person contact me to arrange a first visit when she felt ready. However, she made no further contact, and her details were removed from the study. Therefore, two participants were recruited to the study, via two different PIC sites. I assigned pseudonyms to these two participants as stated on p11 to ensure participant confidentiality. I conducted a total of five interviews. Table 7 gives an overview of demographics, key support sources and physical health conditions disclosed for the two study participants – Susan and Margaret. Their individual frailty scores at each interview are also included to show personal frailty trajectories for each participant

5.2 Frailty and stable disability

Having identified potential participants by asking triage participants to look for a pattern of recurrent contact with health and questions derived from the PRISMA-7 Questionnaire which I then reviewed to confirm a score of 3 or more as part of the inclusion criteria. During my first contact I asked each participant questions about their circumstances to confirm living arrangements, and if they wanted someone to attend the interview with them. During these initial contacts neither participant indicated any disability that would make recruitment inappropriate. This was important as use of the CFS scale is not recommended alongside stable disability as the measure may lead to a false frailty score.

Margaret discloses later during the interviews that she was born with scoliosis, a condition not made apparent when first meeting her as she was unable to move out of her armchair

independently. Margaret describes multiple corrective surgeries and interventions earlier in life but has lived and gone out independently until a specific turning point. I considered at this stage whether it was appropriate for Margaret to remain in the study, however as her scoliosis was not cited as the cause of her reduced independence and overall deterioration, I did not feel her disability would contradict use of the CFS.

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Name	Age	Gender	Rural/ urban area	Property type	Household	Formal care	Domestic support	Mobility/ transfers	Going out	Physical health	Clinical Frailty Score (based on self-reported status)		
											Interview 1	Interview 2	Interview 3
Susan	82	F	Urban	Bungalow (own home)	Lives with husband (Jim[4])	None	Cleaner Gardener Window cleaner	Independent Increasing use of a walking frame	Bus Taxi Neighbours	Reduced movement in shoulder, urinary incontinence, frequent falls, mild visual impairment, long-standing inward turning foot	5 Mildly frail	5 Mildly frail	6 Moderately frail
Margaret	87	F	Rural	Bungalow (own home)	Lives alone	Two carers, four times daily: personal care, toilet, meals and all transfers	Cleaner Gardener	Hoist	N/a Powered wheelchair not used	Scoliosis, Bilateral hip replacements, Unspecific terminal diagnosis, Fluid on the chest, Oedema (lower limbs)	7 Severely frail	8 Very severely frail	n/a

Table 7: Overview of the two study participants

[4]Also, a pseudonym for confidentiality. Jim is a similar age to Susan and discloses several conditions of his own which impact his independence – sleep apnoea, newly diagnosed dementia, a cardiac condition, diabetes, use of a hearing aid and narcolepsy.

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5.3 Data collected

I interviewed Susan three times and Margaret twice at their homes. There were 52 days between Margaret's two interviews. There were 92 days between Susan's first and second interview, and 281 days between her second and third interview.

PRISMA-7: I asked each participant the PRISMA-7 questions prior to each interview.

Interview transcripts: I audio recorded and transcribed each interview. Transcripts were analysed and coded between interviews.

Participant diaries: Weekly diaries focussed on independence with functional activity and confidence asking for help versus managing without help. Completed sections were discussed or completed at each interview as a conversation aid.

Clinical Frailty Scale (CFS): I calculated CFS scores after each interview based on my own observations and separately based on participant accounts.

Frailty Fulcrum: As part of the final analysis, I also re-analysed all five interviews to explore content related to each frailty fulcrum domain, and applied an indicative CFS score to each domain using the CFS description which most closely matched the wording used by the participant.

5.4 Approach to analysis

Analysing the first interviews

Audio recordings from the first interviews were transcribed, checked and audio files deleted, and the transcripts thematically analysed line by line to identify an initial set of codes. Through secondary analysis of transcripts, additional codes were applied to reflect more detail and nuance. Participant terminology and phrasing were retained within codes where possible, alongside codes which reflected my own interpretation. For instance, the exert of coded interview transcript from Margaret's first interview in Figure 14 demonstrates how the codes 'Choice – have to have' and 'Absence of choice' were both applied to the same passage. The supervisory team reviewed key sections of interview transcripts to increase reliability of the thematic analysis. Codes produced from both stages of transcript analysis were then grouped into broader categories. These broader categories and their corresponding codes were collated into one table to support comparison over time for each participant and produce a combined dataset for the study. Figure 15 shows a section from this table, and illustrates in the first column (headed Margaret, Interview 1) how the codes applied to the transcript exert in Figure 14 from Margaret's first interview formed part of the broader category 'choice and decision making', alongside other codes from the wider dataset.

Responding to the research questions

Interview transcripts were colour coded for their relation to the original research questions – whether they related to change, or to maintaining stability:

a. **How do people living with frailty in the community use psychosocial factors to maintain physical, psychological and social stability?**

b. **How do people living with frailty in the community anticipate, experience and respond to physical, psychological or social change?**

c. **Is there a relationship between the role of psychosocial factors during periods of instability and frailty levels calculated using self-reported support needs?**

Prevalent themes identified during each interview were used to guide areas of enquiry during subsequent interviews with each participant, alongside any areas of conversation which needed further clarity with each participant for reliable interpretation. Constructivist grounded theory encourages simultaneous data gathering and analysis to explore emergent leads as they arise, allowing for an open-ended, inductive, and comparative approach (Charmaz, 2014). Conducted longitudinally, this approach allowed analysis of 'incidents' ('actions which lead to outcomes' irrespective of scale (Charmaz, 2015)) as they happened, grounded in data from participants alongside changes in frailty score.

Interviewer	How do you feel about having people come in and help with lots of day to day things now? It sounds as though they're doing quite a lot of things?	Q: How do you feel about having help day to day? How much are they doing?	
Margaret	I... That is the choice I have to have. Because when I was in hospital that time, I went in, I had one carer. But I wondered why I was kept in hospital for over 6 months. It's because, again, the Occupational Therapist said I could only come home if I had *two* carers. Well you've got to find firms that... I mean, I'm not the only one they go out to, lots of people. But you know, there's [pause] there's always some *obstacle*. There really is and you think, 'oh, I'm fed up with *this*' [emphasis on this]. Y'know, you... you don't *wanna* get depressed, but you think 'be patient, be patient', but when that one week turns into two, three, four, five, six, seven, eight, and you're into six months	That is the choice i have to have When i went into hospital i had one carer Again, the OT said i could only come home if i had two carers You've got to find firms I'm not the only one they go out to There's always some obstacle Oh I'm fed up with this You don't wanna get depressed, but you think be patient, be patient One week turns into two, three etc, and you're into six months	Choice – have to have Absence of choice Not coping - perception of professionals Types of support - unsolicited Professionals – lack of shared decision making Professionals – time spent Resolving issues - delays Decision making Carers – availability Resolving issues – fed up/depressed Resolving issues - managing emotions
Interviewer	Goodness, as long as that?		
Margaret	And the doctor, you'd say 'can you do anything?'... As I say, that last doctor was good because they've got a new Physio down, or Occ... he's good	Ask the doctor – can you do anything [about wait to go home] The last doctor was good New PT or OT [at GP surgery] he's good	Resolving issues – drawing upon expertise Professionals – confidence in
Interviewer	Is this at the GP surgery they've got somebody?		

Figure 6: Excerpt from Margaret, Int. 1, p12 - coding process

	Key: How do people living with frailty in the community **anticipate, experience and respond to** physical, psychological or social **change**? How do people living with frailty in the community use psychosocial factors to **maintain** physical, psychological and social **stability**?				
	Margaret interview 1 21.11.23	**Margaret** interview 2 12.01.24	**Susan** interview 1 22.08.23	**Susan** interview 2 22.11.23	**Susan** interview 3 29.08.24
					Got each other – we're both in it p57 Responsive - First one there p58
	Choice and decision making				
	Decision making p12, 16, 35, 36 Choice – have to have p12 Choice – have to have p19 Absence of choice p21, 24, 30	Choice – still have to p22 Expectations of others – supposed to be p22	Decision making – collaborative p41 Decision making – what to do for the best p41 Choice – have to have p33 Choice – have to have p34 Absence of choice p34	Absence of choice p8 Decision making – collaborative p34, 38 Choice – have to p38	Decision making – not discussed p32 Decision making – intuitive p32 Decision making – becoming a liability p32 Decision making – hard decision for the safety of others p33 Decision making – safety of others p32 Decision making - 'got to' p50 Decision making – stopping activity due to health p51 Jim Decision making – having someone to listen p59 Choice – maintaining activities of personal value p37 Not got much choice have we? P52 Reduction in choice p54 Reduction in spontaneity p54

Figure 7: Excerpt from table showing collation of transcript coding into broader themes, including subsequent colour coding to indicate application of each code in relation to change or stability

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Measuring frailty

I used my clinical judgement to calculate each participant's Clinical Frailty score and checked this by also using the Clinical Frailty Scale (CFS) Classification tree (Theou et al., 2021) [Figure 16]. By calculating a CFS at each interview I was able to reflect upon change and continuity described within the detail of each participant account alongside the overall frailty status reflected by the CFS.

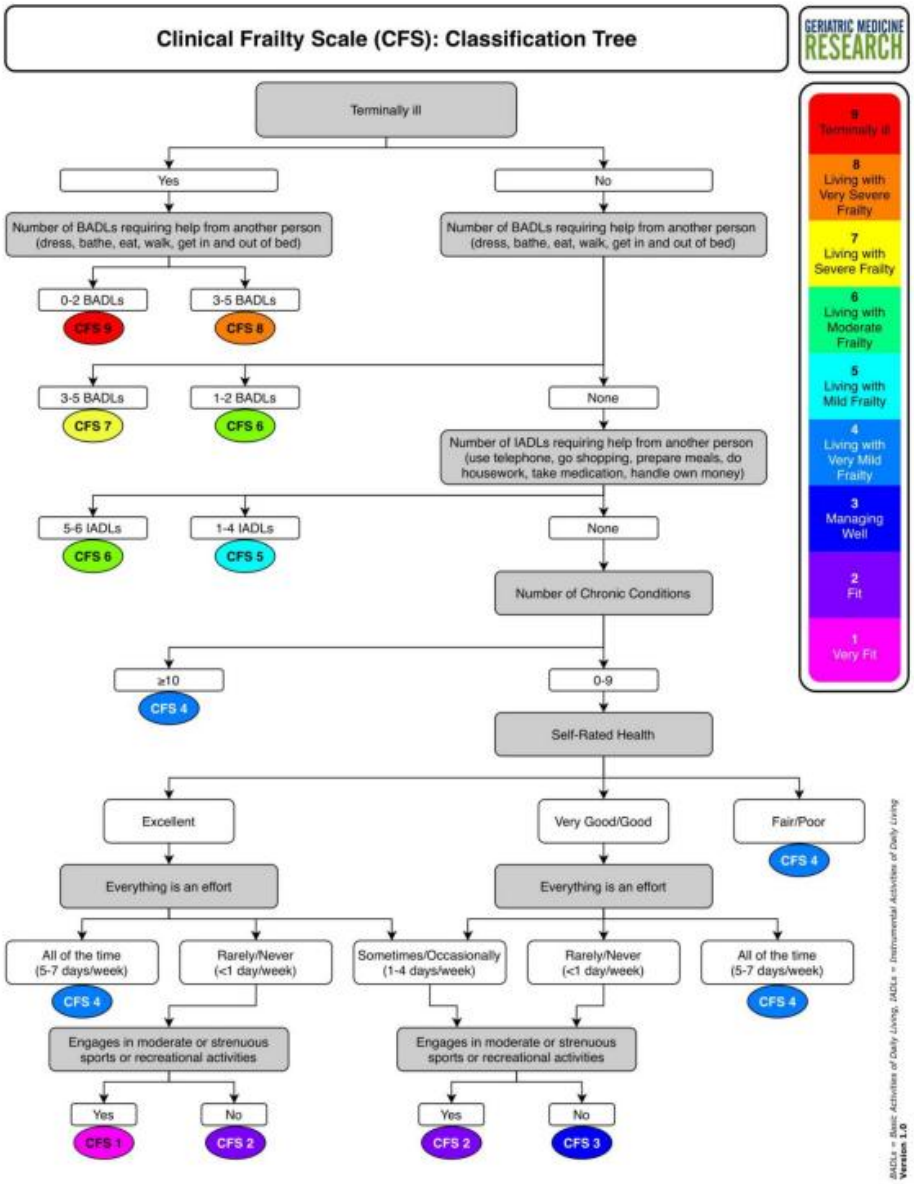


Figure 8: The Clinical Frailty Scale classification tree (Theou et al., 2021)

Influences on categories

At each subsequent interview I followed the same process of transcription, coding and thematic analysis. Decisions around grouping codes into categories were made inductively without the introduction of a model or framework at this stage. Categories were identified through the lens of the research questions and the notions of change versus stability, psychological and social factors, physical health, and anticipating versus responding to change influenced categorisation of codes. The use of the Clinical Frailty Scale (CFS) into the study design as the primary measure of frailty status also influenced the inclusion of categories related to 'doing things', as the descriptors in the CFS represent overall frailty status through levels of functional ability and independence [Figure 17].

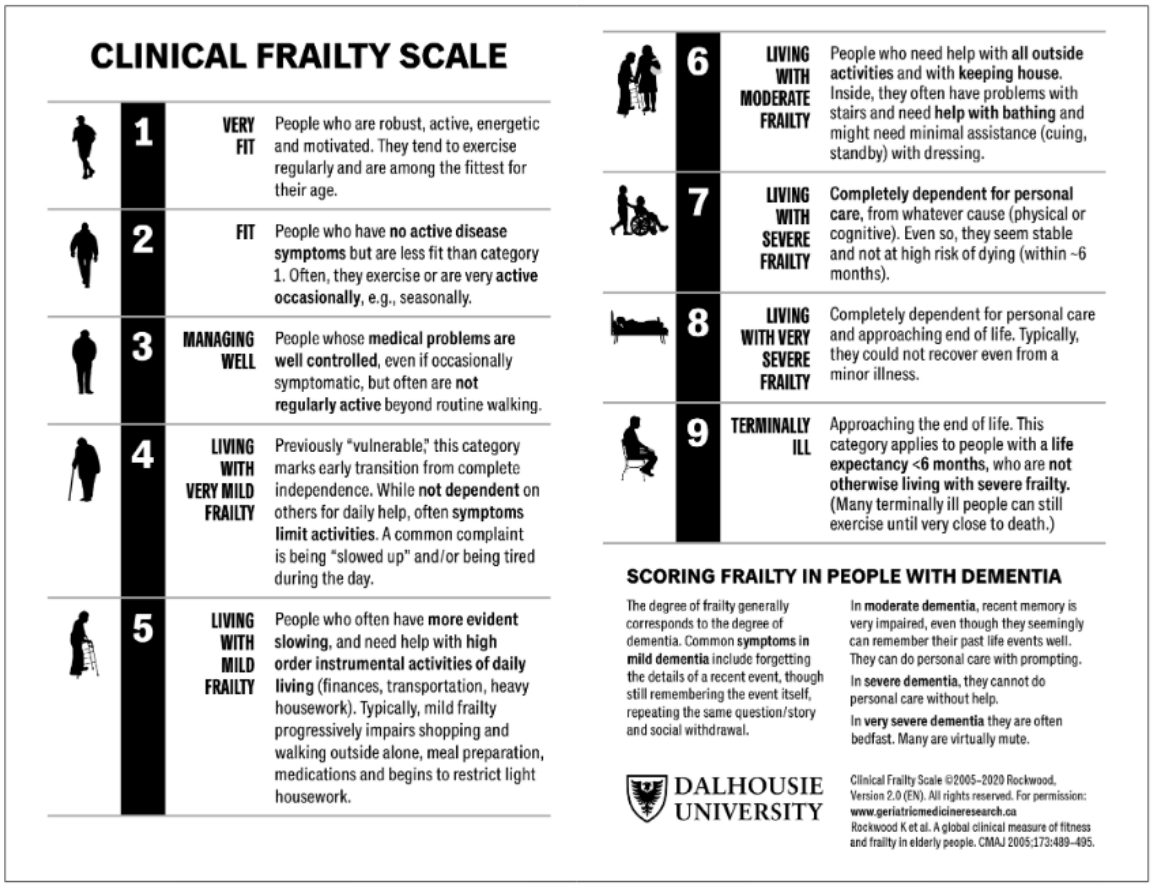


Figure 17: Clinical Frailty Scale version 2.0. See also earlier figure 2. (Rockwood and Theou, 2020)

Frailty fulcrum

After all interviews were completed I analysed the transcripts to explore how each participant described each domain of the frailty fulcrum [Figure 18]. Following on from the findings of my concept analysis and observations that changes across these domains may be perceived differently by different stakeholders, this approach allowed me to explore whether Susan and Margaret's experiences corroborated my concept analysis findings. As interview content was

largely participant lead and focussed on their perceptions of change and continuity, data related to each domain varied between participants and interviews. This limited how comprehensively each domain could be compared, however variation in focus between the domains offered insights into participant perceptions of domain influence when living with frailty.

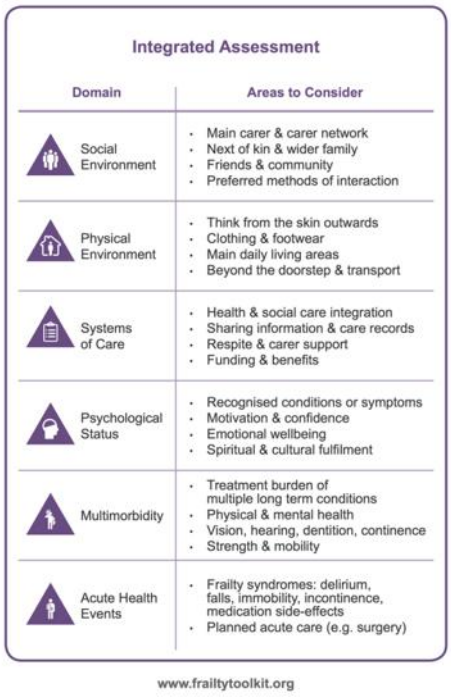


Figure 18: Frailty Fulcrum domains and recommended points of consideration

Summary

In this chapter I provided an overview of the participants and their respective frailty trajectories during the study period, alongside a detailed account of my approach to data analysis. In presenting an overarching indication of participant frailty scores, psychosocial influences described in the following chapters can be considered in relation to these overarching frailty trajectories. In Chapters 6 and 7 I present two separate illustrative cases, detailing change and stability for both participants. The findings of my concept analysis presented in Chapter 2 indicated people living with frailty may perceive domain-specific frailty progression differently to health and social care professions or other stakeholder groups. To explore this further, I include indicative domain-specific frailty levels for each participant across the study period.

Chapter 6: Susan - Illustrative case

In this chapter I provide a detailed analysis of data gathered across three interviews with Susan over a total period of 53 weeks. I present Susan's account of psychosocial influences on change and stability within the frailty domains, in reference to the research questions:

a. How do people living with frailty in the community use psychosocial factors to maintain physical, psychological and social stability?

b. How do people living with frailty in the community anticipate, experience and respond to physical, psychological or social change?

c. Is there a relationship between the role of psychosocial factors during periods of instability and frailty levels calculated using self-reported support needs?

The research questions and methodology allowed participants to talk about what was important to them. As a result, categories emerging inductively from the interview transcripts have been used to structure this illustrative case . I will draw upon Maslow's hierarchy of needs and social psychologist Robert Cialdini's 7 psychosocial principles that influence thinking and decision making to further analyse the data in relation to the study objectives:

1. To increase understanding of the mechanisms which lead to transitions between frailty levels for people living with frailty in the community and how people with frailty or risk of frailty experience those transitions.

2. To understand what people living with frailty see as relevant psychosocial influences on frailty trajectory.

3. To understand which factors influence help-seeking and self-management decisions, and personal responses to change.

6.1 Meeting Susan

First visit

I first contacted Susan in the Autumn of 2023 having received consent through the PIC site. Having introduced myself as a student researcher and provided an outline of the study, Susan told me she wanted to be 'part of anything that would help make a difference'. I had spoken to multiple potential participants to discuss the study and found each time there was a point in the conversation where initial interest turned to disengagement. Although the specific turning point was different for each person, I was aware that my introducing the word 'frailty' into the conversation was a vulnerable moment that could lead to another potential participant lost. Despite this the duty of transparency overrode any concerns I held and to my surprise Susan

barely reacted to the term – I could almost hear the shoulder shrug through the phone line. I posted the participant information pack, followed up with another phone call, and a few weeks later I visited Susan for the first time at the bungalow she shared with her husband Jim.

Susan's home was in a cul-de-sac location near to a busy main road in an urban setting. Approaching Susan's home, I noticed her neighbour on his driveway but passed by without his acknowledgment. Susan answered the door and welcomed me in, showing me through to her conservatory where Jim was just coming in from the garden. Susan walked without an aid indoors, but I noticed her hands close to the surfaces and walls of her home as she went. Introducing myself again, both Susan and Jim asked me to call them by their first names. As we worked through the recruitment process, Susan shared copies of paperwork with Jim – 'so he can see what it's all about'. I asked Susan whether she would like to complete the interview alone or with Jim present. Susan gestured no preference either way but ultimately invited Jim to stay.

Further visits

In total I visit and interview Susan three times over a 12-month period. Jim joins each of these interviews to different extents with Susan's consent – at the first he is present as a bystander – ready with additional details when called on by Susan, or to add thoughts of his own. At the second interview Susan answers the door, this time walking with more pronounced uncertainty – hands rarely out of contact with some feature of her home environment: *"I look all the time, where can I hold on. I mean… I know exactly where…, hold there, hold there and get round"* [Susan, Int. 2, p4].

Susan and I speak alone for around 50 minutes, before Jim returns home having gone into town by himself to resolve a banking issue. Time alone with Susan provides an opportunity for her to speak about changes in Jim's health, his new Alzheimer's diagnosis and her thoughts about the future. Susan tells me although Jim was aware of the diagnosis at the first interview, he had not mentioned it and Susan mirrored this decision. In interview two, with Jim not present Susan tells me how Jim's new diagnosis contributes to her decisions and choices in the present in anticipation of change in the future. Jim arrives towards the end of my second visit and is noticeably tired, his foot barely seeming to clear the raised threshold into the conservatory. Whilst he hangs up his coat in the hallway Susan tells me *"Jim's not walking very well"* (p44). When I suggest we end the interview she says, *"He's alright – I'll make him a cup of tea and he'll revive",* but realising we've reached 1 hour I draw my visit to a close.

For the third and final interview my researcher notes reflect a continued picture of deterioration in Susan's mobility and overall wellbeing:

> "Susan held on to door frames and walls continuously whilst walking and appeared unsteady and unconfident on her feet"

Both Susan and Jim are present throughout the final interview, and Jim becomes a much more active participant. His frustrations with the management of his own health conditions take over the first part of the interview, and his contributions to the discussion are noticeably abrupt at times. I sense something unspoken between Susan and Jim, perhaps a tension that is illuded to in comments about 'too much time together' and life's pleasure now being in 'arguing'. It becomes more difficult to differentiate between Susan's perceptions of her own needs and those relating to Jim. The resulting transcript reflects Susan and Jim's experience of ageing together, however during analysis afterwards I add the word 'Jim' to differentiate between the two experiences represented.

In the following illustrative case, I present Susan's account of anticipating and responding to physical, psychological and social change both during the study period in the context of other life experiences she shares.

6.2 Illustrative case

Changes in mobility

As my observations described, Susan focussed on managing what Maslow describes as safety needs, with one notable change for Susan across the three interviews being her gradual deterioration in mobility. Although she can get around her bungalow independently, she describes increasing use of her walker across the three interviews; initially used just for accessing the wider community with some support from Jim;

> *"Yeah, [I go out] when I'm fit and well [laughs]. I've got a walker, which [Jim] has to put on the bus cos I can't lift it cos this [indicates shoulder] plays up too much… and I do get very tired"* [Susan, Int. 1, p5]

then needed to get to the bird feeder in Susan's own garden; *"Since you came out, I'm on the walker. I don't go out without it. I don't even go down the garden without it"* [Susan, Int. 2, p3]

and by interview three Susan describes "Using [the walker] a lot more" [Susan, Int. 3, p3] both inside the home and out. She responds to her deteriorating mobility and increased tiredness by purchasing a walking aid with an integral seat; *"Got a new walker…. This one is a proper walker with four wheels, and you can sit"* [Susan, Int. 3, p3].

The new walker is a successful strategy for Susan - and for Jim - during a trip to the opticians where only one seat was available, allowing both to sit down. Susan describes planning and limiting her movement at the opticians to take the most direct route to the seating area,

suggesting although she continues to go out with Jim into the local community her actions are carefully planned and controlled around her physical limitations. Other outdoor activities cannot be so readily adjusted, and Susan describes her progressive difficulty using stairs which limits some aspects of going out, most notably leisure activities;

> *"We used to go out with a group '[organised groups name]… but can't do that now. It's a coach… And it's up about four or five steps. And I can't get upstairs, and Jim can't really… we have done [their activities] but I can't do them now"* [Susan, Int. 1, p11]

Making adjustments in response to her changing mobility and increased fatigue, Susan retains her connection to a community she has lived in for many years. The purchase and use of an upgraded walker provides safety against accidents and injury when out walking, however Susan's ability to overcome other features of public spaces such as steps is limited, and as a result she loses connection with some social spaces, both physically and metaphorically.

Response to increasing falls

As the interviews progress, Susan describes diminishing success in compensating for her changes in mobility as she continues to fall with predictable regularity; *"Not this Christmas, yeah the Christmas before that… That's when I first went down… too many [since]… Three-month intervals. But I've never passed that three months [laughs]"* [Susan, Int. 1, p19]. During interview 2 Susan reflects; *"I lose track of how many [falls] there are… I just say, 'oh it's another one'."* [Susan, Int. 2, p17] suggesting a possible increase in the frequency of her falls, although when I ask more directly in interview 3 Susan is not immediately sure, turning to Jim for clarity;

> *"No, yes? [looks to Jim]"* Susan
>
> *"She's more <u>careful</u> [pause] because she can't walk so easily. You just shuffle."* Jim
>
> *"Yeah, I like to erm, I usually walk with the walker if I'm tired, so..."* [Susan, Int.3, p25]

This interaction suggests Susan may not be conscious of changes she makes to her movement and activities which may have stabilised the frequency her falls – an observation on adjustments which Susan acknowledges when pointed out. Susan reflects on first starting to fall, initially feeling worried about falling; *"…but now. I mean, they're only the major ones what I've said to you"* [Susan, Int. 1, p24], suggesting she has adjusted not just her physical activity, but also to her perceptions of what constitutes a 'major' event. This change of perspective is repeated in the third interview when Susan and Jim define major falls as needing a visit to hospital afterwards;

> *"Oh yeah, quite a few haven't I [to Jim]"* Susan [when asked about having more falls since interview 2]
>
> *"Yeah, but there's been nothing <u>major</u>"* Jim

> *"I've not gone to hospital through any of them, plenty of bruises! I come up in bruises for no reason. You know, I don't remember knocking that [looking at bruise on arm], but I must have… in the house, mainly"* [Susan, Int.3 p29]

Susan and Jim's differentiation between falls with or without the need to go to hospital may reflect whether injury had been sustained. However, by interview three Susan is unable to identify when she might have sustained the significant bruising I observed on the underside of her forearms, suggesting injuries without need for medical treatment have become an unnoteworthy expectation of daily life. It is also likely that other features of Susan's experience of hospital attendance following a fall also contribute to her perspective of hospital-related falls as more major events. Susan's altered expectations around safety and perception of acceptable risk seem to influence her perception of support needed from others and therefore her own sense of esteem and independence.

After an ambulance is called following a fall, Susan recalls disagreeing with the ambulance crew about hospital conveyance plans as Jim would be unable to get to the proposed hospital. Susan makes the final decision but is supported to attend her chosen hospital by taxi rather than ambulance. Susan returns home with short-term care support daily; support she describes being put in place automatically to aid her return to independence but feeling *"glad"* to no longer experience an *"open house"* [Susan, Int. 1, p27] once the support was no longer needed. Susan describes a second fall at home overnight whereby she broke her hip. Jim feared causing her further damage, so she remained on the floor for three hours before an ambulance arrived. After four days in hospital Susan describes the decision for her to return home;

> *"it was a bit quick coming out I thought. And so did the other patients who I'd got friendly with… the doctor came round and said 'home tomorrow'. And he went out the ward and [the other patients] said 'what's happening then?' I said, 'I'm going home tomorrow'. 'You're what!?'. I said 'I'm going…' I couldn't walk. I couldn't walk, I… I don't know if I came out with sticks or… I came out with something, but… no, I didn't like that bit"* [Susan, Int. 1, p36]

These accounts both depict hospital admissions due to health changes. During both episodes Susan describes decisions made which directly affect her experience of being at home, but on neither occasion describes herself as the decision maker. Susan's phrase 'open house' alongside her relief when this ended suggests healthcare workers had a freedom of access to Susan's home which she was uncomfortable with. In the second episode Susan describes a decision made by the doctor for her to return home despite her not being able to walk as she did previously. Her account suggests this decision was not made collaboratively with her, and the repetition of the phrase *"I couldn't walk"* gives a sense of panic or distress in recalling this experience,

compounded by telling me *"I didn't like that".* These experiences offer insight into Susan's perception of 'falls with hospital treatment' as more significant events than falls where she has remained at home, perhaps being compounded by associated psychological impact. When I asked Susan in interview 2 whether she considered more change ahead likely for herself and Jim, Susan replies;

> *"For us? I think it's possible. I think one or the other, or both will go downhill as they say. [pause] But we'll cross it when it comes. I mean [daughter]'s down, not far. If we have to go into an old people's home we'll have to go"* [Susan, Int. 2, p39]

Susan uses the phrase *"have to"* on multiple occasions when describing decisions to be made; most commonly to reference deciding to continue an activity but complete it in a different way – *"we just have to walk slow"* [Susan, Int. 2, p14] or *"I have to take my time"* [Susan, Int. 2, p7]. When I question Susan and Jim jointly about their decision to seek their sons support with practical jobs where previously Jim might have completed them – "how do you feel about those decisions" - Susan responds with similar phrasing; *"He's just got to sit back and let the world go by"* [Susan, Int. 3, p50]. Using of the phrase "have to" or "got to" in these contexts suggests she may not perceive much choice in practical options available but exercises choice and control in deciding not just *that* change is needed, but *when* the change should be made.

Although contact with health services is presented as episodic, Susan experiences a cumulative effect which equips her with strategies to influence her own recovery at home, such as the exercise programme she builds over time;

> *"when I first [fell and injured my shoulder] I couldn't lift my arm… I've been doing exercises and I can [move it more] but it's [particular movements] and lifting anything heavy [that I still can't do] … these [exercises] are all from the hospital and therapy and you name it. Different departments... Each one you get more [laughs]. I do some of the new ones, well, i do <u>all</u> the new ones. But I refer back to some of the old ones and do them as well"* [Susan, Int. 1, p21-23]

Injuries which never quite heal to their previous level is consistent with common trajectories of frailty outlined in earlier chapters, however Susan's experience of improved shoulder movement reenforces the exercise programme as a successful strategy to reverse deterioration, which she can use independently.

Confidence in controlling health needs

Susan describes holding little hope of having her shoulder surgically treated despite being offered surgery. During the second interview Susan discloses a new hernia diagnosis, but again, perhaps

influenced by her experience with her shoulder holds little expectation that treatment promised will be delivered:

> *"They can't do anything or they're <u>not</u> doing anything…. I was told two years for [my shoulder] to be done… So I can't see that happening. Not with my age and the national health the way it is. Now I've got a hernia, and they've said well, you're on the list. I don't hold out much hope for that"* [Susan, Int. 2, p2]

As with her expectations around safety, increasing falls, and acceptable levels and risk and restriction, Susan tempers her expectations about potential to treat or manage her health needs more effectively. Despite repeatedly expressing low expectations from the NHS or that any treatment will be possible, Susan raises a concern with her GP regarding her ongoing falls. Again, the outcome leaves her dissatisfied; *"GP. Not interested though - they haven't got time. I do feel that is half of it. Whereas you could sit and talk to them at one time, now… it's like a conveyor belt."* [Susan, Int.2, p18]. When asked whether anyone else was investigating her falls, Susan says; *"No nothing. Nothing at all… I don't know what, but I think they <u>should</u> be [investigating]"* [Susan, Int.2, p18], suggesting Susans concerns have not been fully acknowledged by healthcare professionals.

These excerpts reflect Susan's lack of confidence in the availability of healthcare resources as an older person, which may contribute to a reduced sense of control over health needs expressed clearly when discussing the participant diary questions during interview two;

> *"…so you feel less able to prevent and control health changes than you did…? [in response to Susan's self-scoring on the VAS]"* Researcher

> *"Only the falling. I feel as though I've got no control over that whatsoever. I mean I hold on when I'm walking. …"* Susan [Susan, Int. 2, p25]

Susan's accumulation of injuries and the ongoing effect on her movement, alongside minimal solutions to manage her health issues contribute to gradual reduction in functional independence over the study period. Tiredness and 'slowing down', like falls and injuries, are a consistent and increasing theme. Susan describes falling asleep during the day, and additional time needed to get ready in the mornings which means change to her long-standing routines;

> *"We just get up, take our time, get washed, dressed. I mean, I was always dressed by seven. Now it can be ten o'clock. You just accept it [pause] I mean, not got much choice, have we?"* [Susan, Int. 3, p52]

Towards the end of the final interview Susan almost anthropomorphises the fatigue, giving it a will and autonomy entirely separate and more powerful than her own, again emphasising her

own lack of control over this feature of her health; *"I get tired, very easy… It's more like the nap wants you! Rather than you want the nap, innit [to Jim]. You can't do anything about it"* [Susan, Int. 3, p50].

Seeking help

Susan describes her decision making and strategies for seeking help after incidents such as a falls. Susan has made the decision to always wear a whistle around her neck to seek help from within the immediate vicinity should she fall. This strategy is proven successful when she falls in the garden and uses the whistle to alert a neighbour who arranges help from other neighbours;

> *"[I]bent down to [lock the gate]. Next thing I know I was flat on me back… Because I had me whistle and I blew it. As loud as I could… they didn't hear me around the front. They was making too much noise. But [another neighbour] next door… She came, I heard her come out the front door and she went charging round and she's called out to them [laughs] "you lot better shut up" she said "get round the back" she said "[Susan]'s fallen" [laughs and makes sounds of running footsteps]."* [Susan, Int. 1, p27].

The success of this strategy for seeking help relies on the strength of what Maslow describes as 'love and belongingness' relationships. By developing and retaining these social connections with neighbours and with Jim, Susan has built a network of people close at hand who recognise and acknowledge her as part of an informal community group, and as such are willing to respond and support her as 'one of their own' in the event an incident rather than contacting statutory services for help.

Susan tells me she is nearing the end of a two-year contract with what she describes as an 'electric alarm'. Recommended to her following a previous fall, Susan has never worn or used it. Susan's choice not to use recommended strategies for everyday emergency planning in comparison to her choice to continue her exercise programme to manage her physical care suggest her sense of autonomy and expertise in each of these areas may differ. Despite having a key safe installed to support use of this alarm, she and Jim never put a key inside to allow access into her home to respond to the alarm. Susan trials wearing the alarm instead of her whistle. She falls at home and cannot get up, pressing the falls alarm only to be advised by the operator no capacity is available to respond and help her up from the floor. As Jim is in the garden, Susan remains on the floor until he comes back in and can call for help. The failure of this alarm trial is significant in shaping Susan's decisions about help-seeking strategies, as she tells me she is going to return the alarm and continue with her whistle which has been proven to be more effective.

Resuming Activities after an Incident

In between the first and second interview Susan loses her balance on a sloped surface and experiences a fall on her way to the bus stop. Fortunately, she is not hurt and is assisted up and briefly checked over by a passer-by. Jim, walking ahead and hard of hearing, is unaware of the incident until Susan catches him up at the bus stop. Susan is not injured in the fall but reflects on responses at the time of the incident, including the involvement of the passer-by; *"…some people are very helpful"* [Susan. Int. 2. p13] and on the limited opportunity to thank the man; *"I couldn't turn around quick enough to see and say – I did call out thank you but whether he heard me I'm not sure"* [Susan, Int. 2, p13]. Gratitude for the help of strangers during incidents in public is mirrored during the first interview when Susan describes Jim falling during a trip to the supermarket together. Both Susan and Jim comment positively on the responses of shop workers during the incident; *"They were very good there with you"* [Susan, Int. 1, p8].

Reflecting on their own responses in the time following Jim's fall, Susan tells me how they built up to going out again;

> *"We were shaken up, but… we overcome it. Went up the road for a walk and that when we both felt like it. Then we got a bus. Oh, I think we had a hospital appointment, and so forth to get on with life."* [Susan, Int. 1, p9]

In a similar adjustment, Susan tells me she was initially reluctant to go out for long periods when she first became incontinent: *"It did [put me off] at first, but I said to Jim, 'I'm not sitting in because of that'. I just went out up to the road and then I got a doctor's appointment and other things, so I had to get out"* [Susan, Int 2. P21].

Susan describes negative emotional and psychological responses, however on both occasions Susan and Jim successfully overcome this, initially going out closer to home and building up distance into the wider community as their confidence returned. Appointments which required attendance in person provided motivation to overcome negative psychological responses and return to going out, shown in the phrases "I had to get out" and "to get on with life". These descriptions suggest having a reason to return to going out provided Susan and Jim with an opportunity to reclaim a sense of belonging in their wider community, regain confidence in their own ability and a sense of accomplishment.

Making and avoiding comparison

In 'getting back to normal', or 'adjusting to a new normal' after an incident, Susan describes how comparing herself with other older people, both past and present, contributes. Susan describes her determination not to stop going out after falling in the street;

> *"It won't stop me [going out]. No way. No… we just have to walk slow. I am slow. I mean, especially up this road at the end where the [local building] is, all the leaves are coming off the trees… and the pavement is covered. When they get wet they are very very slippery. I mean the man who lived next door… he went down. I was in the car driving then and I saw him go so I stopped. Got out. At the time he wasn't talking to the neighbours - all the neighbours had upset him… He was a grumpy old git [laughs]. Anyway, I got to him I said Are you right?... do you need a hand… he said 'I'll get up myself'… I did help him up in the end because he couldn't get up"* [Susan, Int. 2, p15]

Here, Susan seems to make sense of and normalise her own experience by drawing parallels with the experience of others, perhaps as evidence that both falls related to environmental hazards in that specific place rather than intrinsic causes. In her description of her neighbour's fall Susan suggests he was not a very likeable or friendly character having stopped speaking to other neighbours and infers fewer people willing to help him when he fell. Throughout the three interviews Susan describes an active and broadly positive relationship with other people on her street – relationships described in more detail later in this case presentation. When she fell in her garden and blew her whistle Jim suggests there were *too many* neighbours assisting – *"We had about seventeen people coming in!"* [Jim, Int. 1, p25].

Following Susan's fall on the way to the bus stop and having completed the first week of her participant diary that week, Susan tells me *"I only done one week [of the diary] and then I went down, wallop"* [Susan, Int. 2, p19]. Drawing this connection suggests the fall disrupted Susan's activities at the time, in this instance influencing her ability or willingness to continue a self-reflective activity.

Despite using comparison with others as a strategy to normalise experiences in some ways, Susan also indicates comparison to a previous version of self or to others might threaten their experience of pleasure. Jim describes a significant change in their reasons for going out; *"We don't go out really, very often for pleasure. We go out for shopping"* [Jim, p53]. When I follow up with a question about having "as much pleasure", Susan tells me; *"You accept what's there. You don't compare it, do you? [to Jim]"* [Susan, Int. 3, p53]. This suggests focussing on the present rather than on what went before as a protective strategy for Susan in the face of change, also seen when I ask in interview 2 about unexpected change. Her response suggests a determination to keep going and respond once something 'crops up' rather than anticipate or plan for future issues; *"Just plodding on day to day the same, you know anything crops up, you cope with it. All we do"* [Susan, Int. 2, p3"].

Freedom

Susan and Jim's reduced association between pleasure and going out, may not simply reflect the shift towards prioritising practical activities, but perhaps also a change in spontaneity. In the third interview Jim describes his decision to stop driving when his health conditions progressed as he and Susan both felt he was *"a liability"* [Int. 3, p32] on the road. Jim tells me; *"Because there's no car, no freedom. You could just go in, get anything you want. Now it has to be planned, and you have to look out for the busses"* [Jim, Int. 3, p31]. Susan reenforces this sentiment when reflecting on the effect of finding activities more difficult*; "I don't think it's the going out, it's going out when you want to, instead of having to wait for a bus or wait for a taxi to pick you up" [Susan, Int. 3, p54].* Whereas Susan presents the change in reason for going out, from pleasure to more practical focus as well managed through her strategy to focus on the present, the loss of choice and control over how and when she goes out appears to have a more significant effect.

Adjusting roles

Being dependent on others for daily help appeared somewhat complex and nuanced. Susan described a gradual shifting of her and Jim's roles from retirement onwards as each of their needs and capacities changed; an ongoing adjustment that continued throughout the study period. Susan acknowledged difficulty in adjusting self-expectations, from a previous version of herself and her physical ability to accepting a newer physical reality. Following her shoulder injury 12 months previously, she no longer felt able to carry out heavier housework tasks such as lifting items from the oven and some aspects of the laundry;

> *"I know the limit. What we can do and what we can't do. I know I can't lift anything hot out the oven. Because I haven't got the control over this arm. So, I won't, I don't lift out. I put it in, and then Jim gets it out. But er, I've not done the cooking what I normally do. Not recently anyway - getting lazy!"* [Susan, Int. 2, p38]

Although much of this statement presents Susan as practical and in control of the adjustments she makes, the final comment hints at self-judgement or detriment to self-esteem experienced through this change in roles.

Changes in roles and compensating for each other's changes was also limited by other factors. Susan and Jim both indicate that finances have been Jim's role during their marriage. During interview 2 Jim has gone to the bank to resolve an issue. Susan describes the support she provided to Jim with preparing for this trip; planning the bus timings and preparing the correct documents. Despite Jim's new Alzheimer's diagnosis and the possible connection to some of these difficulties, it is clear Susan either does not want to or does not feel able to become more involved in this role. Susan described her decision making around encouraging Jim to visit the

bank alone; *"I've pulled back like this morning I said to Jim, you go. Because I mean anything happened to me, he's got to do it for himself" [Susan, Int. 2, p10].*

There appear to be multiple influences on Susan's decision making here and perhaps her perception and weighing up of risk, considering not only Jim's established role and the early stages if his changing cognition, but also seemingly considering the possibility of her own condition deteriorating and what that might mean for Jim's independence if they adjust roles now. When Susan fell on the way to the bus stop Jim was unaware of this for some time, suggesting some reduced awareness of his surroundings. In addition to the difficulty he experienced preparing for the trip that day it might be reasonable to consider Jim somewhat vulnerable going out alone, however maintaining autonomy and independence in previously held roles appears to take higher priority. Again, the expectation of attendance at an appointment influences Jim's choice to go out. Susan reflects on the familiarity of the journey providing her some reassurance that she could "pull back" from going with him;

> *"Today he's got an appointment at the bank. Otherwise, he wouldn't have gone… Oh he'll be alright… once he's down there and on his way. He's got all his papers, so he knows where he's going and what he's doing*" [Susan, Int. 2, p5]

Prior to this when describing her reduced confidence walking to the bird feeder without the walker, Susan indicates Jim's abilities may directly impact her own confidence going out; *"Well since the falls. I think I've just lost confidence… and I've also got Jim. He's not, he's not brilliant. He's got, erm, Alzheimer's"* [Susan, Int. 2, p4]. It may also be the case that Susan did not feel confident to go out with Jim, indicating Susan is attuned to her own changing abilities and is realistic about the tasks she can take on. By framing this decision-making as a way to support Jim it is possible she may be protecting herself from the emotional reality of these changes.

In another section of the conversation Susan describes not feeling able to attend a community visit by their local MP after dark due to being unable to see the uneven pavement in the dark.

> *"I'd like to go, I won't go out in the dark… Jim could. I think he will go on his own but I wouldn't… Jim wasn't too good one day. And I said to him, we'll take the trolley I'll walk alongside. I said I can grab hold if I need it. Jim said 'and we'll both go down'. But he did take it so I knew he was feeling [trails off] …. I don't feel confident to walk up the road in the dark. I mean, I haven't got the best eyesight anyway, which doesn't help. No, I shan't go to that but I'm pushing Jim to go… He knows what I think*" [Susan, Int. 2, p30]

This plan indicates negotiation of roles and a trust in the other person's ability to act on each other's behalf to achieve a desired outcome. Susan's encouragement of Jim going out alone in the dark despite knowing he also experiences some mobility issues on the pavement suggests a

complexity in motivations behind encouraging each other's activities also referenced in the first interview in describing decisions to continue or limit activities; *"I feel and Jim feels that if one of us doesn't want to, we've had enough, and we come home."* [Susan, Int. 1, p9]. The complexity behind this is shown moments later when Jim tells me that since having COVID *"I take two steps, I've had enough"* [Jim, p10], to which Susan comments; *"You get to the end of the road, and I look at him and think 'you want to go home', and I say 'oh the bus is coming, let's…[pause]' [laughs]… [doesn't] hurt him!"* [Susan, Int. 1, p10]. Despite being aware of Jims limitations and preferences, here Susan acts to motivate and encourage him to be active beyond what might initially seem comfortable for him. As a result, Jim remains active and mobile where he might otherwise risk deconditioning through reduced activity.

Later in the second interview whilst discussing intentions not to attend a previously enjoyed annual social event in a public setting, Susan uses the phrase *"We're anxious"* to describe what's putting her off attending. The use of the word "we're" and not "I'm" also indicating the intrinsic link between her own needs and those of her husband, both in decision making and maintaining continuity in life. Perhaps in shared ownership of feelings of anxiety and reduced confidence in their own abilities the emotional effect may be reduced for them both.

Accepting Support

Responding to continued changes in physical ability during the study period, Susan accepts support readily from Jim as a precedent has already been set that their roles would change and flex over time to support each other. Susan describes feeling additional rails and equipment put in place by the Occupational Therapist following her last episode of contact are adequate for her not to need care;

> *"I can [get out of bed] now cos I've got grab rails, but… It's not easy at times getting up off the toilet and down, but… you cope. I don't want a full-time carer in or anything, I can manage without…"* [Susan, Int. 1, p14]

Jim adds; *"Which you do need, you do need help"*, to which Susan replies *"I do need help, yeah, that's what you're here for [laughs]"* [p14], suggesting Susan's perspective that she is managing without care differs slightly from Jim's, or perhaps even that Susan views Jim's support differently to that of a formal carer even if the task completed may be similar.

During interview three Susan and Jim discuss their relationship with their neighbours, whose support had featured consistently and prominently across all three interviews, both with day-to-day tasks and with responding to more urgent needs. Susan described what she felt worked well with this support;

"When we're out there [in the street] they might say 'we're going', 'do you want the lift or anything?' But normally it's up to us if we want it, to ask for it… [it's offered] … but not pushed in any way" [Susan, Int. 3, p18].

Here Susan describes mutual understanding between herself and her neighbours that she will ask for help as and when she needs it, suggesting she has confidence that support will be consistently offered based on previous evidence. The phrasing 'not pushed in any way' reenforces the idea that Susan's control over seeking and accepting support is recognised and respected by others around her. Susan indicates this feature of support is most successful for her. Susan shares a similar confidence in the proximity and reliability of support from her neighbours when requested as important features when I ask what helps 'get back to normal' following an incident or change;

"The support I suppose around me. Like Jim, and friends and that…" [Susan]

"We're not in each other's pockets. If we need help just say." [Jim]

"Yeah, just pick the phone up. Any of them will come over. They can't get in cos we lock the front door [laughs]." [Susan, Int. 1, p42-43]

This last statement reflects Susan's confidence in how to he would seek help if needed and that the response would be forthcoming. The final sentence regarding keeping the doors locked again indicates Susan retains control over who comes into her home even when she has requested assistance. Susan and Jim are very clear that these "*little things*" [p18] have never been asked of the neighbours but are intuitively provided and accepted.

Across the three interviews Susan shares examples of contributions she has made to the local community over the years she has lived there; the neighbours she has helped and the long-standing relationship she has built with the local butcher. This life context may offer insights into her expectations of relationships with neighbours and local community now, and perhaps a sense that the support she now receives from the community may equate to what she has invested.

Community of Support

Susan describes an abrupt change in her social connections during the COVID-19 restrictions;

"Well, because of COVID and everything we've not [got together with friends]. We used to meet up about once a month and used to go to different pubs and that for a lunch thing - can't do that anymore" [Susan, Int. 2, p46]

Despite maintaining regular telephone contact with friends instead, Susan did not consider this a source of support as these friends were not physically present in their lives anymore. Jim states in interview three *"that support doesn't exist"*, with Susan agreeing *"no, not anymore" [p43]*.

They go on to say *"We're all in the same boat" [p43]* describing health problems for the group of friends and each realising they can no longer drive. As they don't live in the same place Jim says; *"So, you just lose them" [p44];* phrasing which suggests despite a commonality and shared experience there is also a sense of loss and disconnection resulting from the loss of face-to-face contact. Alongside the change to long standing relationships COVID-19 brought, Susan and Jim also spoke of the new relationships that grew locally, as the pair met previously unknown neighbours. The 'Clap for Carers' phenomenon offered opportunities to connect with immediate neighbours, and this routine of regular weekly connection continues for them and their neighbours. Through this new connection with neighbours Susan and Jim find a new source of practical support, but also a way to maintain social connection and belonging with others who represent a physical presence.

The willingness or ability of people doing something 'above and beyond' their primary role in Susan's life is a key feature of support in resolving unexpected or 'one-off' issues. Multiple examples are seen in the first interview, in Susan's account of her gardener who despite being described as unreliable in her primary role also picks up small items of shopping where needed, and the neighbour who offers to take the coffee table to be repaired after Jim falls and breaks the top. In interview two Susan explains her local butcher will provide a home delivery service not otherwise provided to other customers, as a result of long-standing connections with the local community; *"we've known him years" [p28].* Here, Susan seems to suggest long-standing or well-established connections with others may provide richer and more flexible sources of support, which enable her to maintain continuity in her own routines and standards.

Frailty Score

I noted a clinical frailty score at the end of each interview, using insights from Susan about her daily life, and observations of her movements and general appearance whilst with her. In my researcher diary I reflected on my own perceptions of Susan's presentation in comparison to the account she provided, such that I could reflexively identify and respond to the influence of my own perspective on scoring and interpretation. Throughout the 12-month period Susan reported no support needed for personal care as she retained independence by adapting tasks and using basic aids, and the presence of privately funded services remained consistent – a regular gardener, domestic support for household cleaning, home delivery for larger shopping deliveries, alongside an informal support network of family, friends and neighbours. At interviews 1 and 2 Susan's frailty level was a CFS 5 – Living with mild frailty, with more evident slowing and needing help with high order ADLs which for Susan was heavy housework and transportation. Mild frailty is described in the CFS as 'progressively impair[ing]' shopping, going out alone, meal preparation and housework, presenting mild frailty as a period of gradual change consistent with Susan's

account. By interview 3 Susan's frailty had progressed to CFS 6, evident through her need for help with all outside activities, keeping house and stairs. There was no single event to which I could attribute the change from CFS 5 to CFS 6, and Susan describes a loss of confidence and need to encourage Jim's independence as drivers behind her change with outdoor activities.

To separate Susan's account from my own observations and perceptions, I objectively collated and reviewed interview data related to each domain of the frailty fulcrum against the descriptors of frailty levels in the CFS and assigned an indicative CFS score to each statement [Appendix 30]. I mapped these individual domain scores across the three interviews to further explore how Susan presents her experience of each domain over the study period [Table 6]. Using this approach, I noticed that Susan experienced the development of frailty differently in different aspects of her life. For example, in passages related to multimorbidity Susan's descriptions at each interview correspond with my own CFS scoring – 5, 5, 6, however in passages describing the physical environment, social environmental and psychological status Susan's descriptions suggest she might perceive a lower level of frailty in these areas initially. Descriptions of change and increased dependence related to the physical environment do not appear to progress as rapidly as the other domains, perhaps a reflection of the adjustments Susan makes through her use of a new walker and changes to the way activities are completed. Descriptions of her social environment or psychological status indicate a level of robustness at the first interview in comparison to descriptions of her physical health or experience of systems of care, although descriptions of psychosocial domains change more rapidly over the course of the three interviews, with a reduced sense of psychological and social resilience by the third interview.

Although I noted a change in frailty score across the 12-month study period and between the timepoints artificially introduced by the interview timings, Susan framed her story using two key points of change within her own life. 1. Susan and Jim's retirement represented a key point of change regarding adjusting roles and responsibilities at home, although the description of mutual reliance and support remained consistent throughout pre and post-retirement. 2. Susan recounts multiple falls requiring help in the immediate aftermath, however her fall resulting in hospital admission and a period of reablement care at home marks a more significant period of change in her story. The end of external support seemingly marked the resolution of this period of change for Susan. Although I noted a change in Susan's frailty score during the study period, the two significant change points Susan described both occurred prior to the study period, with changes and adjustments during the study period more focussed on maintaining status quo.

Table 8: Interpretation of frailty levels within each frailty fulcrum domain - Susan

Fulcrum Domain	'Areas to consider' guidance	Interview 1	Interview 2	Interview 3
		Most closely aligned CFS score based on statements related to each domain:		
	• Main carer & carer network • Next of kin & wider family • Friends & community • Preferred methods of interaction	4	5	6
	• Think from the skin outwards • Clothing & footwear • Main daily living areas • Beyond the doorstep & transport	3	4	5
	• Health & social care integration • Sharing information & care records • Respite & carer support • Funding & benefits	6	6	6
	• Recognised conditions or symptoms • Motivation & confidence • Emotional wellbeing • Spiritual & cultural fulfilment	4	5	6
	• Treatment burden of multiple long term conditions • Physical & mental health • Vision, hearing, dentition, continence • Strength & mobility	5	5	6
	• Frailty syndromes: delirium, falls, immobility, incontinence, medication side-effects • Planned acute care (e.g. surgery)	5	5	6

6.3 Susan, Maslow and Cialdini's principles

The domains of the frailty fulcrum might be considered as broadly aligned with the levels of Maslow's pyramid of human needs, with multimorbidity and physical environment domains representing the essential needs in the lower levels of Maslow's pyramid, and social environment, systems of care and psychological status perhaps closer aligned to the higher levels. Insight into Susan's own perceptions of her frailty status within each of the frailty domains

resonate with earlier assertions that Maslow's levels of need may not be linear or hierarchical. By the third interview Susan's descriptions indicate a similar perception of frailty level across all 6 life domains. However, her descriptions across the study period might suggest her perception of frailty and dependence associated with physical and safety needs increases at an earlier stage than perceived frailty in social or psychological domains. Domains with slower rates of perceived frailty progression – social and physical environments, and psychological status – are all areas in which Susan describes having continued agency and control, whereas domains with earlier frailty progression – multimorbidity, acute health events and systems of care – correspond with areas Susan associates with little choice and control. I interpreted from this observation that for Susan, needs related to the higher levels of Maslow's pyramid might continue to be met even after needs from lower levels are not.

I found limited exploration in the literature of the active role of psychosocial factors in influencing this trajectory or framing the person living with frailty as an active agent in this process. To explore the trajectories I interpreted within my analysis of Susan's individual frailty domains and the potential connection with choice and control, I drew upon social psychologist Robert Cialdini's work to analyse the transcripts further. Cialdini proposes 7 psychosocial principles that influence thinking and decision making (Cialdini, 2021): – reciprocation, liking, social proof, authority, scarcity, commitment & consistency, and unity, which resonated with themes from the interviews.

Commitment and consistency

Cialdini proposed "[o]nce we make a choice or take a stand, we encounter personal and interpersonal pressures to think and behave consistently with that commitment" (Cialdini, 2021, p245). By exploring Susan's commitments against things she chooses to change, insights might be gained into the values or beliefs influencing her decision making and responses. As Susan's mobility deteriorated and falls risk increased across the three interviews, with limited perception of control over this, decisions about committed to previous choices versus making change became a regular feature. Susan made some changes to how she meets basic physical and safety needs, such as managing housework. Susan shares her preference to continue to complete tasks herself and at times describes overriding her established patterns of behaviour to avoid tasks which might now result in a fall.

Susan describes finding compromise in spontaneity in household tasks difficult to adjust to, which mirrors her reflections on reduced spontaneity in going out; suggesting loss of control within tasks has a significant emotional impact. In other tasks at home, Susan and Jim remain independent from others but describe a gradual flexing in roles and adjustment of tasks, such as who completes household tasks, or meals prepared using a slow cooker rather than the oven.

Unlike the cleaning tasks Susan frames this adjustment as personal, as inferred in her self-reflection on 'getting lazy'. This more personal response might indicate cooking tasks hold a different personal meaning or value to Susan and are less readily shared with others. Susan is even clearer in the 'stand' she takes regarding personal care, not wanting support even if the task takes much longer. These examples show Susan's continual review and re-evaluation of what really matters to her as she decides which commitments to continue and which to adjust.

In other ways consistency acts as a protective strategy, used to focus Susan's attention on the present and prevent comparison with a previous version of herself. By *"[j]ust plodding on day to day the same"* [Susan, Int. 2, p3], her focus on the present also prevents looking too far ahead and predicting any future adversity*; "anything crops up, you cope with it"* (p3). Although consistency may have a protective effect psychologically, it may also reduce her ability to mitigate against future change. Susan and Jim return to prior routines such as going out and attending appointments to regain normalcy after an event such as a fall. In resuming previous routines going out together, they both maintain basic mobility and exercise needs and beyond these physical benefits, may also retain connectedness to their community and psychological benefits of overcoming anxiety.

Authority and Scarcity

Cialdini's framework proposes that interactions with authority figures seen as "*in* authority or *an* authority" [Cialdini, 2021, p191] can significantly influence decision making and outcomes. Susan describes interactions with healthcare professionals as figures in a position of authority, who provide (or prevent) access to treatments and interventions that have the potential to improve day to day life. In instances such as her potential surgeries or the exercises provided by various health teams, Susan is clear about what these interventions might be. When the potential treatment is less clear to Susan she retains a belief that 'someone' could intervene in the right circumstances and resulting in frustration that this solution has not been offered. Cialdini's principle of 'scarcity' is consistently associated with authority in Susan's interviews, although to varying degrees. Although Susan believes in a possible healthcare solution, she also references scarcity of NHS time as a barrier to accessing both the treatment itself and personalised care; *"[GPs] haven't got time. I do feel that is half of it. Whereas you could sit and talk to them at one time, now… it's like a conveyor belt"* [Susan, Int. 2, p18]. Whether treatments for Susan's physical needs are known but not provided, or opportunities to identify treatments are perceived to be missed, the overall result is reduced personalisation in care which may deplete Susan's psychological resilience. 'Scarcity' is defined as 'being deficient in quantity compared with demand' [Merriam-Webster Dictionary]. Cialdini's principle of scarcity as an influence on thinking and decision making suggests people may have greater desire for things that are harder to get.

For Susan scarcity in her interactions with healthcare services, particularly in response to raising concerns, may contribute to reduced perception of control over health needs recorded in Susan's only participant diary entry.

The notion of being 'an authority' also arises in relation to Susan's own role in self-managing her needs, a primary example being her decision to continue using her whistle to seek help after a fall. Despite the whistle proving a successful strategy in the past, Susan shows an openness to the expertise of others and a willingness to challenge or grow her own role as 'an authority' on what the best response to falls might be. When the alternative alarm system is unsuccessful for Susan, she resorts back to her whistle, perhaps reenforcing her own position as the expert in what works best for her. Drawing upon the expertise of others to grow or reenforce her own expertise is also inferred when Susan describes an OT assessing her home environment but being unable to identify how any new rails could reduce her falls – an outcome that confirms her own thinking. Whereas scarcity of access to external knowledge and expertise may lead to unaddressed health and safety needs, adequate access, even without an intervention provided, offers opportunities to reenforce Susan's own confidence in self-management and problem solving and position her as an authority over her own needs.

Liking and Unity

A key source of informal support for Susan across all three interviews comes from her relationships with her neighbours – defined here as people living not just next door but within the same cul-de-sac location as Susan. Despite living on the same street for over three decades, the relationships Susan holds now with her neighbours are relatively new, having developed since the COVID pandemic. Susan tells me that even now, contact with those who helped her after she fell was infrequent - perhaps more *friendly* than friendship, however she maintains social contact with her neighbours by joining weekly street gatherings even when later nights and cold weather are not preferable for her. Susan's reflection on helping her own older neighbour in years gone by seemed to suggest she saw vulnerability in those who were not liked by others living around them – perhaps a vulnerability she seeks to avoid in her own experience of older age. Cialdini's principles support her assertion that whether we like the people we interact with can influence our responses and choices towards those people, and therefore potentially contribute to social resilience or vulnerability.

The dynamic Susan feels works well for her in her relationship with the neighbours is the balance of confidence in the reliability of their presence without intrusion into hers and Jims lives – in essence feeling in control over when and how their support is accessed. In addition to 'liking' at perhaps a relatively superficial level given their neighbourly relationship, another of Cialdini's principles seemingly contributing to the mechanisms behind this source of support is unity. This

is the principle that relationships are given a greater sense of trust, cooperation, help and agreement if they are within what we see as "our tribes" – "within the boundaries of "we"" (Cialdini, 2021, p299). For Susan and Jim, the pronoun "we" is understandably used repeatedly in the context of describing the practicalities and support of their shared life and long history together. However, as Susan and Jim age together and develop individual needs, the boundary between adjustments response or anticipation of their individual needs, or in relation to the other person's needs becomes less distinct and may even influence their own individual trajectories. Although their status as "we" undoubtedly fulfils social and emotional needs for them both within Maslow's higher levels of need, some decision-making accounts for Susan and Jim's combined rather than individual needs. For example, Susan not going out so that Jim can maintain his independence means she loses the benefit of maintaining consistent physical activity, and Jim going out in the dark on behalf of them both despite his own cognitive and mobility changes may elevate his risk of an incident of his own. This complexity of combined need may further contribute to Susan's sense of reduced control over her own health needs.

There was a sense that in losing the physical presence of their friendship group, the sense of wider belonging and associated support had been lost, however in building new relationships, crucially with people who *are* physically present a new 'tribe' is formed. In these ways the principles of liking and unity become strategies for Susan, not only to create a network to build practical resilience, but also to retain a sense of belonging and social connection.

Social proof

The principle of social proof is based on the notion that people make fewer mistakes when they act in accordance with social evidence (Cialdini, 2021). For Susan, social evidence contextualises her own experiences against those of others to 'normalise' her negative changes or experiences. In this way, it serves to protect psychological resilience, even where physical or safety needs appear less robustly met. When describing something that's become physically difficult or lead to an incident, Susan references other people with similar or more significant difficulties in the same environment; her brother who also almost fell on uneven pavements outside her house, or her friend with dementia who now can't understand why they're at the theatre so there's *"no point in him going"* [Susan, Int. 2, p43] although Susan feels she and Jim *could* still go. Although Susan keeps in contact with her friend group over the phone now that face to face contact has become difficult, she tells me her friends are 'very private' about their own changing health and responses and therefore the relationship provides limited peer support. Newer local social relationships appear cross generational. As Susan and Jim seem to be the oldest, there is little opportunity to observe or draw upon the experiences of other people in similar circumstances to their own.

Reciprocity

'Reciprocity' is the last of Cialdini's principles and is defined as "a mutual exchange of privileges", or "mutual dependence, action or influence" [Merriam-Webster Dictionary]. Within Susan and Jim's relationship are multiple examples of mutual dependence and exchange as they compensate for each other's changing needs. Paying for domestic support provides one of the first compensatory strategies outside the marital relationship to ensure continuity in day-to-day life. This transactional reciprocal arrangement comes under threat in Susan's third interview, as she and Jim are concerned about forthcoming changes to the benefit system which might reduce their allowances. Susan tells me without any great sense of confidence; *"we <u>should</u> be alright",* and jokes that *"we won't eat so well" [Susan, Int. 3, p37],* suggesting she may anticipate further uncertainty and revised priorities. Susan and Jim decline multiple offers of lifts to the shops by neighbours in favour of paying for a taxi or using the bus; *"They've been moaning, because we've not used them [the neighbours]"* [Jim, Int. 3, p14]. Susan tells me;

> *"We've been going on the busses so I thought this time we would ask [the neighbour]. 'Right' he said, 'I'll sit in the car park and wait for you'. I said, 'no', because we don't know how long we're going to be. We wanted to go over to [another shop] as well, so we sent him home [laughs]"* [Susan, Int. 3, p14]

suggesting they would feel limited in their tasks knowing someone was waiting for them. As the lift from the neighbour would be provided on a non-reciprocal basis it is possible Susan and Jim saw a need to minimise this arrangement particularly if it would mean restricting their activity.

Where Susan and Jim receive support from within social networks and therefore there are no specific expectations around repayment, they draw a distinction between support which is *requested*, and *unsolicited* support. With the example of requesting the lift to the shops, Susan and Jim minimise how much support they receive without being able to reciprocate. In the case of *unsolicited* non-reciprocal support such as the neighbours choosing to bring the bins in for them – *"we've never asked her to"* [Jim, Int. 3, p23]- reciprocation appears less necessary or can be achieved passively such as offering the use of Susan and Jim's driveway which they no longer use themselves. The perception of tasks as smaller or *"little things"* [Susan, Int. 3, p16] may also contribute to Susan and Jim's acceptance of support.

It is possible Susan and Jim resist requesting support, and therefore acknowledge a limitation, because it may threaten feelings of personal ability and confidence. Susan and Jim also appear to choose reciprocal exchange (e.g. bus pass or taxi money) as a preferred strategy to continue to go out, above non-reciprocal strategies (e.g. help from neighbours with limited means to return the favour), however the ability to make this choice is highly dependent on the level and type of

resource available to them and readily compromised by Susan's deteriorating ability to walk to the bus stop and potential change in financial resource ahead.

Summary

In this chapter I have presented a detailed analysis of Susan's case in response to the research questions and study objectives. Susan's account supports the findings of my concept analysis, as her indicative frailty levels appeared lower within psychosocial domains compared to her account of her physical health and experience of the involvement of health and social care. This supports the notion that older people with frailty may maintain psychosocial resilience despite emerging physical frailty. Indicative frailty in psychosocial domains appeared to progress gradually, whereas indicative frailty in physical health domains remained at a higher but consistent level. There is also evidence within Susan's account that all seven of Cialdini's principles may influence her self-management versus help-seeking behaviours in anticipating and responding to change and were applied in highly personal and nuanced ways which drew upon lifelong experiences.

Chapter 7: Margaret – Illustrative Case

In this chapter I provide a detailed analysis of data gathered across two interviews with Margaret over a total period of 8 weeks. I present Margaret's account of psychosocial influences on change and stability within the frailty domains, in reference to the research questions.

7.1 Meeting Margaret

First visit

Margaret was identified as a potential participant by one of the rural PIC sites shortly before Christmas 2023. Whilst talking through the study aims and the intention to interview people multiple times over a year, Margaret was immediately very open about her poor health prognosis and recent news that she may not have long left to live. Margaret asked to book an initial interview straight away, but to allow time to read the Participant Information Pack and reflect on her decision to participate I suggested a date two weeks' later.

Calling ahead on the day, I was pleased to hear Margaret recalled our previous discussion and was expecting my visit. As I stood on her driveway later that day, she directed me over the phone to locate her key safe, providing the code. The property was a modern bungalow in a small cul-de-sac looking out over fields. Inside, the entrance hall led to a wide corridor with hardwood floors leading to a bedroom with ensuite at the far end. At the opposite far end was a living room and bathroom, adjoining a kitchen/diner with a hoist in the hallway outside. Margaret was alone in the property, sat in a recliner armchair in her kitchen/diner. Her legs, noticeably swollen and elevated, stretched out from beneath blankets.

She greeted me with a smile, but a 'no-nonsense' air; directing me where to sit and where to best place my Dictaphone. I was suddenly aware of how little I knew about Margaret's history or circumstances and how under-prepared this made my new role as researcher compared with to the preparedness that reading clinical records would have given me before a clinical visit. Despite entering this space in a new and less familiar role, as an Occupational Therapist, I knew I was already absorbing environmental clues about Margaret functionally, and the level of support and resource needed to maintain the clean and uncluttered space – influences in my thinking that once recognised could be addressed. I had intentionally left scope in my topic guide for health to form part of discussion about Margaret's recent contact with a health team, but for Margaret to direct the content of our conversation to reflect what was important to her. Now feeling somewhat vulnerable myself I confess in this moment I questioned my choice.

I was surprised to learn Margaret had not seen or read the Participant Information Pack (PIP) but noticed her carers had placed it into a pile of paperwork out of reach of her armchair. Living alone and requiring use of a hoist for all transfers, Margaret told me that post arrives and is

placed in a pile by her carers often without her knowledge or out of her reach. Two carers visited Margaret four times every day to support with her personal care, toilet needs, and meals, arranged by Social Care but paid for by Margaret as well as a private cleaner and gardener.

I located and retrieved the PIP easily from her pile of papers having printed it out on distinctive paper and was keen to demonstrate that I had upheld my agreed actions from our initial phone call, hoping this could convey my reliability and professionalism valuable for first impressions. Margaret and I spent considerable time going through this together to ensure she was content to proceed and giving informed consent when we started the first interview. I began to see first-hand the challenges of interviewing someone living with more advanced frailty. Margaret fatigued quickly during the consent stages pre-interview and clearly found repeatedly signing her name challenging. Knowing Margaret may be in the final stages of her life but without access to her medical history to understand the aetiology behind this prognosis I was vigilant for signs of cognitive impairment, excessive fatigue or pain that might hinder Margaret's ability to consent as a research participant. No such concerns arose, and the interview went ahead with Margaret's consent.

The first interview recording was 1 hour 20 minutes in addition to administrative time before and after the interview. Despite my suggesting that Margaret may wish to end the interview she declined, asserting she could 'just go to sleep' in her chair at any time afterwards to recuperate. It seemed Margaret would have continued to talk with me for several hours about her life. However, striving to respect Margaret's autonomy and ability to gauge her own abilities whilst balancing this with the expectations laid out in the study paperwork, I drew the interview to a close at 1 hour 20 minutes.

One further interview

At Margaret's suggestion we arranged a second interview early in the new year, 2024, just 8 weeks after the first interview. My arrival at the property being much the same as at my first visit, I found Margaret sat in her recliner chair again, legs elevated. Margaret was again alert and welcoming but noticeably more challenged by the physical effort of the consent processes, telling me she 'forgets to breathe' when concentrating on writing. The conversation starting point this time was directed by cues within the home environment – a series of Christmas cards still propped up on the shelf suggesting the Christmas period might offer insights into Margaret's social connectedness and current support network. Having spent Christmas with my own family doing all the Christmas traditions, I asked casually, "did you have any visitors over Christmas?":

> *"Not really no. Cause they're all a long way away, or they're dead. No [POA friend]'s at [place name] – she had company. You speak to them on the phone and that but you're not really err… You know, I'm not, [pause] I had calls. Oh, my finance guy, he sent me*

erm, he and his friends sent a parcel [laughs]. Yeah, it's been alright really. I'm not full of expectation long as you can keep alright. But I mean a lot of people can't keep alright. You know, you have days don't you that are not good. Not good at all" [Margaret, Int. 2, p2]

The pause in Margaret's comment *"I'm not, [pause] I had calls"* evoked a sadness for me and left me wondering what Margaret felt she 'was not' that would lead to an absence of visitors at Christmas. I spent around an hour and 45 minutes with Margaret conducting the second interview, again led by Margaret but mindful of the proposed duration laid out in my PIS. This would be the final interview with Margaret as I was unable to contact her again. In the following illustrative case, I will describe what I saw as key areas of change and stability for Margaret during the study period, and how this was reflected in her frailty scoring.

7.2 Illustrative case

Changes in carer support

The opening lines of transcript from my first interview with Margaret read as follows;

"I pay for all my support. I pay for my cleaners, the chap who does the garden. Everything you pay for. The carers" [Margaret, Int. 1, p2]

Having means to access a range of support sources to meet essential needs is a theme that opens the first interview and continues across both transcripts. At the stage of Margaret's life where she joins this study, she has the support of two carers four times per day. The carers help Margaret with washing, personal care, pad changes, all transfers, and meals. Since first needing carer support before the study began, Margaret describes two key changes. The first was increasing from one to two carers; recommended by an OT when Margaret was in hospital about 11 months before we first meet. The care was arranged while Margaret was in hospital, resulting in a prolonged hospital stay. During this period, the healthcare team prioritised Margaret's essential physical and safety need to support her return home safely. However, Margaret frames this in terms of risk to her self-esteem and her emotional response in resisting this threat; *"you don't wanna get depressed, and you think 'be patient, be patient', but when that one week turns into two, three, four, five, six, seven, eight and you're into six months!"* [int.1, p12]. Margaret's description of resisting depression and remaining patient suggests she focussed on resisting her emotional and psychological deterioration whilst others around her prioritised preventing her physical deterioration.

During this period, Margaret indicates decisions around her care and return home were made on her behalf by professionals at the hospital. Margaret's description suggests control over her emotional response and avoiding low mood was important to her. Margaret strives to exert

control over her emotions whilst she has little control over practical elements of her life, and explores more active strategies to advocate for herself, including drawing on her previous experience of identifying the 'problem solvers' around her. She implores the doctors in the hospital; *"can't you do anything?"* [Margaret, int 1. p13], but to no avail.

Secondly, since eventually returning home Margaret experiences a further change of carers; resulting in the loss of carers whom Margaret held in high esteem, and their replacement with carers Margaret is less happy with;

> *"[The carers] all rotated. The original lot we had were from Pakistan and India. [Male carer's name]… they were brilliant they really were. They were good at caring, they were good at everything. And then the firm, [care agency name], forgot to renew their cover with the Home Office. So they all had to go. That was pretty disgusting. They loved their jobs…. This lot are all from Africa. And err, they really are not, quality. And you'd think you'd be able to understand them even."* [Margaret, Int. 1, p11]

Margaret's description of the original carers suggests she was satisfied her needs were met to a high standard as the carers were "*brilliant*", however the change in carers seems to unsettle this confidence. The new carers are described as "*not quality"* and more difficult to communicate with. Margaret makes culturally specific comparisons between the carers from Pakistan and India whom she felt able to communicate with and those from Africa where communication is more difficult. Margaret reflects on this change again later in the interview, showing a new uncertainty in her relationships with others as a result of her limited control over this change; *"Really, it's got to the stage where I can't trust anyone"* [Margaret, Int.1, p-36].

Maintaining control of nighttime and home

As someone who has lived alone most of her adult life, being alone at home overnight is a long-established and important part of Margaret's daily routine but is increasingly threatened by her deteriorating health. The presence of carers day-to-day at home, and the progression from one to two carers has been assessed by an OT as a necessary adjustment in managing basic needs. This is an adjustment that Margaret appears to accept, however in interview 2 she sets out boundaries around any further increase, describing an interaction with her carer one evening. Taking an active role in confirming evening tasks within her home have been completed that night; that the property is secured, lights are off and her hoist has been left on charge, Margaret's carer then suggested that he could begin to stay at her home overnight.

> *"So, I said 'do what?'. He said 'well, I could stay the night here, spend my nights here'. I thought yeah, and I'd have to pay. And I said to him 'but, what's the point?'. 'Well, if you wanted anything…'. 'I do very well once I'm in bed. And let me tell you something, I like*

> *being in control of myself. I don't want anybody else here, sleeping here or anything… and I've got the phone, and I've got the numbers if I need to phone'. 'Well' he said, 'I could look after you…'. 'I don't need looking after!… 'I'm quite capable of looking after myself! … [being alone at night] gives me still control of my own independence… I do welcome my own independence which means my own company '"* [Margaret, Int. 2, p28]

Margaret is clear in declining this offer, equating staying on her own overnight to supporting her independence and control, clearly important to her, and presenting a boundary she does not wish to cross. It is not initially clear why the carer felt overnight support might be needed, and Margaret goes on to elaborate about her new awareness of a 24/7 phone line for community health teams which she finds; *"reassuring and comforting to think there is someone who can help you"* [Margaret, Int.2, p30] - *"[the nurse] said, 'we're all there at the end of the phone'"* [p41]. In addition, she describes practicing deep breathing exercises at night;

> *"I do that most of the night really when I'm awake... So, you know when you feel like… if you're gonna have a panic attack, which I think, was it yesterday morning? Yeah, I could have done and I can now say to myself 'don't go down that path, breathe, do your breathing', and you do it"* [Margaret, Int. 2, p31].

This later description of strategies to control panic attacks in the early hours of the morning, which Margaret associates with her progressive respiratory issues, adds additional context to her carer's offer and potentially why Margaret perceives an independence in managing her needs overnight. Having a way to seek help if distressed overnight offers reassurance for Margaret - perhaps supporting and enabling her decision to be at home alone and strengthening her confidence in her own ability to respond to changes in her needs without having someone with her. She reflects on the various options available to her; *"Sometimes when I'm in bed, like the other night I wasn't too good. And I thought, hmmm [considering using the number], no we'll see, but at least now this avoids 111 don't it? Well no body's gonna come [from 111], are they?"* [Margaret, Int. 2, p41]. Multiple influences on Margarets preferences and decision making are alluded to in these excerpts; from considering the financial cost of carers, the proximity of a local team that she knows and is confident in getting a response from, to her expectations of 111.

The role of professionals

Throughout both interviews and within Margaret's reflections from a life course perspective, she repeatedly references the role and influence of health and social care professionals on change and continuity in her life. In her treatment of her childhood scoliosis, Margaret describes private doctors in a prominent role as a source of trusted expertise; not only providing successful treatments but also acting as advisories supporting Margaret to choose which private hospital to have her surgery in. Reflecting on more recent interactions with professionals, Margaret goes on

to give a particularly negative perspective on interventions from health and social care OTs. After a prolonged stay in hospital prior to interview 1, and an increase to her carer support, Margaret tells me there are still many unresolved issues which she has struggled to access help to resolve despite a clear confidence in what these issues are and which profession's scope of practice they fall within.

A significant change has been moving from the Sara Stedy standing device, to use of the hoist. Margaret vehemently disagreed with the decision to make this change, and she says to the OT; *"you've taken away what little pleasure I had. I stood up on that Stedy. 'Well no, you were being lifted'. I was <u>not</u> being lifted!"* [Margaret, Int.1, p4]. Margaret suggests she perceived herself as more physically able than the OT had stated. Her use of the phrase 'you've taken away' indicates not only disempowerment in this situation, but implies an injustice. Later in the interview when asked about not going out, Margaret describes not *"getting the chance"* to see out to her garden now as with the hoist *"you're laid off [in a more reclined position] and you can't have a good look out"* [Int 1. p25]. Standing allowed Margaret to look out into her garden, and the loss of this seemingly small action in her day represented a significant loss of pleasure for her. Additionally, the hoist has ill-fitting slings which cause pain, so not only represents the loss of something Margaret enjoyed but also represents exchanging pleasure for pain.

A key factor in clinical decision making about moving and handling which Margaret refers to specifically is whether she was able to pull herself up to standing or was being lifted; a practice that might risk injury to herself and her carers. Margaret described what she felt was a very brief assessment, and an outcome which she felt contradicted both her own and her carers' experience. The OT's opinion took precedent leading to a strong emotional response from Margaret, an interpretation supported by Margaret's strong wording when describing her feeling towards the OT who recommended the change; *"She was useless… got no confidence [in her] … [i said] You've not done anything right. You've ruined my life really. I said you've taken away what little pleasure I had"* [Margaret, Int 1. p3].

In addition to the change of moving and handling equipment, Margaret recounts the installation of a bed raise as part of the input from [council] professionals, which she describes as *"so high I was virtually touching the ceiling!... so I had to stay in bed for at least two months"* [Int 1. p3] and took 6 months to resolve. It is not clear from Margaret's description how she was able to get back out of bed after two months despite the issue not being resolved for a further four, perhaps suggesting there may have been additional factors contributing to the period of bed care. What is clear is Margarets perception the equipment provision and perceived error was to blame for the disruption to her day-to-day activity, which further reduced her confidence in the competence of the professional. This negative experience was compounded by the simultaneous involvement of

an NHS OT; *"she said, I could do this [lower the bed] straight away, but [council OT]'s made the mistake and she's got to be responsible for putting it right"* [Margaret, Int 1. p3]. Health and social care professionals here acknowledge appropriate skillsets to resolve Margaret's issue and a commonality in their roles, but service and professional dynamics are prioritised above Margaret's needs.

Margaret describes how clinical specialists involved in her scoliosis management helped her understand self-management of her condition, including the contraindication of being hoisted. The interaction between Margaret and the OT prescribing the hoist is not shared, therefore the extent of shared decision making with Margaret is not clear, however Margaret tells me the introduction of the hoist against clinical advice marked a detrimental turning point in managing her physical needs. Margaret presents a loss of autonomy and control during this period, however her confidence in understanding her own condition means she continues to proactively seek a second opinion. Unlike her descriptions of privately funded doctors earlier in life, Margaret considers these NHS and Social Care professionals to hold a much lower level of competence; *"she'd been new to the job, but she was so poor at it… really really poor."* [Margaret, Int. 1, p4]. The involvement of separate therapists from health and from social care teams adds additional frustration for Margaret in her experience of professional involvement.

Margaret's basic safety needs were prioritised by the therapists involved, but Margaret did not agree with the therapist that there was a safety need linked to moving and handling and felt she was managing with the Sara Stedy. Her own priority was achieving dignity in her toileting and personal care routines. Margaret would like the OT to advise the carers how to support her in using the toilet and shower instead of changing pads and washing her on her bed; *"If I want to go to proper toilet, I have to go up there on my bed. Lots of things that just have not been, loose ends… I mean, I've not just been out of hospital 5 minutes, I came out the week before Christmas!"* [Margaret, Int. 1, p36]. Margaret's needs here have not been resolved despite her ongoing attempts to access further OT input.

The competence of others

Margaret's sense of other peoples' problem-solving ability seems influenced by her perception of their competence. For instance the carers, whom Margaret suggests are 'lower quality' than the previous carers, are described as unable to problem solve access to the toilet; *"They're not gonna do it off their own back, they're not bright enough…"* [Margaret, Int. 1, p35], and even holding insufficient skills to complete core aspects of their role without injuring Margaret in the process; *"some are pretty useless. Some of them I come out black and blue – they will catch my legs on the [hoist]. I get very short and sharp, still, some thing is better than nothing"* [Margaret, Int. 2, p26]. Despite indicating her safety needs are not fully met through the current carer arrangement,

Margaret accepts these shortfalls and adjusts her expectations accordingly, continuing to seek OT input to achieve her toileting and personal care goals instead. Margaret's experience of long delays increasing her care package due to limited care resource in her community may influence her decision-making around raising a new concern with it.

Margaret raises the idea of "backup" [Margaret, Int. 1, p26] several times, perhaps most notably when I ask in interview 1 whether she would have someone she could call on for help if she needed it - a question taken from the PRISMA-7 questionnaire. Margaret tells me her Power of Attorney for finances is a friend who also works as a bank manager; *"she's so good she really is"* [Margaret, Int. 1, p26]. Margaret readily goes to this friend for practical support such as changing utility provider even when the friend encourages her to be more independent with these tasks. Another friend who visits Margaret is cited as part of her 'backup' should an issue arise;

> *"…works at the [care home], she's a carer. And course, a lot of the things she's introduced to make the carers life easier, they're an absolute godsend. But unfortunately, she's not here when the bloody [hoist] breaks down [an incident discussed later] ... But she gets my… shopping"* [Margaret, Int. 1, p10].

Again, in this relationship, Margaret's friend holds expertise of direct value to Margaret's circumstances in addition to completing more practical shopping tasks. As Margaret's physical health deteriorates, she describes increased contact from the community nursing team; *"They always call, I have one call every week. They don't necessarily, they're not coming to give me <u>care</u>. They come to see how I am"* [Margaret, Int. 2, p10]. Margaret presents the nurse's role at this stage as being focused on monitoring and a readiness to respond if/when her health deteriorates. Margaret's references to additional relevant skills held by people in her wider network of 'backup' support suggest this is an attribute she values, having either directly benefited from some of these additional skills or knowing she *could* if a need arose. It is possible this strategy to build a 'backup' network with additional expertise may contribute to Margaret's preference for the 24/7 nursing phone line as an overnight safety net, rather than the physical presence of a carer.

Responding to physical health change

After Margaret's disclosure about her prognosis during our first conversation, the impact and experience of her deteriorating health becomes a consistent interview theme. Although the details of her life-limiting diagnosis or medical management are never specifically shared, Margaret describes her experience of living with a long-term musculoskeletal condition and how this influences her approach to managing changes in her physical health. Having been born with scoliosis and undergone multiple interventions and corrective surgeries earlier in life, when I asked what keeps her going, Margaret suggests the consistent need to manage health needs and

her attitude towards this has played a prominent role throughout her life and continues to shape her mindset now:

> *"I suppose really when you think, all my life I have had to fight my battles. Not bullying or anything like that – health battles. And so that determination is sort of instilled in me"* [Margaret, Int. 2, p44]

Here, Margaret links her lifelong self-determination in managing her long-term health condition and her response to health changes now. Her phrasing '*I have had to fight*' suggests Margaret perceives her role in health management to date as active and autonomous, and the notion that determination is *'instilled'* suggests a permanent and fundamental impact on her attitude towards staying well. This determination to retain autonomy in managing her ongoing health symptoms is also reflected in her descriptions of day-to-day decision making in responding to her changing health needs, such as in her account of using deep breathing techniques independently at night. In these examples, Margaret suggests psychological factors such as determination have a role in controlling the outcome or impact of her physical health changes on day-to-day life. Margaret's sense of esteem developed earlier in life despite living with a long-term condition are protective in her response to the progression of her physical frailty. For example, Margaret describes her reaction when she was first told she may not have much longer left to live;

> *"you know I got that final, y'know when they said… [her prognosis was poor]... one of the nurses said to me 'take no notice' she said 'they all get that'. 'Don't worry'. So I said 'no, it put me down in the dumps at first, two days, and then I thought no, no'"* [Margaret, Int. 2, p10].

Despite being told she may be nearing the end of her life, Margaret resists this deterioration in her physical health by retaining and focussing on her psychological resilience. Where she may not have direct influence over her physical diagnosis, this interaction with the nurse and Margaret's own sense of determination and psychological resilience protect her against her own negative emotional response. The nurse's suggestion here that the prognosis from the doctor may be general, not personalised, combined with Margaret's lived experience of 'fighting health battles' reframe her personal narrative and expectations around her end-of-life prognosis.

Another significant point of change in Margaret's physical health management was the COVID-19 pandemic. Despite living with a long-term condition, Margaret describes a picture of well managed health needs and minimal limitations on independent daily life resulting from her scoliosis up until the COVID lockdown. Restrictions in healthcare services during the COVID-19 pandemic also meant 6-monthly treatments to drain fluid from her chest were stopped, leading to a series of poorer outcomes for Margaret;

"…they got a camera in there… [it's] like a thick net curtain… I was going in [to the hospital] every 6 months… but then when the fluid couldn't be drained, that's why this leg is so fat [indicates swollen legs elevated on recliner chair]. There was no way they could suck it out – that's why it went up here [indicates chest]" [Margaret, Int. 1, p20]

Retaining cognition

Despite changes or perceived flaws in her physical condition, it was suggested to Margaret earlier in her life that her cognition and intelligence may be strengths which compensate for this;

"I can remember one of them saying, 'she may not be very tall but she's certainly not lacking in a brain'. And those remarks stay with you sometimes, when you've heard them when you're a kid. And erm, you can go through life thinking 'you've gotta live up to the family name'. My mum, you didn't give in, never gave in" [Margaret, Int. 2, p44].

Margaret connects these perceived attributes with the determination she described previously as key in managing her changing health needs, alongside an ambition to replicate her mother's example of perseverance. The notion of 'living up to the family name' may by complex and nuanced, but hints at value placed on the perceptions of others, as well as a sense of personal worth and value related to cognitive ability. In the second interview when Margaret finds form completion physically challenging, she asks me; *"Will you explain to [anyone reading the forms] how old I am? She has got her… 'her brain's alright'"* [Margaret, Int. 2, p7], suggesting it may be important to Margaret that her cognition and intelligence are perceived by others as remaining intact, as well as the significance this may hold for her own ongoing sense of self.

Frailty score

Without access to medical records and based on the account provided by Margaret during our first interview I did not consider her to be 'terminally ill' ('approaching end of life but not otherwise living with severe frailty'), however it was immediately apparent that support from another person was required for more than two BADLs (Basic Activities of Daily Living[5]), and that this had been the case two weeks prior. I therefore recorded a CFS of 7 ('living with severe frailty') when reflecting on the first interview. By the second interview it was clear from Margaret's account of her health prognosis and her increased shortness of breath that her frailty level had increased. Although the number of BADLs Margaret needed support with was unlikely to have altered significantly given the carer support already on place, I recorded an increased CFS of 8 ('living with very severe frailty') after the second interview. As the descriptors for CFS 7 and 8 both state 'completely dependent for personal care', the change in scoring reflected my

[5] Basic ADLs include walking, eating and drinking, going to the bathroom, personal hygiene tasks and overall mobility

perception of how close Margaret might be to the end of her life. There was no specific event which could be attributed to this change in scoring.

I reviewed the transcript data against the fulcrum domains in the same way I had with Susan's data – mapping individual domain scores across the three interviews to explore perceptions of change and stability [Table 7]. Margaret's accounts broadly aligned with my overall scoring [Appendix 31]. Notably however, in interview excerpts related to social environment and psychological status Margaret's accounts suggested higher levels of independence and control than in other domains. Despite less physical connection with previous social networks, Margaret maintains contact with friends in other ways and indicates 'friendly' relationships with others around her. Acknowledging and distinguishing between my own perception of some of these relationships as professional in nature, I focussed on Margaret's own descriptions. I interpreted the difference in accounts of psychosocial domains and those relating to physical health as a reflection that Margaret perceived lower levels of frailty in psychosocial areas compared to other domains. Although only 8 weeks apart, Margaret's descriptions across the two timepoints suggested some perceived deterioration. Beyond the study period and specific time points of the two interviews, Margaret told her story in relation to three significant points of change: 1. the COVID lockdown which restricted access to healthcare and stopped Margaret *"circulating"* in her community each day. Before this point Margaret describes a picture of resilience and independence across all life domains despite living with a long-term condition. 2. A hospital admission which resulted in an increase in care at home. Margaret gives little detail of the medical reason for the admission in the first place, instead her account focusses on resisting the emotional and psychological effect of waiting to return home, and 3. Change in equipment use once at home – a decision Margaret did not choose for herself but had significant emotional impact. There was very little change in how Margaret described her physical health and environment or her engagement with systems of care between the two interviews, however I nonetheless noticed a gradual deterioration in the resilience she presented in her psychosocial life domains.

Table 9: Interpretation of frailty levels within each frailty fulcrum domain - Margaret

Fulcrum Domain	'Areas to consider' guidance	Pre-COVID	Interview 1	Interview 2
		Most closely aligned CFS score based on statements related to each domain:		
Social Environment	• Main carer & carer network • Next of kin & wider family • Friends & community • Preferred methods of interaction	4	5	6
Physical Environment	• Think from the skin outwards • Clothing & footwear • Main daily living areas • Beyond the doorstep & transport	4	7	7
Systems of Care	• Health & social care integration • Sharing information & care records • Respite & carer support • Funding & benefits	6	7	7
Psychological Status	• Recognised conditions or symptoms • Motivation & confidence • Emotional wellbeing • Spiritual & cultural fulfilment	3	4/5	4
Multimorbidity	• Treatment burden of multiple long term conditions • Physical & mental health • Vision, hearing, dentition, continence • Strength & mobility	-	7	7
Acute Health Events	• Frailty syndromes: delirium, falls, immobility, incontinence, medication side-effects • Planned acute care (e.g. surgery)	-	-	-

7.3 Margaret, Maslow and Cialdini's principles

Interview excerpts indicating Margaret's resilience within each of the frailty domains support my earlier assertions that Maslow's levels of need may not be hierarchical. Margaret describes higher levels of frailty and dependence associated with physical and safety needs, and dissatisfaction not just with her dependence on others, but that her needs are not fully met. Despite this, she actively pursues social belonging and connectedness in her relationships. Margaret's determined autonomy in managing her needs and the associated sense of personal esteem this brings may contribute to fewer indications of frailty within psychological and social domains. A key outcome is Margaret's continued autonomy in problem solving and proactively drawing upon the skills and expertise of others around her to manage her needs.

When reviewing Margaret's interviews from the perspective of Cialdini's 7 universal psychosocial principles of influence (Cialdini, 2021) – reciprocation, liking, social proof, authority, scarcity, commitment & consistency, and unity – additional insights can be gained into the role of these influences in forming resilience within the domains of the frailty fulcrum.

Commitment and consistency

Margaret draws on commitment and consistency as a strategy to maintain stability, most apparent in her description of activities related to her essential physical and safety needs and through daily routines with her carers. Margaret uses language such as *"nighttime ritual"* [Margaret, Int. 1, p7] to describe the consistency with which her essential needs are met each day. Margaret makes ongoing attempts to adjust her daily routines to more fully meet her emotional and psychological needs, however as her current routines are more newly established, this change would represent a return to more long-established patterns, such as washing and toileting in the bathroom rather than on the bed. Margaret's perseverance with seeking help suggest this is important to her.

The idea of consistency as an emotionally stabilising strategy is reflected in Margaret's language when describing her perception that other people lack compassion towards her prognosis; *"but we solider on"* [Margaret, Int. 1, p12]. The phrase 'soldier on' has connotations of stoicism, bravery, and continuing despite difficult circumstances. These attributes may hold significance to Margaret as similar attributes to the self-determination she cites as key to 'keeping going', perhaps suggesting Margaret equates consistency in the face of adversity as a strategy to maintain stability.

Authority

Cialdini's framework proposes interactions with credible sources of authority can provide significant influences on decision making and outcomes, whether those authority figures are seen as "*in* authority or *an* authority" [Cialdini, 2021, p191]. Within Margaret's account, health and social care professionals were presented as holding a position of authority. Although not always perceived by Margaret as credible sources of authority, they were gatekeepers to treatments and resources in meeting her basic needs and were influential in guiding the actions of others such as Margaret's carers. When I posed my first question to Margaret; "do you have any health problems that require you to limit your activities?", she responded by talking about the limitations she felt were placed on her not by her health directly, but by the professionals she encountered over the past 12 months since returning home from a hospital admission. The input and decision making of professionals had been key in her experience of change;

> *"Oh yeah most certainly… I was limited in my going from day to day really by the fact the original Occupational Therapist took away my real good thing which was that Sara Stedy [moving and handling equipment]"* [Int 1. p2]

Here, Margaret describes the person in a position of authority having a negative effect on her life. Later in the interview, she talks about the past influence of doctors in guiding her decision making around treatment for her scoliosis, taking advice and undergoing a successful surgery and recovery. This previously successful approach to decision making, drawing on the expertise of authority figures is not successful in Margaret's more recent experience of hospital discharge. Margaret asks her hospital doctor for help but as the delay relates to social care support and not medical need they are unable to move the process forwards. This unsuccessful outcome from seeking the input of doctors may reflect a move away from a 'medical model' approach, towards the shared input of a wider multidisciplinary team. If so, this move, while widely considered by health and care professionals more appropriate for those living with frailty, may inadvertently undermine Margaret's previously successful problem-solving strategy, by reducing her ability to self-advocate directly with the actual source of 'authority' in this scenario.

Prevalent features of support cited in Margaret's first interview, were her perception of the competence of others acting on her behalf, alongside the physical proximity of support sources. Describing the overarching authority of the Occupational Therapist in determining the moving and handling plan followed by her carers, Margaret shares her frustration with the OT's absence; *"The Occupational Therapist says we're supposed to do it. I said 'what Occupational Therapist? They don't come!'"* [Margaret, int 1. p6]. Her comment that 'they don't come' suggests for Margaret, a key expectation of a credible authority figure may be for that person to be physically present.

Additionally, Margaret associated professionals or authority figures with providing or using equipment. Margaret described both examples negatively and associated these interactions with loss of choice and control in the face of differing perspectives on risk. In a later section of the interview Margaret describes recovery from surgery earlier in life, and use of a wheeled commode at her friends' cottage where she stayed during her recovery;

> *"It was hilarious… when they were getting the renovation they put a toilet downstairs, so they put in a little room, a little cupboard with a commode thing in there… the floor went downhill! So in the middle of the night, I'd come out from there and you'd, I'd get to my bedroom which was just there [gestures] you'd take off at like 90 miles an hour! [laughs]"* [Margaret, int 1. p24]

In this memory, Margaret's description of her speed on the sloped flooring as 'hilarious' suggests she experienced joy or fun from the uncontrolled movement, with no reference to risk of physical

harm, suggesting for Margaret some degree of physical risk may be acceptable if pleasure might also be gained from the activity. Descriptions of equipment use when provided and used under the risk assessment of an 'authority figure' in comparison to equipment used under Margaret's own perception of acceptable risk showed key differences in her experiences. Margaret seems to accept equipment use more readily where she can identify an element of pleasure alongside practical functionality. However, with the provision of the hoist no pleasure outcome is cited; in fact Margaret describes *"[the sling is] very tight and it's all cutting… [it's]painful cos this squeezes me"* [int 1. p6/7]. An incident shortly before the first interview where her hoist stopped working mid-transfer, leaving her mid-air and in pain suggested to Margaret that her carers lacked the expertise needed to problem solve and resort to:

> *"jump[ing] on the bloody bed… thought what they'd do, they'd try to get a little bit of leverage in the strings just so they could lift them off… eventually… [they] got it free and of course I just went 'BANG' [laughs] on the bed"* [int 1. p8].

During this incident Margaret is prevented from physically helping to problem solve as she is elevated in the hoist sling and in pain. The strategy she describes, to lift her sling from the hoist fittings and allow her to fall onto the bed is presented as the carers' idea, suggesting Margaret has limited agency in the decisions made despite the risk of injury this poses for her. Margaret's account presents carers *in* authority and making decisions on Margaret's behalf as Margaret is incapacitated in the sling, however the experience compounds Margaret's belief that her carers are not "an authority" (Cialdini, 2021) as they are unable to get the hoist working again. She later shares the opinion *"they're not bright enough"* [int 1. p37] to assess for the changes in daily routine Margaret would like. Therefore, despite being physically present and in control of Margaret's moving and handling equipment every day ("in authority" over her daily moving and handling), Margaret continues to actively seek someone with the skills needed to be considered *an* authority. Cialdini groups those *in* authority and those considered *an* authority together as part of the same influence on personal decision making, however for Margaret the two authority roles seem to have quite separate influences. In her account Margaret associates her carers *in* authority with maintaining the status quo in accordance with a predetermined plan, with little opportunity for personal agency. Conversely, figures considered *an* authority are actively pursued by Margaret as a means to achieve greater agency in changing daily routines.

Margaret experiences the input of professionals considered *an* authority most positively when she also has some agency in the outcome. In choosing a private hospital the doctor provides an expert recommendation, however as Margaret is a private health patient she is paying for the treatment and the decision is hers, therefore the key influence on outcome is financial resource, *supported* by access to professional expertise. Conversely, despite Margaret's friendly

relationship with the respiratory doctor, the NHS service decides to stop the clinic during COVID and it is not then resumed as a home-based service post-COVID when Margaret's ability to get out has deteriorated. Here, positive access to an authority figure alone is not enough to influence the outcome as Margaret has limited agency.

In a third interaction with professionals Margaret is complimentary to the OTs she perceives are doing things *"so smoothly"* and critical of the OT who made the contested decision about the hoist. Margaret infers the latter OT was not highly skilled, new in her job and *"so poor"*. These descriptions support the distinction between those *in* or *an* authority, suggesting figures *in* authority are associated with lower skillsets and present a barrier to personal agency, whereas those considered *an* authority may be considered more skilled and a more positive influence on agency.

Margaret's perception of successful outcomes following involvement of authority figures was associated with choice and control over their involvement in her life, and in decisions around her health and care needs. When given a 24/7 phone number to access community health teams at her discretion, Margaret's confidence in continuing to self-manage overnight is strengthened. Similarly, her two friends with 'useful' expertise are readily contactable and can be drawn on flexibly as directed by Margaret. A key feature is assurance that these people or teams *will* respond promptly or even pre-emptively.

Scarcity

Cialdini presents 'scarcity' as a principle of influence; that "opportunities seem more valuable to us when they are less available" [Cialdini, 2021, p206]. For Margaret, whose life could be considered restricted, the reverse effect in response to scarcity could often be seen. Margaret's description of Christmas *"I'm not full of expectation… a lot of people can't keep alright"* [Maragret, Int. 2, p2] suggests rather than prompting her to seek more social contact as a scarce and more valuable resource, the scarcity of contact with others prompts a protective response whereby adjusting expectations protects psychological and emotional resilience. Margaret's expectations around contact with others appear shaped in part by a history of living alone, and as such Margaret may not perceive her social contact as scarce in the way others might, reflected in her interaction with the community healthcare team who initiate a referral to a befriender on Margaret's behalf. Margaret tells me he was; *"going round to the people if he thought they were on their own and they needed y'know, they were lonely"* [Margaret, Int. 2, p19], suggesting others may perceive her as lonely but this may not be how she viewed herself.

Scarcity was also associated with access to healthcare resource and limited opportunities to respond to changing needs earlier; *"[to GP]: 'Well, I'm still alive, but then you wouldn't know that would you"* [Margaret, Int. 2, p15]. For Margaret scarcity leads to both proactive action and

frustration, seen in her persistent search for OT assessment and support to improve her day-to-day routines. The daily carers are dismissed as unable to resolve issues with routines, whereas OT input - which Margaret indicates has been minimal since her return home from hospital 11 months previously - remains in great demand; *"when [the OT] was first coming in she come in on a Thursday, once a week, 4 o'clock so she could greet the carers. She was gone by quarter past, quarter of an hour"* [Margaret, Int. 1, p4]. Despite her dissatisfaction with the amount and outcome of OT involvement to date, Margaret attributes this experience to an individual with unsatisfactory skills not the profession as a whole and continues to actively seek further OT input. Scarcity of access to professionals deemed sufficiently skilled to adjust her routines leads to prolonged periods of reduced, uncomfortable or undignified day to day activity for Margaret – ultimately a source of frustration and dissatisfaction.

Although the cause of scarcity of OT input cannot be surmised from this data, the result for Margaret is that her needs are not addressed holistically – an outcome that contradicts fundamental OT models of practice and suggests scarcity of OT capacity may influence not only Margaret's actions and personal responses, but also the decision-making of the OT. Moving and handling need appears to take primary focus whereas Margaret's own goals - dignified access to the toilet or shower facilities – seem secondary, suggesting where resource is scarce, physical safety of both Margaret and her carers are prioritised over Margaret's quality of life goals, which raises questions about whose needs the input serves. Scarcity of time for this professional results in significant shortcomings in outcome from Margaret's perspective.

The period immediately following hospital admission was significant for both Margaret as the amount of support available fell short of her perceived need. Margaret describes initial provision of equipment and environmental adaptation to support her return home, but long delays (11 months) before further review is made to optimise her wellbeing at home. Although the period post-discharge has been recognised as a period of vulnerability and change, there may be a scarcity of sustained support to respond to this.

The data suggested subtle relationships between the nature of 'scarce resource' and influence on Margaret's behaviours and decision making. For instance, Margaret's perception of scarcity of access to skilled OTs drives her to pro-actively seek a new OT and continue to advocate for changes in her day-to-day routines. In contrast Margaret describes requesting support from her power of attorney (POA)/friend with switching energy providers. Margaret indicates her POA/friend is highly competent with relevant expertise;

> *"She's my power of attorney. She totally organizes all my money, she's the bank manager at [another town] at [bank] where I used to work. She organizes all my finances together*

with her mother. I don't have anything to do with it, nothing at all… as she's so good she really is" [Margaret, Int 1, p26].

Although the same proactive behaviour is used to seek support changing providers and Margaret can clearly articulate the rationale and process needed to make the change, she declines to attempt the task herself despite being given the relevant phone numbers to do so;

"That's a good bloody month or so… Well I know she's busy at the moment, well she's always busy. Anyway, I don't think she took it that well cos she thought [I was chasing her up]. And she sent this bloody 0800 number to do it myself [laughs]. I didn't do it… I told her I'd make a complete hash of it. I make a complete hash of everything else! So she said 'no, don't worry, I'll do it'" [Margaret, Int, 2, p20].

It is possible Margaret may exaggerate the limitations of her own abilities to maintain a need for her friend's 'expert' support. Although it may be speculative to suggest Margaret could have made this call herself, it is possible keeping her highly skilled friend engaged in ongoing support tasks may be a strategy for Margaret to keep these useful and scarce skills around her. Alternatively, avoiding a task that might challenge Margaret cognitively may be a protective strategy in maintaining psychological resilience and continued sense of self.

Although Margaret's reduced mobility creates scarcity in practical terms, such as face-to-face interactions with others, she also comments on scarcity of qualities of the professionals she meets, seen most clearly when Margaret reflects on the qualities of a local physio;

"[Physio's] good… [he] will come down and… he sorted that out with that doc… no, he shows a side of him… a <u>compassion</u>. That something nobody's got really, not in doctors or anything" [Margaret, Int. 1, p13].

In this reflection Margaret indicates her needs were recognised and better met through a compassionate approach to care from the physio than she may have found in other interactions with healthcare professionals, suggesting scarcity in empathy and compassion from healthcare teams may also be perceived as significant to individual experience and outcomes. Margaret's account demonstrates that responses to scarcity are nuanced and personal, and that the scarceness or abundance of valued attributes of support sources influences not just help seeking and problem-solving behaviours.

Liking

The notion of liking or being liked features frequently in Margaret's first interview as a strategy to elicit support and build a sense of belonging. In the transcript analysis this was seen in codes such as 'Relationships with others – getting on with them' and 'Types of support – friends' and was more associated with maintaining stability than in planning for or responding to change. For

Margaret, who herself never married, a couple who were her very close friends earlier in life up until their deaths played a key role in her earlier support system – *"…they did everything [for me]. They were the bestest friends"* [int 1. p27]. These friends provided accommodation and support during recovery from surgery earlier in life and even helped remodel Margaret's bathroom to be more accessible for her return home – *"I didn't ask them to!"* [int 1. p14]. This statement suggests unsolicited support provided due to friendship.

A recurrent theme in Margaret's first interview was seeing duality in the roles of those around her, often seen in professional and practical roles which Margaret also perceived as friendships; *"I got very good friends with the consultant"* [int 1. p21]. Margaret uses the same phrase to describe this and another earlier consultant – *"he was so good to me"* [int 1. p21 and 33], perhaps signalling an association for Margaret between a friendship relationship and better care experience. This dual role is seen again later with friends that visit Margaret socially but also support with practical tasks; one friend *"might do a bit of shopping for me"* p31, and the other *"[Is] my power of attorney. She totally organises all my money"* [int 1. p27]. Despite Maragaret's repeated presentation of social and practical duality in the roles of others around her, neither of these friends chose to visit Margaret in person on Christmas Day, possibly indicating limitations to these friendships.

Margaret's ability to build and maintain what she presents as positive and friendly relationships with her carers seems key to her acceptance and satisfaction with their work, as evidenced through frequently reference to being able to laugh together; *"I pull their leg… we do laugh"* [Margaret, Int. 2, p14]. When I ask what keeps her going, Margaret refers to "*always looking for a laugh"* across her life in addition to *"the support [I] had"* [Margaret, Int. 2, p47]. In addition to this connection between her humour and attracting supportive relationships, at other times she uses humour to soften expressions of her frustrations where an ongoing relationship with the other person needs to be maintained. For instance, Margaret tells me;

> *"I've got a black humour… I shouldn't joke. Cos I could be half dying sometimes. When the doctor's said to me on the rare call 'how are you Margaret?'. 'Well, I'm still alive, but then you wouldn't know that would you?'"* [Margaret, Int. 2, p14]

Margaret later alludes to the key role her doctor may hold over the coming months as her health deteriorates; as such she may be reluctant to damage the relationship despite her dissatisfaction with contact from the doctor, so uses humour. This dynamic is seen in her relationship with the carers; *"…you could take offense at [the racial comments I've just described making to the carer] but it was meant as a joke and he took it as a joke…I laugh so they know I'm not… serious"* [Margaret, Int. 2, p14], indicating humour as a strategy for Margaret to navigate relationships where highly personal tasks are completed by strangers.

Margaret's interviews also convey that laughter may serve to align her with others and play a protective role for her at times of discomfort. This is most notable in Margaret's description of an incident with the hoist which occurred shortly before the first interview. Margaret's hoist stops working one Friday night whilst transferring back to bed. The carers are unable to lower her down. They position Margaret over the bed and attempt to problem-solve how to lower her down. With Margaret's hoist sling too small and causing pain, and no one seemingly holding the expertise to lower the hoist Margaret describes a somewhat chaotic scene;

> *"I'm on the hoist. We've gone up to the bed to swing me over, put me into the bed, onto the bed to do the nighttime ritual. And the hoist it got stuck up in the top…. So there I was, swinging away, and it is painful cos this squeezes me here (indicates where the sling edges come in contact with body). And all the legs hurt, so I said 'I can't take much more of this'. It was two girls. I said 'it's dead!' you know, there's no power going through. Tried another plug, no. So I'm swinging away. 'You've gotta get me down cos this is killing me!'. So, these two are the fat carer ladies, jumped on the bloody bed [laughs]… and thought what they'd try to do, they'd try to get a little bit of leverage in the strings just so they could lift them off… Well the only other way was, which I thought would be quicker, was to cut the bloody strings on the hoist thing. Anyway eventually, bouncing up and down in this bed, and they… got it free and of course I just went 'BANG' [laughs] on the bed. They couldn't save me! [laughs] Well, it was a relief to get down"* [Margaret, Int.1 p7 and 8]

Margeret laughs recounting this story, despite the pain and sense of urgency inferred in her account. Later Margaret reflects on this incident again, giving an account of her experience at the time perhaps not truly reflected in her original account;

> *"And there's me going 'me back! Oh me back!'. And then everybody's laughing which you end up doing! I'm the one in trouble, but you have to laugh because the situation is quite funny!"* [Margaret, Int. 2, p17]

In her reflections Margaret recognises her vulnerability in this incident. Although there are others around her, *"I'm the one in trouble",* yet when others around her laugh she mimics this response perhaps as a strategy to foster positive relationships and feel less alone in her vulnerability.

Unity

Although Margaret lives alone with no family group or partner who might create a traditional sense of belonging (what Cialdini refers to as a 'tribe'), Margaret aligns herself with others around her in other ways which offer insight into her sense of identity and social resilience. Margaret's primary contacts are with paid carers, however her use of the pronoun "we" rather

than “I” at multiple points during both interviews suggests a perception of unity or affinity in these relationships. Having already explored the role of Margaret’s carers as authority figures who may not facilitate her own sense of agency, it may be unlikely Margaret’s pronoun “we” here is intended to suggest a close emotional relationship. Cialdini suggests; “Those within the boundaries of “we” get more agreement, trust, help, liking, cooperation, emotional support, and forgiveness and are even judged as being more creative, moral, and humane” (2021, p299), therefore Margaret’s use of the “we” may reflect the carers as a group she wishes to foster agreeable, cooperative relationships with to manage her needs. When describing daily routines, Margaret switches interchangeably between pronouns “we” and “I”, such as; *“I have a good wash.... And then we’re put into the sling and hoisted… you’re supposed to [be] hoisted from the bed to the wheelchair”* [Maragret, Int. 1, p6], and *“I’m on the hoist. We’ve gone up to the bed to swing me over, put me into the bed, onto the bed to do the nighttime ritual”* [Margaret, Int. 1, p7]. Margaret’s interchangeable use of pronouns suggests complexity in the dynamics of feeling alone in vulnerability but yet united with others and may again reflect the limitations of her relationships with the carers.

Social proof

There is evidence that Margaret compares herself to others as a strategy to normalise and accept her own situation. Cialdini suggests behaviours and actions may be guided by observing and modelling others, however with limited interaction with peers Margaret draws on social proof more broadly to frame her position as ‘survivor’ within her friendship group and perhaps to affirm her choices and behaviours to date. Margaret’s comparison against others perceived as being in a worse position than her, rather than comparing her current circumstances to earlier stages of her own life might be considered a strategy to protect her emotionally and perhaps affirm psychological resilience.

Margaret describes the end of her close friends’ lives, and how she kept in touch over the phone right up until they both passed away. When the first of the pair passes, she recalls the end of his progressive symptoms as a ‘good day’. Margaret does not explicitly comment on whether observing her friends’ experience had influenced her own expectations around end of life, however she seems to value similar features of support, such as regular telephone contact or perhaps the assurance of knowing someone is only a phone call away. Margaret was able to offer this to her friend at the end of her life and now feels comfort receiving too.

Reciprocity

In Margaret’s account, the theme of reciprocity emerges through her experience of funded services versus those she pays for herself. Cialdini’s principle of reciprocity suggests people may be more inclined to offer something to others when they themselves have received something of

value, or vice versa. The narrative approach to research suggests the order in which people tell their experiences reflects the emphasis they place on each subject. Margaret's first interview opens with the statement "I pay for all my support". This becomes a running theme throughout our conversations and is initially presented as; *"I find really, like I say, the things I pay for are good",* whereas the *"[local] Council is not good… [local] Council were getting nothing but complaints about their side of it… they've never fulfilled their part"* [Margaret, Int. 1, p5]. In this distinction between the quality or adequacy of 'paid for' services in comparison to public services, Margaret expresses greater satisfaction with the more reciprocal relationship of 'paid for' services compared to public services.

Conversely, Margaret also describes a long and inconsistent experience of private healthcare. At times additional access to treatments and hospitals has been provided (positive); *"I had all my surgery done in [Hospital name], in [city]. Where [famous family] go… It was in there. Brilliant hospital"* [Margaret, Int. 1, p15] but at others Margaret perceives seeing little by way of outcome for her money (negative); *"…you're paying but they're not finding anything. Any they… reap their lump sums out…"* [Int 1. p15], and; *"…a lot of the private medicine I had at [hospital] the doctors were rubbish! They just took your money and were fit for nothing really"* [Int 2. p24]. This suggests it may not simply be the act of paying for a service that influences Margaret's perception of a positive outcome, but the sense of getting back something equitable to what's been put in, in essence a balanced reciprocal relationship. The perception of balance or equivalence in reciprocal relationships may reaffirm Margaret's sense of agency and control.

Margaret describes taking practical anticipatory steps to sort through her possessions as she recognises the later stages of her life. This action serves two purposes; minimising the potential 'ask' on others to undertake this later, and providing a means to repay support already received, as with Margaret's intended gift for her consultant;

> *"…cos my consultant's so good to me, I spoke to him a long long time ago, a couple of years back… I showed him pictures of [a painting I own] and I said to him, 'it's a strange request, but… what d'ya think of that?'"* [Int 1. P32]

There is evidence that Margaret may use reciprocation to maintain agency when accepting support or help from others. She chooses financial or material resource as methods of reciprocation, which may reflect her limited physical ability to reciprocate in other more practical ways, the financial resource she has available to her, or perhaps even a more complex dynamic of parity preferred between the type of help received and what is offered in return.

Summary

In this chapter I have provided a detailed analysis of Margaret's case in relation to the research questions and study objectives. There is evidence in Margaret's account that her agency in decision making is associated with maintaining stability and continuity in her life. Attributes of others around her such as being perceived as being *an* authority or demonstrating a compassionate approach influence Margarets decisions around continuing to seek help from others or feeling empowered in her own care. At times of change there are instances whereby Margaret successfully retains agency and continuity, and the strategies she uses to do so resonate with each of Cialdini's principles. Although Margaret is aware of her health prognosis and the likelihood of change and deterioration in her future, she uses strategies to retain psychosocial resilience and reduce negative emotional impact. These strategies include drawing on social proof to continue to identify as resilient, maintaining a sense of cognitive ability, and focussing on the present.

Margaret indicates feeling she has little choice and control over her health needs, having already been given a life-limiting prognosis before we first meet, however she continues to actively exert or seek choice and control over how and when her needs are met. This sense that Margaret's physical health and independence deteriorate prior to any equivalent change in her psychosocial resilience is reflected in the domain specific frailty analysis presented in this chapter.

Chapter 8: Discussion

Having presented two detailed illustrative cases in Chapters 5 and 6, and explored psychosocial influences on change and stability within each partitipant's account, in this chapter I will draw together the findings from both illustrative cases in relation to the existing literature and discuss where my findings support or challenge the existing evidence base. I will then discuss the study's strengths and limitations to consider what this study adds to the current evidence base for community frailty management and implications for future practice and research.

8.1 Discussion of the findings

How do people living with frailty in the community use psychosocial factors to maintain physical, psychological and social stability?

Coding for stability versus change

In my concept analysis I discussed the idea that resilience may be considered as a measure of success in the transition between two time points whereas frailty may be thought of as a static measure of potential change and therefore the two may be related but not necessarily opposites. I chose to explore 'stability' and 'change' in this study as more directly opposite states, with a view to understanding how psychosocial factors might influence potential versus actual change across the frailty domains. At each interview I recorded an overall CFS which focuses on the progressive influence of health symptoms on functional independence, but I also applied a more detailed lens to the study data to explore notions of change and stability within each of the 6 frailty domains – social environment, physical environment, psychological status, multimorbidity, acute health problems and systems of care.

Within my coding process I conceptualised 'stability' broadly as the continuation of what had gone before, as opposed to the presence of change. Just as a tightrope walker balanced on a wire might appear static when observed from a distance, on closer examination an observer might begin to notice the complexity of proprioceptive and environmental influences on the walker, and an almost imperceptible series of tiny adjustments made to achieve what might seem static. As I explored examples of 'stability' in my study data in response to my first research question, I noted a similar effect. Working through the process of analysing transcripts and coding for 'change' versus 'stability' across the frailty domains it soon became clear the two were not mutually exclusive as I had originally hypothesised. Instead, I found that multiple small changes and adjustments might take place in one life domain to achieve what appeared to be stability,

either in the same domain or in another. In other instances, continuity and commitment to a particular routine or expectation was used as a strategy to respond to change in another domain. In this way both change and stability could feature simultaneously, just as the participants themselves at times presented as simultaneously frail but also resilient. This reflects Richardson et al. (2014)'s suggestion that the experience of living with frailty may be nuanced and at times dichotomous; that older people can simultaneously live with physical frailty but hold a "resilient sense of self" (p1393) and also supports my earlier reflections on the limitations of a single static frailty measure to reflect this complex dynamic.

Adjusting expectations

Both study participants described a determination to 'keep going', and an acceptance of a new normal as a way to maintain stability and continuity in day-to-day activities. In most instances, a new normal meant changing the task in some way to align with a new physical ability, such as the use of a walker or hoist, or taking longer to complete a task. This was consistent with findings in the current evidence base that adaptation when threatened with change and deterioration may be viewed by people living with frailty as a resilient response. In chapter 3 I described response shift theory, which suggests that a health or social event can act as a catalyst that may change "internal standards, values, or conceptualization of QOL" (Schwartz et al. 2020, p1). In the study data there were indications that response shift acted as a protective mechanism against negative emotional affect. Indication of response shift was most clearly suggested in Margaret's description of managing well and valuing her independence overnight, despite being physically unable to get out of bed. The study period did not include the period of change where Margaret became bedbound overnight, therefore it is not possible to conclusively describe Margaret's perception of independence prior to this time, however the objective picture of her physical reliance on others now compared to going out alone in her car 2 or 3 years previously suggests Margaret's independence in practical terms had reduced greatly. I interpreted from this a possible shift in what Margaret may consider 'independent', and therefore a reframing of what she felt was most important to her.

Similarly, in describing which activities were important to keep doing, and which to reduce, Susan told me she would like to continue 'what we have now', and in other parts of her interviews describes avoiding comparisons to other times in her life. This ambition to maintain her current lifestyle despite adjustments already made in response to her increasing falls and changes in mobility may also suggest a shift in Susan's 'internal standards' and conceptualisations of quality of life. I interpreted this as a protective mechanism through which Susan retained a sense of stability in her day-to-day life.

Selective Engagement theory asserts that older people, particularly those living with increased tiredness associated with frailty, may experience an increasing 'cost' of engaging cognitively and in response engage selectively to preserve their limited resource (Hess, 2014). The theory's author proposes that selectivity is reflected in reduced motivation to engage in cognitively demanding occupations, an increased focus on the personal implications of an activity and selectively engaging with activities which support and maintain the current status quo. This theory is supported consistently in my study data, as both participants expressed limited expectation of regaining or building skills. This theory also prompts reflection on the limitations of the participant diary within the study design and the cognitive demand this task may have posed for people with already limited resource. Framed through Hess' theory, low uptake of diary use may suggest that the 'ask' for reflection on activity levels and sense of choice and control may have posed an increased 'cost' to participants both physically and psychologically.

The study data supported Hess' proposal that the personal implications of an activity may influence decisions around continuing or adjusting that activity. Whereas participant expectations around practical tasks and activities were more readily adjusted, including openness to accepting the support of others, continuity of previous standards and independence was important to both participants within tasks related to personal care. Although personal care forms part of core physiological need in Maslow's pyramid, fundamental esteem needs of dignity and respect related to such personal activities may also contribute to their value. The threat posed to esteem and dignity in losing independence in these tasks appears to elicit a stronger personal response and motivation for self-management and self-advocacy behaviours for both participants than less personal tasks.

As well as the more apparent influence of physical changes on daily activity, there were also examples of diminished psychological or emotional resilience threatening to reduce or change day to day activity or participant's status quo. For instance, Susan's loss of confidence going out after a fall, and Margaret's initial response to her end-of-life prognosis. Whereas tasks and activities were adapted in response to reduced physical ability, both participants were able to overcome changes in psychological or emotional resilience rather than reduce their activity level. Susan used a face-to-face medical appointment as a motivating factor, gradually building up her time and distance outside until she was confident enough to attend the appointment. Margaret described fighting against her low mood and continuing to advocate for herself in trying to get home from hospital; attributing her overall determination to 'keep going' to her experience of managing long standing health needs. These two experiences suggest motivating factors behind determination to maintain continuity in day-to-day activities are highly personal.

For both participants, the means through which social connection was achieved changed as their ability to go out independently deteriorated, and alongside this their expectations of the role of social relationships also changed. Socioemotional selectivity theory was developed by L. Cartensen from 1993 onwards and suggests relatively high social and emotional wellbeing in older people despite the reality of loss often experienced – known amongst academics as the 'paradox of ageing' - can be attributed to a shift in attitude and behaviour towards social connection. The theory asserts that people who perceive limited remaining duration of life focus on close social partners, place less emphasis on more peripheral connections, and "engage in prosocial behaviours" (Cartensen, 2021, p1) all of which contribute to a sense of robustness in emotional and social wellbeing. The pattern described in the 'paradox of ageing' is consistent with the study data, and my interpretation of participants' perception of lower frailty within psychosocial domains despite progressive restriction and deterioration in other domains.

There was evidence in the study data that deciding to make changes in order to maintain continuity elsewhere, and vice versa, was highly personal and complex, with compromise and acceptance of a less satisfactory experience often forming part of this process. For Margaret, deeply unsatisfactory compromises in meeting toileting and personal care needs, and even some level of minor injury and bruising during moving and handling were accepted in order to achieve her greater, more desirable goal of remaining at home. For Susan and Jim at a lower stage of frailty these compromises were more subtle, choosing a less satisfactory version of an activity or outcome to retain their independence and autonomy. This was consistent with notions in my concept analysis that people living with frailty may consider the idea of 'keeping going' as 'adaption to' and 'acceptance of' change, rather than rigid resistance (Nicholson et al., 2013; Richardson et al., 2014; Skilbeck et al., 2018), and with Nicholson's additional suggestion that diminishing of reserves over time may be experienced as a gradual process of multiple adjustments and losses. The experience of small adjustments for Margaret was somewhat different to that of Susan and Jim, perhaps in part due to the involvement of others in this process. Being dependent on carers for the majority of day-to-day activities, Margaret's ability to make small changes was reliant in many ways on her ability to engage and elicit the support of others who could act on her behalf. As such, for Margaret to make purposeful and intentional change to daily routines this process demanded perseverance over a period of time to combat what seemed to be a high rate of failure.

Proximity of backup

Further to these descriptions of the duality of stability and change within the study data, I explored the boundary between the two in more detail. Within the data, there appeared to be a distinction between events arising for which a swift resolution could be accessed and status quo

quickly resumed, and others for which a resolution was less readily available and/or the status quo was disrupted for longer. Where issues could be resolved quickly and without lasting disruption, I conceptualised this as a feature of stability. Both participants described having 'backup' support available, and the study data suggested that close proximity and assurance of responsiveness were key features of support which facilitated stability. In both accounts there was evidence that the nature and role of social support changed as the need for physical proximity of support became more pronounced. The study data suggested that having confidence that support sources would be responsive influenced decision making towards self-management choices. The prior evidence that Susan's whistle could successfully elicit a response from Jim or the neighbours led to her decision to continue this strategy instead of switching to the the call-centre response alarm. For Margaret, the assurance of a locally based community health team with 24/7 presence seemed to enable her to continue her preferred choice to be at home by herself overnight.

Maltby et al.'s 2020 study found three dimensions of social connectedness; "nuclear family, other immediate family and a wider social network" (p1306) and proposed the gradual restriction of social contact down through these dimensions to be a possible early social indicator of the development of physical frailty. This gradual reduction in social connectedness was reflected in the study data, and in both cases roles and relationships with others changed as connections to a wider or even immediate family network reduced, resulting in an increased focus on physically and emotionally closer relationships. Coundouris (2025) suggests that as a result of this shift in focus, smaller social networks may not necessarily mean a sense of social isolation for the older person. The study data detailed strategies and personal responses used by participants to develop and maintain 'nuclear' relationships. Relationships which reflected Maltby's 'nuclear' dimension were indicated in the study data through participants use of the pronoun "we", indicating a sense of unity mostly seen when describing people seen frequently and close by.

Where long standing relationships with a wider social network could be retained through telephone contact, the role of these relationships was perceived to have changed; seen less as a source of tanglible support particularly for Susan. However the continuity of these relationships acted as a connection to earlier stages of life and as such may anchor the participants in an established sense of identity and belonging, which may prolong psychosocial resilience.

How do people living with frailty in the community anticipate, experience and respond to physical, psychological or social change?

Just as I had conceptualised stability as the continuation of what had gone before or the swift resolution of issues, I identified change within the data when participant status quo was more

significantly disrupted, either in terms of the level of support they needed or where a longer period of time was needed to regain stability.

Psychosocial factors as antecedents?

The evidence base suggests people living with frailty may perceive psychosocial influences as antecedents to 'tipping in' to frailty. Although assertions in the current evidence base point to a wider cultural association between frailty and personal failure or weakness, the study data overall did not indicate this was a view the participants took of themselves. Indicative domain-specific frailty levels suggested both participants perceived greater resilience within psychosocial domains than in those related to physical health. As such the study data did not support notions of psychological weakness or 'giving up' as antecedents to overall frailty. In my earlier concept analysis, I observed that 'non-healthcare public' groups represented in the literature perceived associations between frailty and personal or moral failure more than 'professional' or 'frail person' cohorts. In addition, frailty was thought to be recognisable to the non-healthcare public as a 'visible part of the feared ageing process' [Appendix 10]. The study data appeared to support this interpretation of perspectives, as both Margaret and Susan referred to the presence of a negative but unspecific 'external gaze' on their changing physical resilience. Concern about the perception of others seemed to influence engagement with activities and therefore had the potential to contribute to progression in frailty. Susan felt others out in public might perceive herself and Jim as *"two old cronies"* walking together and is deterred from going to the theatre to avoid *"the embarrassment"* if she is unable to stand from her chair again. Susan holds this perception despite her experience that strangers in public have been consistently kind and helpful in the event of incidents such as her own and Jim's falls. This may suggest psychosocial factors, perhaps drawn from more complex cultural and social influences, rather than objective lived experience may shape Susan's perception. Susan also describes herself as 'getting lazy' when reflecting on changes in the meals she prepares for herself and Jim, however it is possible the implied impact on someone else (Jim) here may contribute to this self-judgement, as she makes no equivalent comments when describing changes which only affect herself.

For Margaret it was important that others continue to view her as cognitively resilient regardless of her physical changes. The data suggested intellectual ability played a key role in the personal sense of identity Margaret had built across her life, and as such she was keen for her deteriorating handwriting not to reflect a change in this presentation of her identity to others. This observation in the study data was consistent with the assertions of Mudge and Hubbard (2018) that frailty implied a "fading of personhood", however as the term 'frailty' was not used directly during the interviews, it was Margaret's physical presentation rather than use of the term 'frail' which she saw as threatening to invoke this negative perception from others.

Margaret's experience of changing to the hoist against her wishes was based on the OTs determination that her physical ability may be lower than she herself perceived. This may have reenforced Margaret's association between the negative perception of an external observer and loss of autonomy in her own care.

In the literature, a clear distinction has been laid out between being and feeling frail, with the former described as an externally imposed classification and the latter reflecting a temporary emotional state (Warmoth et al., 2016). The extrinsic labelling of frailty has been observed in the existing evidence base to accelerate deterioration (Warmoth et al., 2016), with Higgs and Gilleard (2014) suggesting frailty is a state of risk "made manifest through third party actions, not… first person accounts" p15. The study data supports this distinction, as although Susan and Margaret both describe being able to overcome temporary emotional changes to regain a sense of stability, the data also supports the suggestion that externally imposed judgements may directly threaten a more permanent state of vulnerability and contribute to psychological or emotional frailty. This observation has implications for engagement with formal support services and cautions against deficit focussed approaches to practice.

Anticipate, experience and respond

In the opening paragraphs of this thesis I discussed the opportunities frailty may pose for delivering preventative approaches, commonly referred to as 'left shift' (Darzi, 2024). Key to my research questions was an intention to explore how people living with frailty anticipate and prepare for change, and whether influences on this decision making are distinct from the influencs that drive response in the event of an unexpected change. Martin (2014) explored self-rated health patterns within frailty trajectories and noted that whilst older people with frailty expected deterioration, anticipation of the timing or severity of a event was less accurate even when associated with a chronic conditon. The study data supported this finding, as expectation of deterioration was a common theme, however focussing on the present appeared to be used as a protective strategy against negative psychological or emotional affect, perhaps reducing the liklihood of taking practical steps to plan for anticipated change. In the absence of a specific or predictable disease trajectory, the study data suggested although future deterioration was expected, the specifics were an unknown, affirming Higgs & Gilleard's (2014) description of frailty as "a condition of high but ill specified risk" (p15). This may also be a reflection of Lillrank's (2002) concept of 'splitting' in which events eliciting 'good' and 'bad' emotions are separated internally and the 'bad' is distanced from the sense of self as a strategy to avoid anxiety. The study data suggested this response may be elicited not only by recalling previous events but perhaps also through anticipating future adverse events, suggesting expectations around future need may play a key role in willingness to actively plan ahead. Older people in Warmoth et al. (2016) used the

term ‘frailty’ to describe a current rather than potential state. My study data echoes this focus on the present and perhaps continuity of what has gone before rather than anticipation of a threatened future.

Alongside subtle adjustments in roles and activities in response to change seen within both illustrative cases, I also noted a consitent and somewhat complex theme around adjusting perceptions of risk and personal decisions around what constituted *acceptable* risk. The study data suggested that although core physical needs at the base of Maslow’s pyramid were consistently prioritised, participants adjusted their perceptions of safety needs to strive to fulfil needs higher up Maslow’s model. The possibility of an unpleasant or physically harmful outcome seemed at times to be consciously and knowlingly accepted where esteem and self-actualisation might be achieved. In contradiction, healthcare professionals involved in later stages of frailty seemed less able to modify perceptions of acceptable risk and continued to prioritise safety ahead of esteem or self-actualisation outcomes. In Clarke et al.’s (2011) study of risk perceptions in dementia care, the authors observed that professionals may seek to achieve certainty rather than work with a person to manage uncertainty, which actively contributed to deskilling the person and increasing their dependency on services. In my personal reflections after my second interview with Susan I noted this phenomenon in my own discomfort with what I perceived to be high levels of risk in some of the decisions and activities Susan and Jim described.

Martin’s (2014) study noted associations between the outcome of a destabilising event and timely access to appropriate support – something that both participants also referred to within this study. Confidence that the ‘right’ support could be accessed promptly in the event of a crisis was shown to be an influencing factor in the day to day activities the participants chose to engage with, including retaining independence with daily occupations at home, and continuing to take opportunities for physical exercise by going out. This confidence was influenced by personal experience, and also social proof through observing and hearing the experience of others. The themes ‘scarcity’ and ‘figures of authority’ were key in the study data in relation to all aspects of change. Both participants expressed a sense of scarcity in accessing authority figures who could provide medical treatments, adaptive equipment and guidance for carers – a barrier which appeared to disempower and to limit participants autonomy. Authority figures also represented a reduction in choice and control at times of crisis. The study data showed that self-management, or management through informal social networks was preferred in the event of an unplanned or crisis event. Where authority figures such as healthcare professionals’ involvement could not be avoided, periods of reduced choice and control followed. Dolan and Holt’s (no date) assertion that the combination of the older age group and recurrent contact with services may indicate that a person could be reaching the ‘last 1000 days’ of life may also offer some insight as to why

the involvement of healthcare professionals might be resisted by the participants until absolutely necessary.

The data from this study also suggested that far from being passive recipients of support as frailty progresses, the participants actively applied strategies of psychosocial influence to elicit and guide support from others. Although 'liking' did not appear to significantly influence decisions around reaching out for help from others, it did appear to influence satisfaction with the outcome of the interaction. Conversely, 'being liked' appeared to be perceived as an influence in the support offered by others, and as such both participants indicated they had taken steps to ensure they were liked by those they anticipated providing future support. 'Reciprocity' also featured within the study data in relation to how participants navigated the need for support whilst retaining personal esteem and autonomy. Participants appeared to ask for support more readily where they perceived a means to reciprocate. The means through which they did so was varied and where possible proportionate to the level of support received. Unsolicited support was accepted sparingly, but with some suggestion that on this basis a means to reciprocate may be less needed. Asking for support with no means to reciprocate appeared to be the least preferred option.

As both participants had access to the financial resources to pay for additional support, whether as general household assistance or as a full package of care, recriprocity was potentially an easier strategy to draw upon in accepting help than it might be for individuals with lower financial resource. Spangler's (2025) study noted financial resource contributing to more positive frailty trajectories. Protection of personal esteem through monetary reciprocation may be one aspect of this relationship.

Proactive approaches

In a 2024 commentary on opportunities to identify and support people at an earlier stage of frailty and in doing so improve years spent living well, Hughes et al. suggest "current health care systems are not well prepared to deal with the chronic and complex medical needs of older patients living with frailty with a significant part of this being delivered in primary care" (p3), and suggest there is "a desperate need to move the focus towards truly proactive care and outcomes… at an earlier stage of [the] frailty trajectory and crucially defin[e] what proactive interventions might look like to try and mitigate the risk of increased variation in service provisions" (p3). The study data supported this observation that current healthcare systems may be focussed on reactive and later stage illness rather than proactive approaches. In both illustrative cases healthcare input was predominantly associated with acute and more advanced episodes of deteriorating physical health, and response to crisis events. In these scenerios support from the healthcare system was provided episodically and for relatively short periods,

whereas best practice guidelines propose frailty should be managed as a long term condition due to its conceptualisation as a trajectory of change over time. The exception to this pattern was the increase in contact that Margaret received from healthcare teams when she reached 'severe' levels of frailty, however without interviewing the professionals involved in Margaret's care it is not possible to know whether her end of life prognosis, severe frailty, management of her long term respiratory condition or perhaps a combination of these led to this increased response. Margaret's case highlights similarities conceptually between 'severe' to 'very severe' frailty, and other clinical classifications such as 'end of life'. Whereas both would require similar clinical knowledge and judgement to anticipate and plan for potential trajectories of decline, condition-specific end of life care might offer opportunities for individual management which frailty as a concept might not.

Health and social care professionals within these illustrative cases combined compensatory and rehabilitation approaches; a positive indication that the systems involved may be equipped to recognise opportunities to reverse frailty to some extent and act upon this. However, the focus of professionals in both cases appeared to be physical safety within basic ADLS at home, with minimal evidence of personalised goal setting. The data suggested that limited focus of the input received and apparent disparity between service and individual priorities was unsatisfactory for both particpants.

Autonomy and Control

In my earlier concept analysis, Maltby et al (2020) suggested the notion of 'enforced withdrawal' from social contacts and going out as a transfer of control away from the person. This was echoed in my study data through participants consistent use of phrases such as 'have to' or 'got no choice' which suggested an acceptance and inevitability of some changes. However, observations from the study data suggests that where such changes in activity were needed, a sense of agency and control may be maintained by reframing the purpose of the change. For instance, 'pulling back' from going out for the benefit of someone else's independence may be less impactful on autonomy and control than the 'enforced withdrawal' of pulling back due to loss of one's own ability. Symbolic interactionism proposes that individuals "act towards things on the basis of meanings they have for them" (Burns et al. 2022, p3), and that meaning is shaped through interactions with others and personal experience. For Susan, adjusting the meaning she attributes to the activity of going out - from pleasure or practical necessity for herself, to facilitating the continued independence of her husband - may make those adjustments to her own activity more acceptable whilst protecting her sense of esteem and autonomy. It has been suggested that personal narratives are significant in adaptation to frailty trajectories and coping with chronic illness (Lloyd et al. 2020), and that disclosing this narrative to others may even act as

a preventative strategy against frailty (Frietag & Schmidt, 2016). It is possible that with every retelling of this narrative about reducing activity as a preventative strategy for someone else rather than a reaction to her own changing needs Susan reaffirms her own sense of resilience. In this way, opportunities for people living with frailty to share their personal narratives with others may provide opportunities to reenforce personal esteem and autonomy.

Going out

Within the study data change in the ability to go out was an indicator of change and deterioration within other frailty domains. For Margaret, the COVID lockdown and subsequent changes in her health treatment led to losing her ability to walk and to drive independently. Having previously maintained a wide but perhaps not close social network locally, Margaret seems to respond to this change by developing similar 'light' social connections with her carers. Margaret changes her approach to practical tasks such as having a friend do her shopping, although continues to actively seek ways to have more choice and control over this task. The study data suggests that although alternative means to go out (powered wheelchair) may have been available, a return to going out via a different means was proposed by others rather than Margaret herself, perhaps indicating the activity no longer held the same value or purpose for Margaret.

Going out remains possible for Susan but becomes increasingly restricted across the study duration. As Susan's mobility decreases and her fear of falls increases, she restricts going out to higher priority activities which do not include going out for pleasure. High priority activities include medical appointments and her preference for autonomy in shopping tasks. For Susan, reliance on others to go out was associated with restriction in freedoms over activities whilst out.

The urban setting for Susan offered opportunities to access the immediate neighbourhood environment once travel into the wider neighbourhood became difficult, whereas for Margaret in the rural setting, connection to both the wider and local neighbourhood changed more abruptly when she could no longer drive independently to retain contact. For both participants, when going out into neighbourhood environments became difficult, access to the outdoors physically via their own garden, or even retaining a sense of connection the outdoors visually was presented as significant in maintaining emotional wellbeing. The idea of 'housebound' vs 'non-housebound' is often operationalised as a binary threshold representing service boundaries within the community, however the study data highlighted this as potentially problematic. Far from being binary, 'going out' presented in the study data across a gradient, within which personal choices and adjustments were made. As such a more integrated approach to housebound status amongst service providers might reduce the potential of people living with frailty falling into gaps between services.

Is there a relationship between the role of psychosocial factors during periods of instability and frailty levels calculated using self-reported support needs?

Social connection and frailty progression

Similar compromises were made by both participants in the way they maintained social connectedness during the study period as their physical ability to go out progressively deteriorates. Ageing social networks and the loss of peers was a common theme in the study data, resulting in a need for change and adaptation in order to maintain belonging and connectedness. Nicholson et al.'s (2017) assertion that the oldest old are 'the survivors - individuals with proven successful resilience', may resonate with Susan and Margaret's lived experience and their ability and willingness to adapt to new relationships in the face of these social losses was key to maintaining social connection. The study data also indicated that intergenerational relationships, whereby individual needs may not increase in parallel, may also contribute to a robustness of support from social sources.

Margaret describes what seems to be a discrepancy in perceptions between herself and the professionals she meets about whether she may be socially disconnected or even lonely and seems to suggest this is not how she views herself. Although this interaction does not appear to have elicited a strong emotional or negative response from Margaret, the implication that Margaret perhaps *should* be dissatisfied with her social connectedness even when it appears she herself has not suggested this, could be detrimental to the professional relationship or to her sense of esteem. Older people in Nicholson's (2013) study discussed strategies to anchor themselves into their daily lives, including maintenance of routine, continuing social relations, and the integration of "…previous, present and future realities" (p1178). Margaret's experience highlights the importance of understanding the context of 'previous realities' and asking 'what matters to you' in delivering person centred care. In addition, those aiming to support the person to retain social connection should give attention to the person's occupational history, what adjustments and compromises they have already made and what's been 'normal' for them over the wider course of their lives. Doing so may offer valuable insights for person centredness.

In Spangler et al.'s 2025 study of frailty trajectories and social determinants of health among older adults in North Carolina, marital status was not found to be significantly associated with any of the four frailty trajectories identified (improving, stable, mild worsening or drastically worsening), however the study found some evidence that married adults were more likely to experience 'stable' and 'improving' trajectories, whereas the 'improving' frailty trajectory had the lowest proportion of never married individuals represented. In my study data I noted that as a married couple Susan and Jim had developed a supportive bidirectional relationship. As such

some decisions and activities were influenced by combined rather than individual need. This presented not just in terms of decision making about day-to-day activity, but also in the shared impact of treatment burden and the influence of individual health symptoms on each other's day-to-day life. Jim's declining cognition meant Susan took on the cognitive load of prompting his medications and the snacks to manage his diabetes. At nighttime Jim's sleep apnoea not only disrupted his own sleep patterns but also Susan's, contributing to increased fatigue the following day. It is possible that sharing of vulnerability and resilience may have the overall effect of mitigating against individual extremes and producing a more averaged perception of frailty. The study data also suggested specific features of the supportive role of a spouse, perhaps unique to the nature of this type of very close personal relationship. Observed from a life course perspective, the spousal relationship offered examples of flexibility and adjusting of roles and responsibilities on an intuitive basis, such that it may be possible for subtle changes in individual resilience and vulnerability to be disguised perhaps even to the person themselves. It is possible that early deterioration and onset of frailty may be disguised and unrecognised where a very close support source such as a spouse is present, perhaps also giving the false impression of more rapid advancement of frailty later on.

In Spandler's (2025) study, the authors identified a "possible role for community/relational support in the mitigation of worsening trajectories" (p12), speculating that social connectedness including access to transport would be significant due to its role in accessing regular medical care. In my own study, this assertion appeared to be supported as the availability of transport combined with the motivation to return to a previous 'norm' in going out to medical appointments played a significant part in Susan's mitigation of worsening frailty trajectory. Perhaps beyond this however, the ability to travel independently and adjust timings freely in accordance with personal limits was presented as equally significant in maintaining esteem and empowerment.

Kojima et al. 2020 reported similar findings to Spangler, noting that living alone may "decrease positive health behaviours, such as exercise" (p7), however crucially this was found to be a more significant issue for those who were previously married and lost a spouse than those who had never married – "it might not be living alone that's psychologically problematic, but instead whether one chooses/is relieved to be" (Coundouris, 2025, p6). This further supports the importance of avoiding assumption about the perceived vulnerability of those living alone. It could in fact be argued that older people with frailty who live with a spouse with their own independent health concerns may face a more pronounced potential vulnerability should that primary support source be lost unexpectedly. Study data from Susan's account suggests this

vulnerability may be recognised by people living with this scenario and may present a combination of variables that could be considered in offering targeted proactive support.

The Clinical Frailty Score

In my analysis of each participants frailty scoring, I noted that although participant scoring broadly aligned with my own, it was their scoring of domains related to physical health and practical support which aligned with my overall CFS scoring. In both illustrative cases I noted a different level of frailty with a separate trajectory within psychosocial domains, which aligned less closely with the overall CFS I had selected. It is likely this discrepancy reflections the focus on physical health and function within the CFS descriptors, with psychological influences – motivation – referenced only once and in relation to CFS 1 'Very fit'. If scoring frailty in this way, psychosocial factors may be less visible in the static scoring of each stage of frailty but play as active, albeit less visible role in the process of change from one stage to the next.

Frailty across the fulcrum

Consistent with the notion of the frailty fulcrum, both participants described a depletion in reserve across holistic life domains which formed part of their overall frailty status. Although the detail and nuance of each participants experience was unique, in-depth analysis of their interview transcripts suggested perceptions of frailty and resilience differed from one domain to another [Appendixes 30 and 31]. Consistent for both participants was a perception that dependence and poorer outcomes related to multimorbidity, acute health and interactions with systems of care increased at an earlier stage than equivalent outcomes related to social environment, psychological status or the physical environment. It was not possible to comment on the rate of frailty change as data for frailty scoring was only collected during interview visits, at two or three time points per participant over the study period. It was my intention that participant diary data would suppliment this and offer more detail of events between interviews however diary uptake was low.

Although use of the participant diary was low overall both particpants provided a response to questions about self-management and perceived control, and both shared that they perceived low levels of control over the management of their physical health. Within each overall clinical frailty score, both participant accounts suggested that frailty and resilience did not present globally and consistently across all life domains. My analysis of the study data supports the findings of my concept analysis in indicating that older people living with frailty place significant emphasis on psychosocial factors when describing their frailty trajectories. However, indicators of psychosocial frailty showed resilience in these domains even after physical frailty indicators were present, suggesting psychosocial factors did not precede other contributors to frailty. Additionally, the data showed loss of autonomy and control as key indicators of changes in

perceptions of psychosocial frailty rather than changes in physical health itself. The recognition and acknowledgement of physcial restrictions in both illustrative cases may also align with suggestions in the existing literature that attributing frailty to a specific physical limitation may play some part in avoiding association with the overall state of frailty (Warmoth et al., 2016).

8.2 Reflections on the Study Design

As I reflect on this study and its strengths and limitations, I cannot overlook the absence of coproduction in the design and analysis phases due to limited resource, and consider what influence how this might have shaped the design. In the absence of this specific feature, I chose other aspects of my study design intentionally and thoughtfully to place emphasis on the perspective of the person living with frailty. My initial, perhaps somewhat naïve aim was to minimise assumptions on my part about what might constitute signficant or influencial psychosocial factors on frailty trajectory – an ambition that was reflected in my broad research questions. On reflection I have wondered whether the combination of broad research questions and a conceptually difficult subject area which I had minimised naming 'frailty' proved too much for some potential participants and contributed to low uptake at the recruitment stage. My challenges around use of language may have been more successfully navigated with greater involvement of Patient and Public Involvement and/or coproduction in the earlier stages of study design. I shared the study protocol and PIP within a PPI network for feedback and comment on the terminology and length, with no recommendations for change in terminology received, however feedback did highlight the length of the pariticpant information pack as potentially challenging for the proposed cohort. Although it is possible the length of this pack may have deterred potential participants, most potential participants declining to join the study dropped out at the intial contact stage, prior to receiving this pack. Time invested in exploring PPI involvement did not produce the participant engagement I had originally hoped for, however the process provided an opportunity to explore existing PPI groups locally.

As a result of my broad research questions, in the analysis phase I wrestled with deciding which key points should form the focus of my conclusions. However, the themes identified as a result of navigating this inductive approach may be considered a reliable reflection of the participants perspective, and may form the basis for future studies. Future studies would benefit from Patient and Public Involvement in developing the study design, particpularly to navigate the use of language and methodolgies which minimise cognitive or physical demand on the participant, thus aiming to increase participant engagement.

I used recruitment through gatekeeprs which posed multiple problems, namely in maintaining gatekeeper engagement across multiple sites alongside the demand of their clinical roles. Gatekeepers were from a range of professional backgrounds, and I noted variation in

engagement between different PIC sites and professional roles. Engagement with social care professionals as gatekeepers was particularly challenging, and I hypothesised this may have reflected the historic focus on physical rather than social factors within frailty. Despite taking steps to scope referral numbers meeting the study criteria prior to commencing this study, the actual number of potential participants was lower than anticipated.

Mindful that people contacting the Integrated Neighbourhood Teams (INTs) may not have a CFS already recorded and that eFI scores would not be available in INT records, I sought to identify frailty through other indicators including repeated episodes of change [figure 1]. I drew upon my own experience of information gathering in triage conversations to shape the study criteria, however if the episodic focus of service involvement observed in the data is replicated in current triage practice, the pattern of repeated need may be less readily identified. It may be too speculative to directly attribute recruitment challenges in this study to this observation of episodic care, however this reflection highlights a potential 'real-world' challenge in recognising frailty trajectories early.

By attempting to recruit participants via their initial contact with the INTs, I was trying to engage with a cohort of people who may have been in a potentially vulnerable and or distressed state. I factored this into my study design by including time for potential participants to reflect on the study before deciding whether to participate. To ensure people had a clear understanding of what was being asked, ethical approval rests on a long participant engagement with the study with opportunities to withdraw throughout the study period. It is possible participants may have been encouraged to remain in the study despite diminishing health and energy levels due to time already invested, however participation time including diary use was participant led.

Furthermore, even when people expressed an initial interest, in several cases I found a lack of follow up engagement. It is possible this was due to the association between the study and the period of illness or vulnerability leading to each person's contact with the INT. My focus on the period whilst participants might be awaiting support from community teams may have influenced accounts of the roles of people in authority, as both participants expressed dissatisfaction with the availability of input from health and social care professionals.

Given observations in the study data that people living with frailty may minimise focus on previous or future change by focussing on the present, it is also possible that the study may have been considered a threat to these protective strategies. Even amongst the two recruited participants, Margaret did not respond to several contacts for the third interview which again brings to the fore the complexity of research with extremely frail older people.

I used the Clinical Frailty Scale (CFS) to record participant frailty levels during the study period, using my own observervations and clinical experience, and participant reported accounts. The CFS is a judgement-based scoring system intended to reflect a person's overall presentation, and as such the scoring applied relies upon my own interpretation of the accounts provided. I used the frailty fulcrum alongside the CFS to support a more detailed analysis of the individual frailty domains over time and align my approach to tools recommended in nationally recognised guidance. The fulcrum provides recommended considerations for each domain, but no guidance or tool for scoring each domain separately, therefore my approach to analysing in this way was bespoke to this study. By providing objective examples of transcript data drawn upon for each score I strived to achieve rigor in my approach to data analysis, providing an auditable and systematic approach to analysis as described in Daniel's (2018) TACT model. Although this approach offers new insights into indicative frailty in each domain over time for these two participants, this approach to scoring has not been validated and as such holds some limitations in the conclusions drawn. Further studies of these initial observations might seek to include validated assessment tools within each domain and a larger cohort to explore these provisional findings further.

In discussions of the existing evidence base presented in chapters 2 and 3 I described the notion that psychological adaptation to change may be affected by the presence or absence of a 'catalyst' (Schwartz et al. 2020), but that catalysts to change may be major or more subtle life events. In response to this finding, I included a participant diary in my study design with the intention of recording subtle changes and continuities within participants' lived experience of frailty. Intending to use these records as discussion points within the interviews, to reduce the possibility of recall bias and to diffuse the directness of conversations about change and personal response, this approach proved ineffective as uptake of the participant diary was low. This reduced overall data exploring subtle catalysts to change. Neither participant cited a specific event or cause for change, yet both participants experienced an increase in CFS over the study duration, suggesting the study duration was appropriate to the research questions. Detail around the lived experience and subtlty of change for each participant was discussed retrospectively at each interview. By identifying potential participants in contact with the INTs within the last 12 months recruitment may have favoured people who were susceptible to further change rather than those whose frailty remained more stable. Recruitment of participants during stable periods of frailty trajectory therefore not in contact with the INT may have required a longer study duration to observe frailty change.

I identified a top threshold for recruitment based on limitations of resources available as a part time student researcher. The actual number of participants recruited was lower than the

maximum capacity I had identified. With individual participant tolerance of interview duration unknown, interviews completed were longer than I had anticipated and as a result the time needed to transcribe and analyse data was greater. Although the range of experiences represented in the study data was narrower than anticipated, this smaller sample size enabled an in-depth analsysis of individual relationships, events and experiences presented as illustrative cases, which offer an opportunity to take a holistic view well suited to conceptualisations of frailty presented in Chapter 2. Compiling detailed illustrative cases developed over 12 months enabled me to explore the development of a theory that psychosocial factors may influence the onset or progression of overall frailty. The study data suggested psychosocial frailty may develop after, but not necessarily in direct response to physical frailty.

The inclusion/exclusion process of study recruitment posed particular challenges for me personally, as I navigated the extent to which a disability or specific health condition should influence whether a person is considered 'frail'. Having made the decision to prohibit my own access to health records to ensure the account provided was participant led and to avoid any potential power imbalance, I was not aware of Margaret's lifelong disability until during the study period. This situation may have been avoided by building structure into my initial contact with each participant. By including a question about long standing health conditions or disability, combined with broader scoping questions about other life domains I might have avoided this scenario without steering future conversations artificially towards physical health. The British Geriatrics Society published a Frailty Briefing on their website in February 2025, providing an overview of what frailty is and some of the associated challenges. The briefing references "genuine clinical uncertainty as to whether [frailty] represents a terminal illness, or a disability" p1, suggesting the considerations I navigated in deciding whether to continue Margaret's interviews were not unique to myself as a new frailty researcher but a reflected a wider discussion.

The existing evidence base exploring psychosocial influences on frailty relied predominantly on cross-sectional study designs that offered little opportunity to explore the relationship between psychosocial factors and frailty over time. I included a participant diary as a way to explore subtle changes between interviews. This aspect of the study design was not successful, as uptake of diary completion was overall very low. There were multiple potential reasons for this noted in the study data. I adjusted my approach to data gathering to include some of the self-assessment questions from the diary verbally to gather additional data around perceptions of control and decision making. In light of the study data indicating significance in maintaining a 'resilient sense of self' despite phsyical deterioration, it is possible that use of the diary to encourage reflection on autonomy and control alongside objective notes on weekly activity may have posed

threatened this self-defence mechanism. These questions may be met with a more receptive response in future studies if combined with discussion around how the participant might improve these self-assessed scores.

8.3 Implications for practice and future research

The implications for practice need to be considered within the context of a distinct, small sample of two older ladies living in a coastal region. While the specificity of the sample may limit transferability to other cohorts, the depth and quality of data gained across several interviews provides rich contextual learning about the lived experience of managing increasing frailty predominantly without input from health and social care services in the case of Susan, and with health and social care provision seemingly imposed in the case of Margaret. In conceptualising frailty earlier in this thesis I referenced Aristotle, and the idea that frailty is 'more than the sum of its parts'. As illustrated in Margaret's experience of equipment provision, community healthcare teams were described as prioritising physical need over other contributing domains, even to the detriment of her autonomy and psychosocial resilience. This finding from my study data, viewed in the context of my concept analysis findings, suggests such focus on the physical health domain may risk damaging the presence of a 'resilient sense of self' – a key attribute in avoiding the tipping point 'giving up'. Resilent sense of self and maintaining esteem and confidence in one's own abilities may lead to needs being met outside statutory services.

This thesis illustrated that people living with frailty adjust their expectations of day-to-day activities as a strategy to maintain continuity in the face of change. This finding places greater importance on the need for health and care professionals to ask 'what matters to you', as in both illustrative cases participants indicated misconceptions about their needs. The study data also indicated people living with frailty make multiple adjustments and highly personal compromises to achieve what may appear to be continutiy or stability in their lives. When working with people at risk of frailty, practitioners should not only ask 'what matters to you' but pause to ask the additional question 'what adjustments are you comfortable making to achieve that?'. Through these two simple questions a practitioner might better seek to understand and support personal choice and control as frailty progresses.

Further work is needed to address silo'd working across health and social care to seamlessly support people living with frailty, including governance and organisational culture change which supports clinicians to prioritise the needs of the person rather than service or intra-professional boundaries. The study data showed organisational boundaries detrimentally impacted the experience of receiving Occupational Therapy support at home. Far from the core professional values of OT, firmly founded on the empowerment of the individual in the occupations they need or want to do, study data suggested operational and organisational processes were prioritised. If

resourced appropriately to deliver the full scope of the role, and with goverrnance that supports integrated practice, OTs would be well-placed to lead a new way of working.

The integration of community health and social care teams alongside ambitions to work more closely with voluntary and community groups within new Neighbourhood models presents opportunities to operationalise a more holistic approach. To truly deliver this, statutory providers will need to radically rethink their approach to risk. For both participants, decisions to seek support were influenced by a perception that their own stance on acceptable risk may not align with that of statutory services. The critical balance between seeking support from 'an authority' versus the loss of autonomy and control through the involvement of someone 'in authority' was central to their experiences of engaging with services. If Neighbourhood health and care models seek to promote earlier engagement and preventative approaches to reduce the impact of frailty, it is essential that models allow for engagement with 'an authority' that compliments and enriches individual decision-making. There is a need for further research exploring changes in perceptions of risk and resulting behaviours across the frailty trajectory for older people and for clinicians or service leads. Greater understanding of decisions to engage with services versus self-management decisions or use of informal support sources would inform emerging Neighbourhood models.

Practitioners reflecting on this study's findings should weigh the benefits of continuous versus episodic support when working with people living with frailty. Particularly pertinent around CFS 4 and 5, which are described in the newest version of the CFS as periods of change; 'early transition' and being 'progressively impaired' (Rockwood and Theou, 2020). The study data showed consistent access to support whilst living with mild frailty may lead to improved outcomes related to falls and associated psychological consequences. Similarly, limited availability of community resources and poorly aligned systems of integrated care was shown to contribute to poorer functional and psychological outcomes. Episodic and short-term input from healthcare teams also contributes to disempowerment for people living with frailty, as risk-adverse interventions requiring infrequent monitoring may be favoured. In guidance published by the Royal College of Occupational Therapists in 2018, 'Embracing risk; enabling choice', risk is acknowledged to be dynamic and fluctuating. It is proposed that safe risk-taking may be enabled through a process of regular review, which should take place after any incident or change to a care and support plan and be proportionate to the change that has occurred (p9). Practitioners and service providers should consider models of sustained contact over a longer period and approaches to support proportionate and collaborate thinking about risk. This may require a significant enhancement to the existing model of delivery for community frailty services,

particularly at earlier stages of frailty where changes in care and support plans may be subtle and may not involve formal services.

Finally, the study data illustrated that a single point of access to seek support, particularly to a locally based team, contributed to a sense of assurance of a prompt and forthcoming response. Having a local contact point, irrespective of actual usage, contributed to a sense of independence and confidence with self-management at home. This finding suggests community teams should simplify and well-publicise routes of contact into their services.

8.4 Personal reflections

As an Occupational Therapist, my professional career has been underpinned by a belief that biological, psychological and social aspects of a person's life are so intrinsically entwined that meaningful and fulfilling engagement with life cannot truly be achieved without taking a holistic approach. However, the reality of my professional experience over the past 15 years has been that despite this rhetoric, the medical model often prevails in the structure of systems of care. Observing the reality of community Occupational Therapy provision and how it may be received by older people was at times uncomfortable and initially disillusioning for me personally - seeing the holistic ethos of the profession reduced to short episodes of input and participant stated goals left unaddressed. Perhaps this is what first sparked my curiosity into the concept of frailty; a presentation that considers the interaction between holistic life domains in a way that resonates with models of Occupational Therapy, suggesting a potential opportunity for Occupational Therapists to resume the full scope of their professional roles.

In my doctoral study I have sought to explore and challenge my own understanding of the concept of frailty and how my experience of working within a system based on a medical model might contribute to this understanding. My ability to recognise and respond reflexively to this influence has been challenged over the past 6 years in parallel to this doctoral journey by changes in my professional role - away from a clinical role in community health and now in an integrated leadership and system transformation role. Through the experience of trying to recruit via health and social care as part of this study I have seen first-hand the different understandings of frailty across different professions, and perhaps the gaps in resonance with the idea of frailty as a state that might prompt tangible and meaningful action, not simply a score recorded in a patient record. I hope the insight gained through this study will go some way towards addressing these gaps.

8.5 Thesis Conclusion

In the context of this study I defined frailty as a state of depleted reserve across multiple holistic life domains, which reduces an individual's ablity to 'bounce back' after a stressor, resulting in

reduced independence and overall wellbeing over time. Drawing upon insights gained from my concept analysis and the perceptions of older people living with frailty in Chapter 2, I conceptualised psychosocial factors as potential opportunities to prevent, reduce or delay the trajectory of frailty. In Chapter 3 I provided a review of the current literature, and outlined a paucity of UK-based research into psychosocial factors as opportunities to manage frailty in the community, or into personal responses to change. I also found limited evidence within UK cohorts exploring the relationship between psychosocial factors and frailty indicators over time.

The aim of this thesis was to explore and identify psychosocial influences on change and stability for people living at home with frailty, and to consider implications for supporting personalised, preventative care closer to home. I developed a robust qualitative study which drew upon the principles of grounded theory. In depth longitudinal data collection over a 12 month period with two older ladies living in a coastal region provided detailed contextual data.

Using an illustrative case approach and drawing upon Cialdini's principles of psychosocial influence, socioemotional selectivity theory and selective engagement theory, I illuminated adjusting expectations, perceptions of acceptable risk, and retaining autonomy and control as themes in the study data. Key features of support which facilitate stability were identified – proximity, assurance of responsiveness and being *an* authority. This new understanding adds unique considerations for how health and social care practitioners might support people living with frailty. The notion of psychosocial factors as antecedents to frailty was not supported by the study data as indicators of psychosocial frailty showed resilience in these domains even after physical frailty indicators were present. The data showed loss of autonomy and control as key indicators of change in perceptions of psychosocial frailty rather than changes in physical health itself. The work is timely, proving new insights into the way in which service provision through neighbourhood teams might open up opportunities to support people's autonomy and access to relevant expertise outside statutory services and at an earlier stage of frailty.

In conclusion this study adds to our knowledge of frailty as a term and as a lived experience by illuminating the role of psychosocial factors in shaping support choices outside statutory services, and the key role of autonomy in people's self-management versus help seeking decisions.

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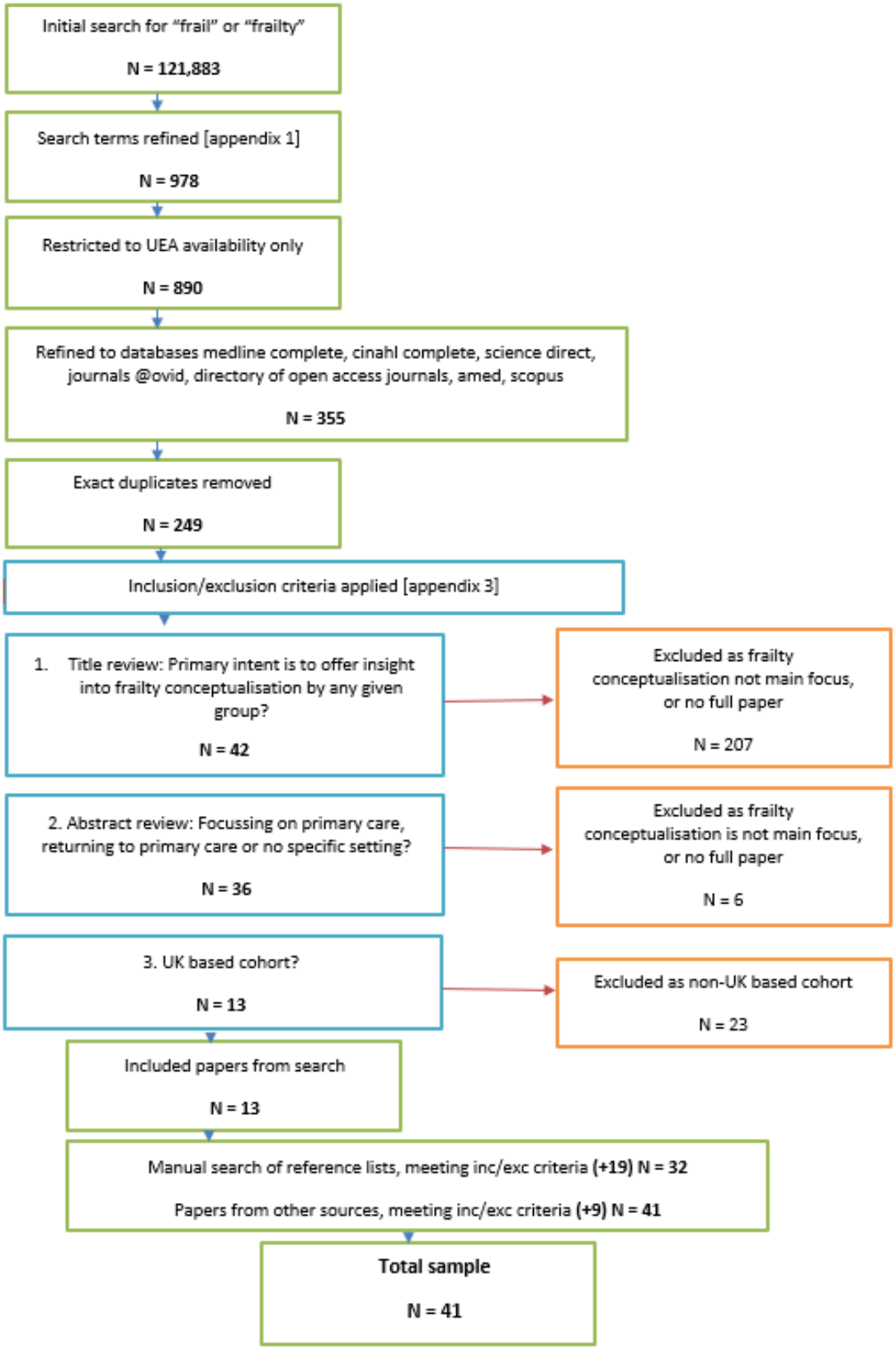
Appendices

Appendix 1: Concept Analysis - Search terms used to identify initial sample of papers for concept analysis

Database search strategy																	
Key word		Alternative terms		Alternative terms		Alternative terms		Alternative terms		Alternative terms				Alternative terms			
Frail	OR	Frailty															N = 121,883
AND																	
Concept	OR	Meaning	OR	Definition	OR	Interpretation	OR	Understanding	OR	Perception							N = 15,540
AND																	
Patient	OR	Public	OR	Client	OR	"Service User"	OR	"Lay-person"	OR	Clinician	OR	Older	OR	Professional	OR	Team	N = 12,165
AND																	
UK	OR	United Kingdom	OR	England	OR	Ireland	OR	Scotland	OR	Wales			OR	Britain	OR	NHS	N = 1,844
AND																	

Community	OR	"Primary care"	OR	Home													N = 978

Appendix 2: Concept Analysis - Process to identify final sample for concept analysis



1

Appendix 3: Concept Analysis - Application of inclusion/exclusion criteria applied to 249 papers plus papers from reference lists in concept analysis

	Authors	Year	Title	Journal	Primary intent is to offer insight into frailty conceptualisation by any given group?	Focussing on primary care, returning to primary care or no specific setting?	UK based cohort?	Paper included?
1	Aggar C et al	2014	Residential respite care is associated with family carers experiencing financial strain	Australasian Journal of Ageing	No Focus on financial barriers to accessing respite	-	-	No
2	Akehurst J et al	2017	Building workforce capacity and capability for integrated working	International Journal of Integrated Care	- Conference abstract only	-	-	No
3	Amblas-Novellas J et al	2016	Identifying patients with advanced chronic conditions for a progressive palliative care	BMJ Open	No Focus on end-of-life care	-	-	No

			approach: a cross-sectional study of prognostic indicators related to end-of-life trajectories					
4	Apostolo J et al	2016	Mild cognitive decline. A position statement of the Cognitive Decline Group of the European Innovation Partnership for Active and Healthy Ageing (EIPAHA)	Maturitas	No Focus is mild cognitive decline	Yes Literature review – no specific setting	Yes No specific setting	No
5	Arksey H and Moree M	2008	Supporting working carers: do policies in England and The Netherlands reflect 'doula rights'?	Health and Social Care in the Community	No Comparison of caregiver experience in two different cultures	-	-	No

6	Audisio RA	2016	Preoperative evaluation of older patients with cancer	Journal of Geriatric Oncology	No Frailty as a preoperative risk factor	-	-	No
7	Avgerinou C et al	2019	Health promotion for mild frailty based on behaviour change: Perceptions of older people and service providers	Health and Social Care in the Community	No Focus is behaviour change as an intervention	Yes Community based. Older people in community: mean age 80. N=16. Two community-based workers	Yes London and Hertfordshire, UK.	No
8	Baillie L et al	2014	Care transitions for frail, older people from acute hospital wards within an integrated Healthcare system in England: A qualitative study	Integrated Journal of Integrated Care	No Focus on care transitions between acute and community	-	-	No
9	Barber K and Wallace C	2012	'Happily independent' –	Journal of Integrated Care	No	Yes	Yes Gwent, UK	No

			configuring the Gwent frailty support and wellbeing worker		Proposes a need for a new social care role to support frailty as an intervention			
10	Barker K et al	2016	COmmunity-based Rehabilitation after Knee Arthroplasty (CORKA): study protocol for a randomised controlled trial	Trials	- Proposal for future study	-	-	No
11	Barrie K et al	2019	Co-creating well-being and community connections: understanding what matters to older housed residents	International Journal of Integrated Care	- Conference abstract only	-	-	No
12	Basic D et al	2002	Standardised assessment for older patients by a	Australian Health Review	No Focus on identifying high risk of admission in emergency	-	-	No

			nurse in an emergency department		departments. No frailty measure used			
13	Baylis D et al	2013	Immune-endocrine biomarkers as predictors of frailty and mortality: a 10-year longitudinal study in community-dwelling older people	Age	**No** Explores biological factors as predispositions to becoming frail – operationalisation of frailty	**Yes** Community	**Yes** Hertfordshire, UK	No
14	Bellinda L et al	2014	Factor structure for the frailty syndrome was consistent across Europe	Journal of Clinical Epidemiology	**Yes** Explores frailty measurement and levels across Europe	**Yes** No specific setting	**No** 12 European countries included but non-UK based	No
15	Best H	2010	Educational systems and the	Journal of Dental	**No** Focus on work roles	-	-	No

			continuum of care for the older adult	Edu123456catio n				
16	Bhan N et al	2017	Health needs, access to healthcare, and perceptions of ageing in an urbanizing community in India: a qualitative study	BMC Geriatrics	Yes	Yes	No Cohort in India	No
17	Bolzeta F et al	2018	Low-dose vitamin-D supplementation and incident frailty in older people: An eight year longitudinal study	Experimental Gerontology	No Focus on exploring vitamin D as a frailty prevention intervention	-	-	No
18	Bone A et al	2016	Developing a model of short-term integrated palliative and supportive care for frail older people in	Age and Ageing	No Focus on palliative care intervention for frail older people	-	-	No

			community settings - perspectives of older people, carers and other key stakeholders					
19	Bone AE et al	2016	Factors associated with transition from community settings to hospital as place of death for adults aged 75 or older: A population-based mortality follow-back survey	Journal of the American Geriatrics Society	No Explored strategy to reduce number of end-of-life transitions to hospital	-	-	No
20	*Bortz W	2010	Understanding frailty	Journal of Gerontology				
21	Boscart V et al	2018	Impact of the applied simulated and integrated learning approach on nursing	Pilot and Feasibility Studies	Yes Focus on nursing assistants' knowledge and perception of frailty	Yes Community	No Canadian study	No

			assistants' knowledge and confidence caring for frail seniors in nursing homes					
22	Boullion K et al	2011	Validation of the phenotype of frailty measurement in the Whitehall II Study	Journal of Epidemiology and Community Health	No Focus on predictive validity of a specific measurement tool	-	-	No
23	Bowling A	2008	Enhancing later life: How older people perceive active ageing?	Aging and Mental Health	No Focus on perceptions of active ageing	-	-	No
24	Brazil K et al	2020	Anticipatory care planning intervention for older adults at risk of functional decline: study protocol for a primary care	Trials	No Proposal for future study	-	-	No

			cluster feasibility randomised trial					
25	*Britain Thinks	2015	Frailty: Language and Perceptions. A report prepared by BritainThinks on behalf of Age UK and the British Geriatric Society	https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/rb_june15_frailty_language_and_perceptions.pdf				
26	Britton H	2017	What are community nurses experiences of assessing frailty and assisting in planning	British Journal of Community Nursing	Yes Nurses	Yes 6 community nurses	Yes UK	Yes

			subsequent interventions?					
27	Brown S et al	2004	Care in the Community	BT Technology Journal	**No** Focus on use of technology to support wellbeing			No
28	Burton E et al	2019	Physical activity programmes for older people in the community receiving home care services: systematic review and meta-analysis	Clinical interventions in aging	**No** Focusses on effectiveness of physical activity interventions	-	-	No
29	Bruun SB et al	2019	Selective serotonin reuptake inhibitor use in hip fracture patients: a Danish nationwide prevalence study	Acta Orthopaedica	**No** Focus on adverse drug effects in hip fracture cohort	-	-	No
30	Byles J et al	2014	Supporting housing and neighbourhoods for	Australasian Journal on Ageing	**No**	-	-	No

			healthy ageing: Findings from the Housing and Independent Living study (HAIL)		Focus on supportive extent of housing and neighbourhoods			
31	*Campbell J and Buchner DM	1997	Unstable disability and the fluctuations of frailty	Age and Ageing				
32	Canning SH et al	2005	Healthcare worker beliefs about influenza vaccine and reasons for non-vaccination – a cross-sectional survey	Journal of Clinical Nursing	No Focus on engagement with vaccine interventions	-	-	No
33	Cantley M et al	2016	Hospital at Home as enhancement to an existing rapid response team in a semirural setting in Scotland	International Journal of Integrated Care	- Conference abstract only	-	-	No

34	Castaneda-Gameros D et al	2017	Low nutrient intake and frailty among overweight and obese migrant women from ethnically diverse backgrounds ages 60 years and older: a mixed methods study	Journal of Nutrition Education and Behaviour	**No** Focus on dietary intake as a predictor of frailty	-	-	No
35	Castro-Rodriguez M et al	2016	Frailty as a major factor in the increased risk of death and disability in older people with diabetes	Journal of the American Medical Directors Association	**Yes** Clinicians	**Yes** No specific setting	**No** Spanish cohort	No
36	Challis D and Hughes J	2002	Frail old people at the margins of care: some recent research findings	The British Journal of Psychiatry	**No**	**Yes** Community and transitional settings	**Yes**	No
37	***Chao Y-S et al**	2019	**A proposal for a self-rated frailty**	BMC Research Notes				

			index for patient-orientated research					
38	Chatfield MD et al	2005	A systematic literature review of attrition between waves in longitudinal studies in the elderly shows a consistent pattern of dropout between differing studies	Journal of Clinical Epidemiology	No Focus on dropout in longitudinal studies	-	-	No
39	Cheraghi-Sohi S et al	2020	Patient safety in marginalised groups: a narrative scoping review	International Journal for Equity in Health	No Focus on patient safety in marginalised groups	-	-	No
40	Chesterman J et al	2001	Satisfaction with the care-managed support of older people: an empirical analysis	Health and Social Care in the Community	No Focus on satisfaction with care	-	-	No

41	Coker JF et al	2019	Frailty: an in-depth qualitative study exploring the views of community care staff	BMC geriatrics	Yes Community care staff	Yes Community setting	Yes 22 staff members from various professions. 4 neighbourhood teams across Cambridgeshire, England	Yes
42	Coles L et al	2009	Including fathers in preventing non-accidental head injury	Community Practitioner	No Focus on non-accidental head injury in babies	-	-	No
43	Colin-Thome D	2013	Development opportunities in the "new" NHS for personal, population and	Clinical Governance: An International Journal	No Focus on clinical governance and commissioning	-	-	No

			system care: The coming of age for clinical governance?					
44	Compton L et al	2017	North West Surrey's locality hubs – delivering integrated care	International Journal of Integrated Care	- Conference abstract only	-	-	No
45	Conroy S et al	2013	Understanding readmissions: An in-depth review of 50 patients readmitted back to an acute hospital within 30 days	European Geriatric Medicine	No Focus on causes and prevention of readmission	-	-	No
46	Conroy SP et al	2019	Comprehensive geriatric assessment for frail older people in acute hospitals - the HoW-CGA	Health Services and Delivery Research	Yes Acute clinicians' assessment of frailty	No	-	No

			mixed-methods study					
47	Conroy S and Elliot A	2016	The frailty syndrome	Medicine	No Focus on operationalisation and identification of frailty	Yes No specific setting	Yes No specific cohort	No
48	Cook G	2006	The risk to enduring relationships following the move to a care home	International Journal of Older People Nursing	No Explores meaning ascribed by older people to living in a care home	-	-	No
49	Cook GA	2008	Older people actively reconstruct their life in a care home	International Journal of Older People Nursing	No Focus on understanding care home life	-	-	No
50	Cornally L et al	2019	332 GEMS: Geriatric Emergency Service – Outputs and outcomes from the acute floor team	Age and Ageing	Yes Focus on identification and management	No Acute setting	-	No
51	Cos X et al	2020	Impact on guidelines: the	Diabetes Research and Clinical Practice	No Focus on Type 2 Diabetes management	-	-	No

			general practitioner point of view					
52	Cox NJ et al	2020	New horizons in appetite and the anorexia of ageing	Age and Ageing	No Focus on loss of appetite in ageing	-	-	No
53	Craig C	2016	Photography as method in care home research	British Journal of Occupational Therapy	No Explores potential of photography as a research tool	-	-	No
54	Crocker TF et al	2019	Quality of life is substantially worse for community-dwelling older people living with frailty: systematic review and meta-analysis	Quality of Life Research	Yes Explores patient subjective well-being measures in relation to frailty status	Yes Community	No Only 2 out of 12 included studies UK based	No
55	Dale J et al	2018	Coproduction of a theory-based digital resource for unpaid carers (The Care	JMIR Aging	No Focus on web-based resilience tools	-	-	No

			Companion) Mixed-Methods study					
56	*D'Avanzo B et al	2017	Stakeholders' views and experiences of care and interventions for addressing frailty and pre-frailty: A meta-synthesis of qualitative evidence	D'Avanzo B et al				Yes
57	Davies S and Nolan M	2006	'Making it better': self-perceived roles of family caregivers of older people living in care homes: a qualitative study	International Journal of Nursing Studies	No Focus on nature of family caregiver role	-	-	No
58	Davis SF et al	2019	Hearing the voices of older adult patients: processes and findings to	Research Involvement and Engagement	No Focus on research priorities and PPIE of older patients	-	-	No

			inform health services research					
59	Dew R and Wilkes S	2018	Attitudes, perceptions and behaviours associated with hospital admission avoidance	The British Journal of General Practitioners	No Focus on admission avoidance	-	-	No
60	Dickinson A et al	2014	Food safety and older people: the Kitchen Life Study	British Journal of Community Nursing	No Focus on food safety in the home	-	-	No
61	Doody P et al	2019	Frailty Levels in Geriatric Hospitals paTients (FLIGHT) – the prevalence of frailty among geriatric populations within hospital ward settings: a systematic review protocol	BMJ Open	Yes Proposal for a systematic review of frailty identification	No Acute setting	-	No

62	Dosa D et al	2009	Frequency of long-acting opioid analgesic initiation in opioid-naïve nursing home residents	Journal of Pain and Symptom Management	No Focus on medications	-	-	No
63	Droz JP et al	2017	Management of prostate cancer in elderly patients: Recommendations of a task force of the International Society of Geriatric Ontology	European Urology	No Frailty as a factor in treatment of prostate cancer	-	-	No
64	Drysdale C	2017	Integrated Care in Practice	International Journals of Integrated Care	- Conference abstract only	-	-	No
65	Dwyer R et al	2015	Unplanned transfer to emergency departments for frail elderly residents of aged	Journal of the American Medical Directors Association	No Focus on reducing transfers/admissions to A&E	-	-	No

			care facilities: A review of patient and organizational factors					
66	Eden J and Eden N	2010	Views of older native American adults in colonial new England	Journal of Cross-Cultural Gerontology	Yes Explores perceptions of cohort as frail	Yes Community	No American study	No
67	Eldh AC et al	2016	'I have the world's best job' – staff experiences of the advantages of caring for older people	Scandinavian Journal of Caring Sciences	No Focus on experiences of caring for older people	-	-	No
68	Erusalimsky J et al	2016	In search of 'Omics' –based biomarkers to predict risk of frailty and its consequences in older individuals: the FRAILOMIC Initiative	Gerontology	No Operationalising frailty	Yes Community and clinic	Yes No specific cohort. EU population data	No

69	Evans L	2017	The 'frailty' concept – implications for occupational therapy practice	British Journal of Occupational Therapy	- Conference abstract only	-	-	No
70	Fabian PH	2016	Association rules analysis of comorbidity and multimorbidity: The Concord Health and Ageing in Men Project	Journals of Gerontology Series A: Biomedical Sciences and Medical Sciences	Yes Association between multimorbidity and frailty	Yes Community	No Sydney, Australia	No
71	Fairhall Net al	2014	Effect of a multifactorial, interdisciplinary intervention on risk factors for falls and fall rate in frail older people: a randomised controlled trial	Age and Ageing	Yes Proposing a frailty measure	Yes Community	No Australian cohort	No
72	Finucane A et al	2017	Gradual physical decline	International Journal of	Yes	Yes Community	Yes Scotland	No

			characterises the illness trajectories of care home residents	Palliative Nursing	Trajectories of frailty progression – identifying presentation to operationalise			
73	Fletcher A et al	2010	A reliable measure of frailty for a community dwelling older population	Health and Quality of Life Outcomes	**No** Operationalisation of frailty	**Yes** Community	**Yes** UK	No
74	Freer K and Wallington SL	2019	Social frailty: the importance of social and environmental factors in predicting frailty in older adults	British Journal of Community Nursing	**Yes**	**Yes** Community	**No** Canadian cohort	No
75	***Fried LP**	2004	**Untangling the concepts of disability, frailty and comorbidity: Implications for**	Journal of Gerontology				**Yes**

			improved targeting and care					
76	Froggatt K and Payne S	2006	A survey of end-of-life care in care homes: issues of definition and practice	Health and Social Care in the Community	No Focus on understanding of end-of-life care	-	-	No
77	Frost R et al	2017	Identifying acceptable components for home-based health promotion services for older people with mild frailty: A qualitative study	Health and Social Care in the Community	Yes Patient	Yes Community	Yes 53 stakeholders, including 14 mildly frail older people, 12 family carers, 19 community health and social care professionals, and 8 homecare	No Later version included

								workers, in one urban and one semi-rural area of England	
78	Frost R et al	2018	Identifying acceptable components for home-based health promotion services for older people with mild frailty: A qualitative study	Health and Social Care in the Community	Yes Patient	Yes Community	Yes	53 stakeholders, including 14 mildly frail older people, 12 family carers, 19 community health and social care professionals, and 8 homecare workers, in	Yes

							one urban and one semi-rural area of England	
79	Gafoor R et al	2019	Importance of Frailty for association of antipsychotic drug use with risk of fracture: cohort study using electronic health records	Journal of the American Medical Directors Association	No Focus on intervention effectiveness and risk	-	-	No
80	Gale C	2011	A life course approach to psychological and social well-being	Journal of Epidemiology and Community Health	- Conference abstract only	-	-	No
81	Garner A and Holland C	2020	Age-friendliness of living environments from the older persons viewpoint:	Age and Ageing	No Focus on interventions for frailty	Yes Community	Yes Midlands, UK	No

			Development of the Age-Friendly Environmental Assessment Tool					
82	***Gilleard C and Higgs P**	2010	**Frailty, disability and old age: A re-appraisal**	Health				**Yes**
83	Gjestsen MT et al	2018	Characteristics and predictors for hospitalizations of home-dwelling older persons receiving community care: a cohort study from Norway	BMC Geriatrics	**No** Explores risk of acute admission	-	-	No
84	***Gobbens R**	2010	**Toward a conceptual definition of frail community dwelling older people**	Nursing Outlook				**Yes**

85	Gordon A et al	2014	Now that we have a definition for physical frailty, what shape should frailty medicine take?	Age and Ageing	No Operationalising the concept of frailty	Yes No specific setting	Yes No specific population	No
86	Gordon A et al	2014	The Optimal Study: Describing the key components of optimal healthcare delivery to UK care home residents: A research protocol	Journal of the American Medical Directors Association	No Focus on healthcare delivery in care homes	-	-	No
87	Gowing A et al	2019	Patients' experiences of a multidisciplinary team-led community case management programme: a qualitative study	BMJ Open	No Focus on patient perceptions of community healthcare provision	-	-	No

88	Greaves M and Rogers-Clark C	2009	The experience of socially isolated older people in accessing and navigating the healthcare system	Australian Journal of Advanced Nursing	No Focus on access to healthcare	-	-	No
89	Green J et al	2018	Ambulance clinicians' perceptions, assessment and management of frailty: thematic analysis of focus groups	British Paramedic Journal	Yes Ambulance clinicians	Yes	Yes South Western Ambulance Service	Yes
90	Greenhalgh T et al	2015	What is quality in assisted living technology? The ARCHIE framework for effective telehealth and telecare services	BMC Medicine	No Focus on quality in telehealth and telecare	-	-	No

91	Greensitt B	2020	Specialist Physiotherapist leading in the frailty revolution in ambulatory emergency care at the John Radcliffe Hospital, Oxford	Age and Ageing	- Conference abstract only	-	-	No
92	Gregory S	2018	Diabetes care in care home and residential settings	British Journal of Community Nursing	No Focus on diabetes management	-	-	No
93	*Grenier A	2006	The distinction between being and feeling frail: Exploring emotional experiences in health and social care	Journal of Social Work Practice				Yes
94	*Grenier AM	2019	The conspicuous absence of the social, emotional	Ageing and Society				Yes

			and political aspects of frailty: the example of the White Book on Frailty					
95	Grol S et al	2018	The role of the general practitioner in multidisciplinary teams: a qualitative study in elderly care	International Journal of Integrated Care	- Poster abstract only	-	-	No
96	Gulliford M and Ravindrarajah	2018	Frailty: from clinical syndrome to epidemiological construct?	The Lancet Public Health	No Operationalisation of frailty	Yes No specific setting	Yes No specific population	No
97	*Gwyther H et al	2018	Understanding frailty: a qualitative study of European healthcare policy-makers' approaches to	BMJ Open				Yes

			frailty screening and management					
98	Hale M et al	2019	Frailty, inequality and resilience	Clinical Medicine	No Focus on interventions for frailty	Yes Community	Yes No specific population	No
99	Hall S et al	2009	Living and dying with dignity: a qualitative study of older people in nursing homes	Age and Ageing	No Focus on dignity in end of life	-	-	No
100	Hamano J et al	2019	Prevalence and characteristics of patients being at risk of deteriorating and dying in primary care	Journal of Pain and Symptom Management	No Frailty group combined with dementia group ("frailty/dementia")	-	-	No
101	Hanlon P et al	2018	Frailty and pre-frailty in middle-aged and older adults and its association with multimorbidity and	The Lancet Public Health	No Operationalisation based on age ranges associated with frailty	Yes No specific setting	Yes Data used from UK Biobank	No

			mortality: a prospective analysis of 493737 UK Biobank participants					
102	Harrison J et al	2015	Managing frailty as a long-term condition	Age and Ageing	**No** Focus on management of frailty as a long-term condition	**Yes** Community and integrated community/acute working	**Yes**	No
103	**Heath H and Phair L**	2009	**The concept of frailty and its significance in the consequences of care or neglect for older people: an analysis**	International Journal of Older People Nursing	**Yes** Aims to conceptualise frailty and its implications for care or neglect	**Yes** No specific setting – literature review and concept analysis	**Yes** No specific setting	**Yes**
104	Heather G	2012	Integrated working between residential care homes and primary care: a	BMC Geriatrics	**No** Focus on relationship between services. Explores poor “fit” between patient needs and services available	**Yes** Community	**Yes** England	No

			survey of care homes in England					
105	Heaven A et al	2014	Pilot trial of Stop Delirium!: (PiTStop) - a complex intervention to prevent delirium in care homes for older people: study protocol for a cluster randomised controlled trial	Trials	No Focus on prevention of delirium	-	-	No
106	Hebert R et al	2008	Evaluation of the implementation of PRISMA, a coordination-type integrated service delivery system for frail older people in Quebec	Journal of Integrated Care	No Focus on service structures and working styles	-	-	No
107	Heid AR et al	2016	"It Depends": Reasons why	The Gerontologist	No	-	-	No

			nursing home patients change their minds about care preferences		Focus on wellbeing in pre-defined frail cohort			
108	Held FP et al	2016	Association rules analysis of comorbidity: The Concord Health and Aging in Men Project	Journals of Gerontology: Medical Sciences	No Exploration of comorbidity and multimorbidity	-	-	No
109	Heyhoe R et al	2019	Cross-sectional associations of dietary and circulating magnesium with skeletal muscle mass in the EPIC-Norfolk cohort	Clinical Nutrition	No Focus on relationship between magnesium and muscle mass	-	-	No
110	Hillcoat-Nalletamby S	2014	The meaning of “independence” for older people in	Journals of Gerontology Series B: Psychological	No Focus on independence – link to frailty implied by research design not participant	-	-	No

			different residential settings	Sciences and Social Sciences				
111	Hilmer SN et al	2012	Thinking through the medication list – appropriate prescribing and deprescribing in robust and frail older adults	Australian Family Physician	No Focus on prescribing	-	-	No
112	Hockley J	2014	Learning, support and communication for staff in care homes: outcomes of reflective debriefing groups in two care homes to enhance end-of-life care	International Journal of Older People Nursing	No Focus on end-of-life care	Yes Community care homes	Yes UK	No
113	Holmes E et al	2018	Patients' preferences and existential perspectives: what	Aging Clinical and Experimental Research	No Focus on ethics and capacity considerations for patient decisions around surgery	-	-	No

			to consider and how should patients' expectations be guided?					
114	Horsfall D et al	2016	Love stories: understanding the caring journeys of aged Greek-Australian carers	Health and Social Care in the Community	No Focus on creating culturally appropriate support services	-	-	No
115	Hubbard G et al	2003	Including older people with dementia in research: challenges and strategies	Aging and Mental Health	No Focus on methods through which to capture patient perspective	-	-	No
116	Hubbard R et al	2010	Frailty, body mass index and abdominal obesity in older people	Journals of Gerontology Series A: Biomedical Sciences and	No Explores relationship between frailty and BMI	Yes Community	Yes England	No

				Medical Sciences				
117	Jansen J et al	2017	General Practitioners' decision making about primary prevention of cardiovascular disease in older people: A qualitative study	PLoS ONE	No Focus on CVD management	-	-	No
118	Jeon Y-H et al	2006	'Give me a break' – respite care for older carers of mentally ill persons	Scandinavian Journal of Caring Sciences	No Focus on respite care in mental illness	-	-	No
119	Jonkman NH et al	2016	What are effective program characteristics of self-management interventions in patients with heart failure? An	Journal of Cardiac Failure	No Focus on self-management in heart failure	-	-	No

			individual patient data meta-analysis					
120	Jovicic A et al	2015	Identifying the content of home-based health behaviour change interventions for frail older people: a systematic review protocol	Systematic Reviews	**No** Focus on health-related behaviour change within predefined frail cohort	-	**-**	No
121	***Junius-Walker U et al**	2018	**The essence of frailty: A systematic review and qualitative synthesis on frailty concepts and definitions**	European Journal of Internal Medicine				**Yes**
122	Kamaruzzaman et al	2010	A reliable measure of frailty for a community dwelling population	Health and Quality of Life Outcomes	**No** Evaluation of a specific frailty measurement tool	-	**-**	No

123	Keevil VL and Romero-Ortuno R	2015	Ageing well: a review of sarcopenia and frailty	The Proceedings of the Nutrition Society	No	Yes No specific setting	Yes No specific region	No
124	Kendall M et al	2015	Different experiences and goals in different advanced diseases: comparing serial interviews with patients with cancer, organ failure or frailty and their family and professional carers	Journal of Pain and Symptom Management	Yes	Yes No specific setting	No Includes participants from South Asia	No
125	Kenigsberg PA et al	2015	Dementia beyond 2025: Knowledge and uncertainties	Dementia	No Dementia presented as distinct from frailty	-	-	No
126	Kidd T et al	2019	What are the most effective interventions to improve physical	BMC Geriatrics	No	Yes Literature review of papers including primary	- Not specifically stated	No

			performance in pre-frail and frail adults? A systematic review of randomised controlled trials			and secondary care settings		
127	Kim D et al	2019	Route to heart failure diagnosis in English Primary Care: a retrospective cohort study of variation	British Journal of General Practice	No Focus on routes to heart failure diagnosis	-	-	No
128	Knight P	2016	The Indicator of Relative Need (IoRN) – information for integrated working	International Journal of Integrated Care	- Conference abstract only	-	-	No
129	Knight T et al	2020	Advance care planning in patients referred to hospital for acute medical	EClinicalMedicine	No Focus is on advanced care planning as a related topic. Patients	Yes Home and placement	Yes 123 acute hospitals	No

			care: results of a national day of care survey		Uptake of ACPs in home v placement settings		across the UK	
130	Kojima G	2015	Prevalence of Frailty in Nursing Homes: A systematic review and meta-analysis	Journal of the American Medical Directors Association	**Yes** Identifying frailty and pre-frailty	**Yes** Care Homes	**No** 9 studies included, non-UK based	No
131	Kojima G et al	2017	Prevalence of Frailty in Japan: A systematic review and meta-analysis	Journal of Epidemiology	**Yes**	**Yes**	**No** Japanese study	No
132	Kojima G et al	2019	Frailty syndrome: implications and challenges for health care policy	Risk Management and Healthcare Policy	**No**	**Yes** No specific setting	**Yes** Includes analysis of various European policies separately	No
133	Konn SSC et al	2013	The 4-metre gait speed in COPD: responsiveness and	The European Respiratory Journal	**No** Focus on effect of pulmonary rehab on gait speed in COPD	-	-	No

			minimal clinically important difference					
134	Koskela S et al	2017	Active Residents in Care Homes (ARCH): study protocol to investigate the implementation and outcomes of a whole-systems activity programme in residential care homes for older people	Physiotherapy	No Whole systems intervention with interviews to document experience of intervention. Patients (care home residents) Therapists Family members Care home staff	Yes Community based care homes	Yes	No
135	Kuh D et al	2005	Grip strength, postural control, and functional leg power in a representative cohort of British men and women:	The Journals of Gerontology, Series A, Biological Sciences and Medical Sciences	No Focus on physical measurements associated with functional limitation and socioeconomics	-	-	No

			associations with physical activity, health status and socioeconomic conditions					
136	Kumpers S et al	2005	A comparative study of dementia care in England and the Netherlands using neo-institutionalist perspectives	Qualitative Health Research	No Focus on dementia care	-	-	No
137	Kydd A et al	2016	What doctors needs to know: Prescribing or not for the oldest old?	Maturitas	No Focus on prescribing	-	-	No
138	Lai J et al	2019	Frailty in liver transplantation: An expert opinion statement from the American Society of Transplantation	American Journal of Transplantation	Yes Operationalisation of frailty	No Acute focus	-	No

			Liver and Intestinal Community of Practice					
139	Layzell B et al	2009	The elderly demographic time bomb – sharing the load with the active ageing: Can eHealth technologies help diffuse it?	Studies in Health Technologies and Informatics	No Focus on use of technology in self-management	-	-	No
140	Le Reste JY et al	2013	The European General Practice Research Network Presents a Comprehensive Definition of multimorbidity in family medicine and long-term care, following systematic review of the literature	Journal of the American Medical Directors Association	No Focusses on definition and management of multimorbidity – proposes multimorbidity as a precursor to frailty	-	-	No

141	Levack W et al	2018	Development of an English-language version of a Japanese iPad application to facilitate collaborative goals setting in rehabilitation: a Delphi study and field test	BMJ Open	No Focus on collaborative goal setting tools	-	-	No
142	Lie MLS et al	2015	Technology and trust: older people's perspectives of a home monitoring system	Ageing and Society	No Focus on use of technology	-	-	No
143	Lien C et al	2002	Heart failure in frail elderly patients: diagnostic difficulties, co-morbidities,	European Journal of Heart Failure	No Focus on heart failure management	-	-	No

			polypharmacy and treatment dilemmas					
144	Liljas A et al	2016	Vision impairment and risk of frailty: the English Longitudinal Study of Ageing	The Lancet	**No** Explores link between vision and frailty	**Yes** No specific setting	**Yes**	No
145	Lipman V and Manthorpe G	2015	Social Housing provision for minority ethnic older people with dementia: Findings from a qualitative study	Dementia	**No** Audit of practice and policy in Housing Associations	-	**-**	No
146	Lirio-Romero C et al	2015	Mobilisation with movement for shoulder dysfunction in older adults: a pilot trial	Journal of Chiropractic Medicine	**No** Focus on shoulder dysfunction	-	**-**	No
147	Llibre-Rodriguez JJ et al	2018	The prevalence and correlates of frailty	Journal of the American	**Yes**	**Yes**	**No**	No

			in urban and rural populations in Latin America, China and India: A 10/66 population-based survey	Medical Directors Association			Latin America, China and India	
148	Loranzo-Montoya I et al	2017	Nonpharmacological interventions to treat physical frailty and sarcopenia in older patients: a systematic overview – the SENATOR Project ONTOP Series	Clinical Interventions in Aging	No Critical appraisal of treatments for frailty and sarcopenia	-	-	No
149	McCann P et al	2017	Integrated care in practice: A novel approach	International Journal of Integrated Care	- Conference abstract only	-	-	No
150	McInnes E and Askie L	2004	Evidence review on older people's views and experiences of falls	Worldviews on Evidence-Based Nursing	No Focus on falls prevention interventions	-	-	No

			prevention strategies					
151	MacInnes J et al	2019	Think local, act personal: Lessons from an integrated primary care initiative for frail, older people	International Journal of Integrated Care	- Poster abstract only	- Poster abstract only	- Poster abstract only	No
152	Mackenzie L et al	2015	Narratives of home and place: findings from the Housing and Independent Living Study	Ageing and Society	No Explores patient perspectives on supportive homes and communities	-	-	No
153	Macleod A and Counsell C	2016	Predictors of mortality in Parkinson's disease and the development of a prognostic model	The Lancet	No Focus on mortality in Parkinson's	-	-	No
154	Magnusson L and Hanson J	2003	Ethical issues arising from a research,	Health and Social Care in the Community	No	-	-	No

			technology and development project to support frail older people and their family carers at home		Focus on ethical issues associated with trialling new technologies			
155	Malva JO et al	2018	The quadruple helix-based innovation model of reference sites for active and healthy ageing in Europe: The Ageing@Coimbra Case Study	Frontiers in Medicine	Yes Operationalisation of frailty	Yes No specific setting	No Portuguese cohort	No
156	Mann R et al	2006	Exploring the relationship between fear of falling and neuroticism: a cross-sectional study in	Age and Ageing	No Focus on psychological aspects of Falls management	-	-	No

			community-dwelling women over 70					
157	*Manthorpe J and Iliffe S	2015	Frailty – from bedside to buzzword?	Journal of Integrated Care				Yes
158	*Manthorpe J et al	2018	Frailty and social care: Over- or under- familiar terms	Social Policy and Society				Yes
159	*Markle-Reid M and Browne G	2003	Conceptualizations of frailty in relation to older adults	Journal of Advanced Nursing				Yes
160	Masterson A et al	2014	Inspiring senior nurses to lead the delivery of compassionate care	Nursing Older People	No Focus on nurses values in compassionate practice	-	-	No
161	Matthews F et al	2013	A two-decade comparison of prevalence of dementia in individuals aged 65	The Lancet	No Explores prevalence and trends in dementia diagnosis	-	-	No

			years and older from three geographical areas of England: results of the Cognitive Function and Ageing study I and II					
162	Meeks S et al	2016	Psychological and social resources relate to biomarkers of allostasis in newly admitted nursing home residents	Aging and Mental Health	No Focus on allostasis and resilience resources	-	-	No
163	Miller EA et al	2017	Staff perceptions of key factors guiding nursing home search and selection within the veterans health administration	The Gerontologist	No Focus on factors influencing nursing home choices	-	-	No

164	Moore G et al	2018	Health and social factors associated with delayed discharge amongst patients in acute geriatric wards: A retrospective observational study	Geriatrics and Gerontology International	Yes Operationalisation of frailty	No Acute setting	-	No
165	*Mudge AM and Hubbard RE	2018	Frailty: Mind the gap	Age and Ageing				Yes
166	Mulholland A et al	2019	336 GEMS: Geriatric Emergency Service – Home Team Outcomes	Age and Ageing	- Poster abstract only	- Poster abstract only	- Poster abstract only	No
167	Murphy J et al	2005	Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats™ as an interview tool	Health and Social Care in the Community	No Focus on engaging individuals with communication difficulties	-	-	No

168	Musselwhite C	2018	The importance of a room with a view for older people with limited mobility	Quality in Ageing and Older Adults	No Focus on environmental factors for housebound patients	-	-	No
169	Nanton V and Dale J	2011	'It don't make sense to worry too much': the experience of prostate cancer in African-Caribbean men in the UK	European Journal of Cancer Care	No Focus on experience of prostate cancer	-	-	No
170	Nasejje J et al	2015	Understanding the determinants of under-five child mortality in Uganda including the estimation of unobserved household and community effects using both	BMC public health	No Focus on under-five mortality	-	-	No

			frequentist and Bayesian survival analysis approaches					
171	Naughton C et al	2016	The development of the Older Person's Nurse Fellowship: Education concept to delivery	Nurse Education Today	No Focus on academic pathway for nurses	-	-	No
172	Nettleton S et al	2018	Envisioning bodies and architectures of care: Reflections on competition designs for older people	Journal of Ageing Studies	Yes Architectural students' perceptions of the needs of frail bodies	Yes Community	Yes	Yes
173	Ni Mhaolain AM et al	2011	Depression: a modifiable factor in fearful older fallers transitioning to frailty?	Geriatric Psychiatry	No Operational focus	Yes Community	Yes Dublin, Ireland	No
174	Nicholson C et al	2012	Living on the margin:	Social Science and Medicine	Yes Patient experience	Yes Community	Yes	Yes

			Understanding the experience of living and dying with frailty in old age				17 frail elders living at home in the UK	
175	Nicholson C et al	2013	The experience of living at home with frailty in old age: A psychosocial qualitative study	International Journal of Nursing Studies	Yes Patient	Yes Community	Yes 15 frail older people in inner London, UK	Yes
176	*Nicholson C et al	2017	Changing the way "we" view and talk about frailty…	Age and Ageing				Yes
177	North C	2016	Comprehensive geriatric assessment of a mental health service user with safeguarding needs	Nursing Older People	No Focus on complexity of combining physical and mental health needs	-	-	No
178	Notter J et al	2004	Taking the community into the home	Health and Social Care in the Community	No Focus on concept of cultural safety	-	-	No

179	O'Caoimh R et al	2014	Screening for markers of frailty and perceived risk of adverse outcomes using the Risk Instrument for Screening in the Community (RISC)	BMC Geriatrics	No Explores frailty associated risk factors	Yes Community	Yes 803 patients in South Ireland	No
180	O'Caoimh R et al	2017	Prevalence of frailty at population level in European ADVANTAGE Joint Action Member States: a systematic review and meta-analysis	Annali Dell'istituto Superiore Di Sanita	Yes Focus on identification of frailty	Yes No specific setting	No Only 10 out of 68 included studies UK based	No
181	Oakland K et al	2016	Systematic review and meta-analysis of the association between frailty and outcome in surgical patients	Annals of the Royal College of Surgeons of England	No Explores link between frailty and mortality	Yes Acute and community setting (1 year post op)	Yes English study	No

182	Ofori-Asenso R et al	2019	Global incidence of frailty and prefrailty among community-dwelling older adults – A systematic review and meta-analysis	Journal of the American Medical Association	Yes	Yes	No Only 3 out of 46 included studies used full or partial UK cohorts	No
183	Oh KM and Warnes AM	2010	A nurse-led rapid response service for frail older people: an assessment	British Journal of Community Nursing	No	Yes Community	Yes UK	No
184	Orellana K et al	2017	What do we know about care home managers? Findings of a scoping review	Health and Social Care in the Community	No Focus on care home manager role and skills	-	-	No
185	Papoutsi C et al	2018	Improving patient safety for older people in acute admissions: implementation of	Age and Ageing	Yes Exploring use of a new checklist to identify frailty	No 12 UK hospitals	-	No

			the Frailsafe checklist in 12 hospitals across the UK					
186	Parry S et al	2014	The STRIDE (Strategies to Increase confidence, InDependence and Energy) study: cognitive behavioural therapy-based intervention to reduce fear of falling in older fallers living in the community - study protocol for a randomised controlled trial	Trials	No Study proposal focussing on falls	-	-	No

187	Patel HP et al	2015	Skeletal muscle morphology in sarcopenia defined using the EWGSOP criteria: findings from the Hertfordshire Sarcopenia Study (HSS)	BMC Geriatrics	No Focus on underlying mechanisms of sarcopenia	-	-	No
188	*Pel-Little RE et al	2009	Frailty: Defining and measuring of a concept	The Journal of Nutrition, Health and Ageing				Yes
189	Petrova M et al	2017	Between “the best way to deliver patient care” and “chaos and low clinical value”: General Practitioners’ and Practice Managers’	International Journal of Medical Informatics	No Focus on data sharing in GP practice	-	-	No

			views on data sharing					
190	Philp I et al	2013	Reducing hospital bed use by frail older people: results from a systematic review of the literature	International Journal of Integrated Care	No Focus on strategies to reduce admissions	-	-	No
191	Pisano-Gonzalez M et al	2019	Health and Social Care Systems reaching out to vulnerable populations with chronic conditions: the EU-project EFFICHRONIC	International Journal of Integrated Care	- Poster abstract only	-	-	No
192	Poltawski L et al	2011	Frailty scales – their potential in interprofessional working with older people: a discussion paper	Journal of Interprofessional Care	No Explores frailty concept to evaluate interprofessional working	Yes No specific setting	Yes No specific population	No

193	Prestmo A et al	2015	Comprehensive geriatric care for patients with hip fractures: a prospective, randomised, controlled trial	The Lancet	No Focus on interventions for hip fracture	-	-	No
194	*Provencher V et al	2012	Frailty: A concept under-utilised by occupational therapists	Australian Occupational Therapy Journal				Yes
195	Ravindrarajah R et al	2013	The ability of three different models of frailty to predict all-cause mortality: Results from the European Male Aging Study (EMAS)	Archives of Gerontology and Geriatrics	No Explores three common frailty models specifically as predictors of mortality	-	-	No
196	Reginster JY et al	2016	Recommendations for the conduct of clinical trials for	Aging Clinical and Experimental Research	No Frailty cited as a precursor to focus of sarcopenia	-	-	No

			drugs to treat or prevent sarcopenia					
197	Reynolds R et al	2018	Application of the five stages of life model to support health impact assessments: a case study of the Llanelli Wellness and Life Science Village	The Lancet	No Focus on stages of life model within health impact assessment	-	-	No
198	Richards S and Coast J	2003	Interventions to improve access to health and social care after discharge from hospital: a systematic review	Journal of Health Services Research and Policy	No Focus on post discharge care services	-	-	No
199	Richardson JC et al	2014	'Keeping going': chronic joint pain in older people who describe their health as good	Ageing and Society	Yes Explores resilience, wellness and frailty as related concepts	Yes No specific setting however community implied by	Yes North Staffordshire, UK	Yes

						contact methods used		
200	***Richardson S et al**	2011	**I may be frail but I ain't no failure**	Canadian Geriatrics Journal				**Yes**
201	Rinnan E et al	2018	Joy of life in nursing homes: A qualitative study of what constitutes the essence of Joy of life in elderly individuals living in Norwegian nursing homes	Scandinavian Journal of Caring Sciences	**No** Focus on Joy of life	-	-	No
202	Roberts C and Mort M	2009	Reshaping what counts as care: Older people, work and new technologies	Alter	**No** Focus on implementation of telecare	-	-	No
203	Roberts JL et al	2017	Development of an evidence-based complex	BMJ Open	**No** Focus on improving outcomes post hip fracture	-	-	No

			intervention for community rehabilitation of patients with hip fracture using realist review, survey and focus groups					
204	Rochat S et al	2010	Frailty and use of health and community services by community-dwelling older men: the Concord Health and Ageing in Men Project	Age and Ageing	**Yes** Frailty and service use	**Yes** Community	**No** Australian cohort	No
205	***Rockwood K et al**	1994	**Frailty in elderly people: an evolving concept**	Canadian Medical Association Journal				**Yes**
206	Roe B et al	2001	Elders' perceptions of formal and	Journal of Clinical Nursing	**No**	-	-	No

			informal care: aspects of getting and receiving help for their activities of daily living		Focus on older people asking for or accepting help			
207	Rogers S et al	2014	Medicines management support to older people: understanding the context of systems failure	BMJ Open	No Focus on medication management in frail cohort	-	-	No
208	Romero-Ortuno R et al	2010	A Frailty Instrument for primary care: findings from The Survey of Health, Ageing and Retirement in Europe (SHARE)	BMC Geriatrics	Yes Operationalisation of frailty	Yes Community	No 12 European countries, non-UK based	No
209	Romero-Ortuno R et al	2013	A Frailty Instrument for primary care of the Survey of	Geriatrics and Gerontology	No	-	-	No

			Health, Ageing and Retirement in Europe predicts mortality similarity to a frailty index based on comprehensive geriatric assessment		Comparison of two frailty scores in ability to predict mortality			
210	Rosen H et al	2009	Symptoms following day surgery: a review of the literature	Journal of Advanced Perioperative Care	No Focus on patient experience of post-operative recovery in comparison to clinician expectation	-	-	No
211	Russell C et al	2002	Independence as a practice issue in Occupational Therapy: The safety clause	American Journal of Occupational Therapy	No Focus on meaning OTs attach to independence	-	-	No
212	Ryan-Wooley BM and Rees JA	2005	Initializing concordance in frail elderly patients via	The Annals of Pharmacotherapy	No Focus on medication concordance	-	-	No

			a medicines organizer					
213	Sanchez A et al	2016	Integrated care programme for the very old adults	International Journal of Integrated Care	- Conference abstract only	-	-	No
214	Sargent P et al	2007	Patient and carer perceptions of case management for long-term conditions	Health and Social Care in the Community	No Focus on patient perspective on case management	-	-	No
215	Schenker S	2003	Undernutrition in the UK	Nutrition Bulletin	No Focus on nutrition	-	-	No
216	*Schoenborn NL et al	2018	Older adults' perceptions and informational needs regarding frailty	BMC Geriatrics				Yes
217	Schreuders LW et al	2019	Understanding the perspectives of care home managers when managing care of	Geriatric Nursing	Yes Care Home Managers	Yes Community	Yes 8 managers from 7 care homes in	Yes

			residents living with frailty				the North of England	
218	Seale H et al	2009	The use of oseltamivir during an influenza B outbreak in a chronic care hospital	Influenza and Other Respiratory Viruses	**No** Interventions for outbreak of influenza	-	-	No
219	Sempe L et al	2019	Multidisciplinary interventions for reducing the avoidable displacement from home of frail older people: a systematic review	BMJ Open	**No** Focus on interventions to avoid displacement from home	-	-	No
220	***Sezgin D et al**	2019	**Defining frailty for healthcare practice and research: A qualitative systematic review**	International Journal of Nursing Studies				**Yes**

			with thematic analysis					
221	Sharp T et al	2018	GPs' perceptions of advanced care planning with frail and older people: a qualitative study	British Journal of General Practice	Yes GP	Yes Primary care/community	Yes 21 GPs in Cambridgeshire	Yes
222	*Shaw R	2018	Understanding frailty: meanings and beliefs about screening and prevention across key stakeholder groups in Europe	Ageing and Society				Yes
223	Shickle D and Griffin M	2014	Why don't older adults in England go to have their eyes examined?	Ophthalmic and Physiological Optics	No Explores understanding of eye health	-	-	No
224	Signore SD and Roubenoff R	2017	Physical frailty and sarcopenia (PF&S): a point of view from the industry	Aging Clinical and Experimental Research	No Focus on operationalisation	Yes No specific setting	Yes No specific setting	No

225	Simpson P et al	2016	The challenges and opportunities in researching intimacy and sexuality in care homes accommodating older people: a feasibility study	Journal of Advanced Nursing	No Focus on intimacy and sexuality in care homes	-	-	No
226	Sinclair A et al	2011	European diabetes working party for older people 2011 clinical guidelines for type 2 diabetes mellitus	Diabetes and Metabolism	No	-	-	No
227	Skilbeck JK et al	2018	Making sense of frailty: An ethnographic study of the experience of older people living with complex health problems	International Journal of Older People Nursing	Yes	Yes Community	Yes North of England	Yes

228	Song HJ et al	2019	What matters to people with chronic conditions when accessing care in Australian general practice? A qualitative study of patient, carer and provider perspectives	BMC Family Practice	No Focus on patient access to primary care	-	-	No
229	Southey S	2018	Influencing building design in care for older people	British Journal of Nursing	No Focus on environmental enhancement	-	-	No
230	Spangaro J et al	2016	'They aren't really black fellas but they are easy to talk to': Factors which influence African Aboriginal women's decision to disclose intimate partner	Midwifery	No	-	-	No

			violence during pregnancy					
231	Spangaro J et al	2016	Deciding to tell: Qualitative configurational analysis of decisions to disclose experience of intimate partner violence in antenatal care	Social Science and Medicine	No	-	-	No
232	Steven A et al	2019	The implementation of an innovative hydration monitoring app in care home settings: A qualitative study	JMIR Mhealth and Uhealth	No Focus on patient hydration in care homes	-	-	No
233	Stone L et al	2013	Advance care planning in care homes: the experience of staff,	International Journal of Palliative Nursing	No Focus on advance care planning	Yes Community Care Homes	Yes South East England	No

			residents and family members					
234	Struyf T et al	2020	International consensus definition of a serious infection in a geriatric patient presenting to ambulatory care	Journal of the American Medical Directors Association	No Focus on recognising infection	-	-	No
235	Stuart L	2015	What matters most to older people? Implications for Occupational Therapists…	British Journal of Occupational Therapy	- Plan for a workshop at 2015 conference	-	-	No
236	Sugarhood P et al	2017	Participation in advanced age: enacting values, an adaptive process	Ageing and Society	No Focus on the concept of participation	-	-	No
237	Sultana J et al	2016	Measuring frailty in population-based healthcare databases: multi-	Geriatric Care	Yes Frailty as a prognostic indicator of adverse event	Yes Community	No Italian cohort	No

			dimensional prognostic indices for the improvement of geriatric care					
238	Summers M et al	2018	The My Active and Healthy Aging (My-AHA) ICT platform to detect and prevent frailty in older adults: Randomised control trial design and protocol	Alzheimer's and Dementia: Translational Research and Clinical Interventions	- Proposal for future study	-	-	No
239	Sydall H et al	2015	Self-reported walking speed: A useful marker of physical performance among community-dwelling older people?	Journal of the American Medical Directors Association	No Focus on self-reported walking speed to gage physical performance	-	-	No

240	Sydall HE et al	2017	Mortality in the Hertfordshire Ageing Study: association with level and loss of hand grip strength in later life	Age and Ageing	No Explores change in grip strength as an indicator of poor ageing outcomes	-	-	No
241	Tamang S et al	2005	Improving end of life care: An information systems approach to reducing medical errors	Studies in Health Technology and Informatics	No Focus on end-of-life care	-	-	No
242	Tan HM et al	2014	Men's Health Index: A pragmatic approach to stratifying and optimizing men's health	Korean Journal of Urology	No Focus on health status indicators	-	-	No
243	Tester S et al	2004	What does quality of life mean for frail residents?	Nursing and Residential Care	No	-	-	No

					Explores quality of life perceptions of older people pre-defined as 'frail'			
244	Thompson A et al	2016	Multi-morbidity as a driver of high cost, high resource utilisation and future risk	International Journal of Integrated Care	- Conference abstract only	-	-	No
245	Thompson A et al	2018	Inter-relationship between frailty and multi-morbidity in East Berkshire, UK	International Journal of Integrated Care	- Conference abstract only	-	-	No
246	***Tomkow L**	2020	**The emergence and utilisation of frailty in the United Kingdom: a contemporary biopolitical practice**	Ageing and Society				**Yes**
247	Trahan L et al	2016	Decisions to transfer nursing home residents to emergency	Journal of the American Medical	**No** Focus on avoidable transitions between care settings	-	-	No

			departments: A scoping review of contributing factors and staff perspectives	Directors Association				
248	Travers J et al	2019	41 From ward to classroom: Service evaluation to increase awareness of frailty and resilience and encourage greater physical activity	Age and Ageing	- Poster abstract only	- Poster abstract only	- Poster abstract only	No
249	Troya MI et al	2019	Role of primary care in supporting older adults who self-harm: a qualitative study in England	British Journal of General Practice	No Focus on access to care for people who self-harm	-	-	No
250	Tullo E et al	2020	Improving access to outpatient services for older people	Age and Ageing	No Explores triage pathways for frailty referrals	-	-	No

			using a clinical microsystems approach					
251	Vadher K et al	2018	COmmunity-based Rehabilitation after Knee Arthroplasty (CORKA): statistical analysis plan for a randomised controlled trial	Trials	No Focus on recovery after knee replacement	-	-	No
252	Vercelli A et al	2018	The My Active and Healthy Aging (My-AHA) ICT platform to detect and prevent frailty on older adults: Randomised control trial design and protocol	Alzheimer's and Dementia: Translational Research and Clinical Investigations	No Proposal for future study on detection of frailty	Yes No specific setting	Yes Although proposal for full study is multinational, proposal is based on broader conceptual challenges	No

253	Veronese N et al	2017	Polypharmacy is associated with higher frailty risk in older people: An 8-year longitudinal cohort study	Journal of the American Medical Directors Association	No Focus on polypharmacy as a frailty risk factor	-	-	No
254	Veronese et al	2017	Frailty and incident depression in community-dwelling older people: results from the ELSA study	International Journal of Geriatric Psychiatry	No Explores psychological aspect of frailty	Yes Community	Yes English cohort	No
255	Wade R et al	2015	Carers' perceptions of the impact of home telehealth monitoring on the provision of care and sustainability of use	Australasian Journal on Ageing	No Explores perceptions of telehealth use	-	-	No

256	Wagg A et al	2007	Overactive bladder syndrome in older people	BJU International	No Focus on management of overactive bladder syndrome	-	-	No
257	Wallington S	2016	Frailty: a term with many meanings and a growing priority for community nurses	British Journal of Community Nursing	Yes Frailty conceptualisation	Yes Community	Yes No specific setting	Yes
258	Walsh KM and Waldmann T	2008	The influence of nursing home residency on the capacities of low-dependency older adults	Aging and Mental Health	No Focus on mental capacity in nursing homes	-	-	No
259	Warmouth K et al	2016	'Thinking You're Old and Frail': A qualitative study of frailty in older adults	Ageing and Society	Yes Patients	Yes Own homes or institutional settings	Yes UK	Yes
260	Webster C et al	2019	30 Occupational Therapists delivering patient	Age and Ageing	No Focus on evaluating an education intervention	-	-	No

			and caregiver home safety education in a rehabilitation setting… 67th Annual and Scientific meeting of the Irish Gerontological Society, innovation, advances and excellence in ageing, 26-28 September 2019, Cork, Ireland		
261	*Whitson HE et al	2007	**Frailty thy name is… Phrailty?**	Journal of Gerontology	**Yes**
262	*Whitson HE et al	2018	**Physical resilience: Not simply the opposite of frailty**	Journal of the American Geriatrics Society	**Yes**

263	Wicke D et al	2004	Teamworking in nursing homes	Journal of Advanced Nursing	No Focus on experience and perception of teamworking	-	-	No
264	Wiles J	2003	Daily geographies of care givers: mobility, routine, scale	Social Science and Medicine	Yes Carers	Yes Community	No Study from the USA	No
265	Willard S et al	2018	Development and testing of an online community care platform for frail older adults in the Netherlands: a user-centred design	BMC Geriatrics	Yes Interviews patients to identify their self-management needs. Unclear in abstract how cohort identified	Yes Community	No Cohort in the Netherlands	No
266	Williams FR et al	2019	Review article: impact of exercise on physical frailty in patients with chronic liver disease	Alimentary Pharmacology and Therapeutics	No Focus on impact of exercise as an intervention within specific frailty population	-	-	No

267	Wilson E et al	2018	Managing medicines for patients dying at home: A review of family caregivers' experiences	Journal of Pain and Symptom Management	No Focus on medication management in end-of-life care			No
268	Woo J et al	2016	Successful ageing and frailty: Opposite sides of the same coin?	Journal of the American Medical Directors Association	Yes	Yes Community	No Chinese study	No
269	Woo J et al	2018	Variability in repeated blood pressure measurements as a marker of frailty	The Journal of Nutrition, Health and Aging	Yes Explores blood pressure as a frailty marker	Yes Community	No Hong Kong cohort	No
270	Wou F and Conroy S	2013	The frailty syndrome	Medicine	No Operational definition	Yes No specific setting	Yes No specific cohort	No
271	Yates A	2019	Understanding incontinence in the	British Journal of Community Nursing	No Focus on continence	-	-	No

			older person in community settings					
272	Young J and Clegg A	2010	Community-based specialist nurses for older people with long term conditions in England	Journal of Clinical Gerontology and Geriatrics	No Explores roles of community-based practitioners	Yes Community based	Yes	No
273	Zhang D et al	2020	Cohort profile: The prospective study on Chinese elderly with multimorbidity in primary care in Hong Kong	BMJ Open	No Focus on biopsychosocial profiles of older people with multimorbidity	-	-	No
274	Zwakhalen S et al	2018	Pain in older adults with dementia	Schmerz	No Focus on pain and dementia	-	-	No

Appendix 4: Concept Analysis - Rationale for inclusion/exclusion criteria of concept analysis

	Inclusion and Exclusion criteria		
	Inclusion	Exclusion	Rationale
1	Articles written within any date range available in databases	None	To reflect all academic writing about frailty and capture any change over time
2	Articles written in English	Articles written in any other language	Limited access to translation routes due to resources and time. Researcher speaks only English. Potential for altered interpretation of texts through translation process.
3	Primary intent is to offer insight into frailty conceptualisation by any given group	Articles mentioning frailty but only as a secondary factor alongside another primary focus. Articles focussing on operationalisation to produce or compare objective quantifiable measures.	To ensure focus is on interpretation of frailty as a concept. To identify attributes of frailty related to lived experience Evolutionary view suggests development of concept is influenced by its significance, use and application.

			To identify historic trends and current thinking in responding to frailty.
4	Articles focussing on primary care, returning to primary care or no specific setting	Articles focussing predominantly or exclusively on acute settings	Research design will be aimed at community-based patient groups. Care experience in acute setting may influence perception of personal relationship with frailty.
5	Studies of UK based cohorts, or predominantly UK based cohorts only	Studies using participants outside the UK	To limit variation in cultural contexts and social norms.

Appendix 5: Concept Analysis - Codes used for core analysis for concept analysis

The Core Analysis Phase					
Attributes			Consequences		
Code	Description	When to apply	Code	Description	When to apply
Att1	Has Frailty been operationalised?	Clear operational definition of Frailty provided	Con1	Occurrences that follow Frailty defined	Occurrences following Frailty clearly stated
Att2	Presents key characteristics, qualities or features inherent to Frailty?	Clearly states key characteristics, qualities or features inherent to Frailty			
Att3	Is Frailty a useful concept?	Clear positionality on the usefulness of Frailty to produce positive health or wellbeing outcomes			
References			Related concepts		
Code	Description	When to apply	Code	Description	When to apply
Ref1	Identifies situations, incidents or phenomena in which Frailty can be considered.	Specific situations, incidents or phenomena related context	Rel1	Identifies and/or discusses other concepts related to Frailty	Related concepts clearly stated

		identified within which Frailty is considered			
Ref2	Seeks to clarify the perception of perspective of a specific professional or population group	Clearly identified professional or population group represented	Rel2	Presents the important aspects of the relationship	Clearly demonstrates or states how and/or why the secondary concept relates to Frailty
Antecedents			Model case		
Code	Description	When to apply	Code	Description	When to apply
Ant1	Events or phenomena preceding Frailty	Specific events or phenomena clearly stated	Mod1	Provides a clear example of Frailty	Clear example of Frailty given
Identification			Management		
Code	Description	When to apply	Code	Description	When to apply
Ide1	A specific means to identify or assess frailty is recommended and commented on?	When a method or tool to identify the presence of frailty is proposed	Man1	A specific management approach or intervention is recommended for frailty?	When a clear approach is stated
Philosophical view					
Code	Description	When to apply			
Phi1	Entity, dispositional or evolutionary view of Frailty concept?	When one clear or predominant view is being used			

Appendix 6: Concept Analysis - Sample code recording sheet for concept analysis. Completed for all 41 included papers

Code recording sheet									
Green J et al. (2018) *Ambulance clinicians' perceptions, assessment and management of frailty: thematic analysis of focus groups* British Paramedic Journal									
Discipline/population group	Attributes	References	Identification	Antecedents	Consequences	Management	Related concepts	Model case	Philosophical view
	Att1: Has Frailty been operationalised, defined or conceptualised?	**Ref1:** Identifies situations, incidents or phenomena in which	**Ide1:** A specific means to identify or assess frailty is recommended and commented on?	**Ant1:** Events or phenomena preceding Frailty	**Con1:** Occurrences that follow Frailty defined	**Man1:** A specific management approach or intervention is recommended for frailty?	**Rel1:** Identifies and/or discusses other concepts related to Frailty	**Mod1:** Provides a clear example of Frailty	**Phi1:** Entity, dispositional or evolutionary view of Frailty concept?

	Att2: Presents key characteristics, qualities or features inherent to Frailty? **Att3:** Is Frailty a useful concept?	Frailty can be considered. **Ref2:** Seeks to clarify the perception of perspective of a specific professional or population group					**Rel2:** Presents the important aspects of the relationship		
• Paramedics (P)	**Att1: Yes** "two third of older patients are	**Ref1: Yes** Within ambulance	**Ide1: Yes** "two third of older patients are assessed using the	**Ant1: Yes** (P) "gradually weaken as	**Con1: Yes** "increased levels of frailty are associated	**Man1: Yes** "Ambulance services can be	**Rel1: Yes** "failed discharge" p29	**Mod1: No**	**Phi1:** Entity view

	assessed using the Rockwood Clinical Frailty Scale" p24 (Rockwood) "frailty is a long term condition characterised by 'the cumulative decline in many physiological systems during a lifetime'" p24	attendance **Ref2:** (P) "I think we see it; we just don't put a title to it" p26	Rockwood Clinical Frailty Scale" p24 "Timed-Up-And-Go… whereby a time of less than 13.5 seconds is associated with a low likelihood of having frailty" p25 (re GP contract) "the aim is to proactively identify… severe or moderate frailty" p25 "Ambulance services are well placed to improve recognition of and	they get older" p26 (P) "increasing number of comorbidities… has a knock-on effect in frailty" p26 (P) "recognition of evidence that people with dementia, who are particularly prone to	with increased mortality, institutionalisation, occurrence of 'geriatric syndromes'… and post-operative complications" p25 "risk of hospital admission" p25	instrumental in early intervention and decision making… for example… escalation plans" p25 "clinical education relating to frailty" p25… "can develop a more diverse vocabulary" p26 (P) "proactively change the	"reablement" p29 "discharge planning" p30 "rapid response…acute care at home… early intervention service" p30 **Rel2:**		

	(P) "vulnerable to a range of things… multiple system failure where people gradually weaken as they get older" p26 "modest understanding of the medicalised theories of frailty… direct		response to frailty through recognising patients who are frail or on the 'cusp' of becoming more frail, and accurately communicating this to primary care whether admitted to hospital or not" p25 (P) "particular value in using recognised assessment tools… evidence bases my decision" p26 (P) "a simple, clear score stands out as something to mention to fellow	frailty…" p29		way that patients with frailty are managed... prehab rather than rehab" p26 (P) "there was discussion regarding whether more point-of-care testing could facilitate the management of patients in their homes" p28			

	knowledge of common concepts of frailty… limited to one or two participants" p31 "Variation in knowledge of frailty, its assessment and managemen t, reflected the emerging nature of the condition both academically		healthcare professionals when patients are conveyed" p26 (P) "convey succinctly important information… instant picture of that patient" p27 (P) "more than one clinician was sceptical of the value of formal frailty evaluation…" p27 (P) "the apparently simple nature of the CFS, seen by some as a strength, was			(P) "there should be a specific field on the ePCR to document supportive information … more detailed, perhaps more accurate assessment tools should be made available… PRISMA 7… collated information could be presented as a patient			

	ad clinically" p32 Att2: "vulnerable to major deterioration in their physical and mental health as a result of apparently minor events" p24 "may be in contact with many health and social care		perceived as a weakness by others, who disliked its apparent subjectivity…" goes on to say 4/5 people could give 4/5 different scores p27 (P) "lack of direction regarding information which should be considered when applying the CFS… potential to misinterpret evidence" p27 (P) "falls can (effect)…			profile or frailty profile" p28 (P) "services which are perceived to take time, that clinicians will follow: 'paths of least resistance'" p28 (P) "easy access to information about which care pathways			

	professionals and are vulnerable to risks associated with transitions between care settings" p32 Att3: Yes "recognition … may enable initiation of interventions which may help reverse or postpone		confidence and consequently… presentation…loss of strength… after a long period lying on the floor, leading to an unrepresentatively high CFS score" p27 (P) "value of an educated guess regarding usual levels of functioning was questioned" p27 (P) "useful contextual information… gradual process of discovery" p27			are available locally would help" p28 (P) "managing patients at home: risks to patient (…may deteriorate in a relatively unmonitored environment) and risks to clinicians (…they may be perceived to have failed to anticipate such			

	the development of severe frailty" p25 (P) "can contribute to decisions" p26 "inform healthcare professionals of frailty status, so that it may be incorporated into risk/benefit assessments" p31		(P) (CFS) "holistic view of the patient" p27 (P) "broad consensus… the TUG tool is not widely completed… lack of understanding of its purpose… and a perception that it is difficult/risky to carry out" p27 (P) "frustration…expressed… the perceived inability of other care providers to			deterioration and are therefore held responsible)" p29 (P) "a certain amount of risk is acceptable, if trying to act in patients' best interests" p29 (P) "risks to frail patients of being admitted to hospital" p29			

			share information" p28 "familiarity with current guidance seemed to vary substantially" p31 Re CGA "multidisciplinary process… aims to identify the particular combination of deficits (leading to frailty) and assets (contributing to resilience) that a person has" p31			(P) "traditional culture of hospitalisation" p29 (P) "complications of the discharge process… managed at home in suboptimal conditions… medication changes" p29 (P) "joined-up working…			

						multidisciplinary working with a single point of access" p29 (P) "occupational therapy" re: meeting immediate needs when OTs not available p30 (P) "avoiding the ED is always best for frail patients (but) admitting to			

						a medical ward… more likely to 'get into the process', implying that under some circumstance s, ED may be the more efficient option" p30 (P) "a general sense was conveyed that more referral pathways are being made			

						available to ambulance clinicians… specifically for frail older people" p30 "Many of the care pathways discussed seem likely to support the goals of the wider health service for patients with frailty, including the new GP			

						contract” p31 “the effectiveness of… interventions may differ depending on the degree of frailty… Physical exercise, for example resistance training, seems to be particularly valuable” p31			

						“different geographical regions have adapted differently to changing needs, resulting in considerable diversity of services” p31			

Appendix 7: Concept Analysis - Category grouping used for concept analysis

Code	Description in text	Category
(A)	Academics	Academia
(R)	Researchers	
(D)	Dictionary	
(RC)	Researchers and Clinicians	
(S)	Statisticians	
(SS)	Social Science	
(CHM)	Care Home Managers	Non specialist qualified or senior staff delivering interventions
(CM)	Community Matron	
(CL)	Clinicians	
(CN)	Community nurses	
(NHCPs)	Non specialist Health Care Professionals (GPs, practice and district nurses, hospital ward managers, OTs, PTs, TAs, psychiatric nurses, social workers)	
(GPs)	GPs	
(P)	Paramedics	
(SCPs)	Social Care Professionals	
(OP)	Older People age 69+	The people being described as frail
(F)	Frail people	
(OW)	Older women	
(Pt)	Patients	
(GP)	General Public/lay people	Non-healthcare public (PINK)
(CR)	Cultural representation	
(AS)	Architecture students	
(NFP)	Non-frail participant	
(IC)	Informal carers	Informal carers of frail individuals (LIGHT BLUE)
(FF)	Family of frail people	
(OPS)	Older peoples' specialists	Clinical experts (DARK BLUE)
(G)	Geriatricians	
(ME)	Medical Experts	
(BGS)	British Geriatrics Society	Professional and national governing bodies
(SH)	Stakeholders	
(PM)	Policy Makers	
(PO)	Professional Organisations	
(GM)	Governments	
(NHS)	NHS England	
(WHO)	World Health Organisation	
(HS)	Healthcare Systems	

Appendix 8: Concept Analysis - Sample of Code Recording Sheet - All representations of 'The people being described as frail' taken from all 41 papers included in the concept analysis. Completed for all 7 categories in Appendix 7.

Code recording sheet									
Discipline/ population group	Attributes	References	Identification	Antecedents	Consequences	Management	Related concepts	Model case	Philosophical view
	Att1: Has Frailty been operationalised, defined or conceptualised? **Att2:** Presents key characteristics, qualities or features inherent to Frailty? **Att3:** Is Frailty a useful concept?	**Ref1:** Identifies situations, incidents or phenomena in which Frailty can be considered. **Ref2:** Seeks to clarify the perception of perspective of	**Ide1:** A specific means to identify or assess frailty is recommended and commented on?	**Ant1:** Events or phenomena preceding Frailty	**Con1:** Occurrences that follow Frailty defined	**Man1:** A specific management approach or intervention is recommended for frailty?	**Rel1:** Identifies and/or discusses other concepts related to Frailty	**Mod1:** Provides a clear example of Frailty	**Phi1:** Entity, dispositional or evolutionary view of Frailty concept?

		a specific professional or population group					**Rel2:** Presents the important aspects of the relationship		
The people being described as frail	**Att1:** older people and their carers associated the term with end-of-life, cancer syndromes and high degrees of functional dependency END OF LIFE (OP) "requiring the mobilisation of resources to create	**Ref1:** (OP) "irreversible state… very final stages of their lives… recovery period (such as after breaking leg) not synonymous	**Ide1:** (OP) "as the ability to do… things without significant support start to slip out of reach… this can	**Ant1:** (OP/ICs) "mixed awareness of main risks for frailty (and) available preventative strategies" p8	**Con1:** (OP) "barriers to identifying with the term 'frail'… deep fear of losing independence, dignity and control" p7 IDENTITY/LOSS /	**Man1:** (F/OP) "keeping frailty at a distance means resisting… impact frailty can have on… integrity and identity… the possibility to see continuity between the past and present self" p11 MAINTAINING	**Rel1:** **Rel2:**	**Mod1:** (OW) "isn't strong… doesn't have a lot of emotional resources … needs to be	**Phi1:** **OP – combining entity and dispositional views** **Dispositional –**

	wellbeing" p10 LACKING- WELLBEING **Att2:** (OP) "refer to the condition in psychological terms, as a state of mind" p20 PHYCHOLOGCIAL CONDITION (OW) "associated with emotional vulnerability… unfulfilled wishes or desires… loss and unmet need" p434 LACKING/ VULNERABILITY (OP) "thinking of yourself as frail then you gonna have some	with OP definition of frailty" p11 END OF LIFE/PERMANENT/ IRREVERSIBLE **Ref2:** "Older adults understanding is not often acknowledged and reflected… perceptions regarding health can play an important role in determining	act as a 'trigger point' to accessing… care/support services" p7 FUNCTIONAL THRESHOLD/ TRIGGER POINT (R:BGS) "Older people described frailty as something they could	KNOWLEDGE/RISK (OP) "thinking of yourself as frail then you gonna have some subsequent frail behaviour" p20 PSYCHOLOGICAL CONTRIBUTORS (OP) "the process of ageing is dependent	INDEPENDENCE/ DIGNITY (OP/Puts) "reduced ability to cope with their physical limitations, negative emotions, impaired cognitive functioning and poor social interactions" p1484 EMOTIONAL CONSEQUENCE/ SOCIAL CONSEQUENCE	IDENTITY/ RESISTANCE (OP) "She then explained why she did not identify as frail: because I fight against it" p1491 RESISTANCE (F/OP) "Frail older people work hard to shape and maintain daily routines" p2 ROUTINE/MAINTAINING IDENTITY (OP) "objectification of impairment… avoid exposure to… assessment methodologies of		taken care of… they don' have the resources themselves, they haven't found the resources themselves… dependent… at risk… deteriorating… more and more isolated" p434	**dependent on the mindset of the individual** **Dispositional** **Dispositional** **Dispositional** **Dispositional** **Dispositional**

	subsequent frail behaviour" p20 PSYCHOLOGICAL CONTRIBUTORS/ BEHAVIOURAL CONTRIBUTORS (OP) "Identifying as frail was not only informed by health but was also a believed determinant… depended on resistance strategies and aspects of self-identifying… informed by both individual and social context" p1489 PSYCHOLOGICAL CONTRIBUTORS/IDENTITY	the progression of illness" p1484 UNDER-REPRESENTED (NHCPs/OP) "the views of (NHCPs and OP) on factors contributing to a definition of frailty in the medical and nursing literature were considered, albeit few were found… an inherent limitation of	recognise in others but which they would never use to describe themselves." P349 DIVIDING (NHCPs/Pt) "most clinicians and patients apply the term frailty by gestalt: they know it when they see it. However	on one's attitude and outlook on life as much as one's physical state" p17 PSYCHOLOGICAL PRECURSERS (OP) "for some a gradual decline and for others a sudden and shocking rupture which they	(OP) "Physical decline towards dependency and death" p1490 PHYSICAL CONSEQUENCE/ DEATH (OP) "the social consequence of being excluded was very damaging, reducing their motivation for social participation and increasing	h&sc services… to escape such objectification… (pension, bus pass etc) increasing the 'resourcefulness' of the recipients… For disabled people on the other hand, objectification of their status is more intrusive and more intimately connected to shaping their identity" p481 RESISTANCE/ ACCEPTANCE /REWARD (F) "Agency within chronic illness… (is) highly valued, as are		(OP) "losing independence, dignity and control" p7 "a person that's sitting in the armchair all the time" p397 (OP) "for some a gradual	**Dispositional and evolutionary views**

	(OP/Puts) "described frailty both as a state of general physical impairment and disease, and as a condition with delineable social and psychological ill-effects" p1484 PHYSICAL/SOCIAL/ PSYCHOLOGICAL CONSEQUENCE (A/OP)" with Fried's criteria… the obvious conclusion is that frailty is not compatible with successful ageing… many investigators, as well as old persons themselves, would disagree" p26 UNSUCCESSFUL	current frailty discussions and definitions" p23 UNDER-REPRESENTED "Frailty is not a word people use to define themselves or their experience of everyday living" p1175 IDENTITY/LIN GUISTICS "wellness and resilience… are not usually terms	confusion becomes likely when this clinical understan ding is at odds with the research definition" p730 VISIBILITY/ GESTALT	related to a specific event, for example a fall" p1428 TRAJECTOR Y (F) "common experiences of pain, increasing tiredness and lack of strength" PHYSICAL SYMPTOMS – PAIN/FATIG UE *Antecede	their risk of further exclusion" p1493 SOCIAL CONSEQUENC E/ EXCLUSION/ PSYCHOLOGIC AL CONSEQUENC E (OP) "a lack, a loss of independence" p1494 LOSS - INDEPENDENC E (F) "loss of autonomy and a challenge to self-identity"	autonomy, choice and self-expression" p483 AUTONOMY/ CHOICE (F/OP) "Despite feeling afraid Martha did not stop taking risks with her mobility… Her attitude to risk taking appeared to change as she regained control of her body" p7 RISK/CONTROL/AUT ONOMY (F/OP) "they focused on continuing to engage with daily living and in doing so		decline and for others a sudden and shocking rupture which they related to a specific event, for example a fall" p1428 (R:BGS) "older people and their carers	

	(F/OP) "frustration and occasionally anger" p8 EMOTIONAL EXPERIENCE (F/OP) "lead them to contemplate the end of their lives" p8 MORTALITY (F/OP) "for some… episodes of feeling frail were accommodated and therefore became a temporary feature of their experience. For others, the situations became more permanent" p8 PERMANENCE/INDIVIDUAL	used by participants themselves" p1385 IDENTITY - LINGUISTICS "importance of considering OP's own definitions… they will shape the actions they take, and have taken over their lifetime… consider OP's own definitions… as part of a patient-		nt or consequence? p1177 Joint pain PHYSICAL SYMPTOMS - PAIN	p1176 LOSS – AUTONOMY/ LOSS - IDENTITY (OP) "becoming increasingly dependent… unplanned hospital admissions" p1428 ADMISSION/ LOSS - INDEPENDENCE (OP) "losses of physical capacity" p1428	they defined themselves in relation to what they could achieve" p9 FOCUS ON ABILITY (OP) "a stressor… might be experienced with different degrees of adversity, depending on the perceived severity and the meaning and significance of the loss for the individual… the wider setting in which the individual lives also has the potential to affect the experience of adversity" p1391		associated the term with end-of-life, cancer syndromes and high degrees of functional dependency" p349 (F/OP) "nothing wrong with my health	

	EXPERIENCE/TRAJECTORY (OP) “the degree of felt adversity is contextually contingent” p1388 EMOTIONAL EXPEREINCE/CONTEXTUAL/ INDIVIDUAL EXPERIENCE (F) “loss of autonomy and a challenge to self-identity” p1176 IDENTITY/AUTONOMY/ THREAT (OP) “transition from ‘keeping going’ to ‘letting go’” p1430 TRAJECTORY/PSYCHOLOGICAL CONTRIBUTORS	centred approach” p1392 VALUE/PATIENT-CENTRED (OP) “nobody in the study used the term “frail” to describe themselves or their situation” p1428 LINGUISTIC			PHYSICAL CONSEQUENCE (OP) “the challenges of decreased physical and social mobility within frailty make social connections hard to sustain” p1429 PHYSCIAL CONSEQUENCE/ SOCAIL CONSEQUENCE/ LOSS - CONNECTIONS	PERCEPTION/PSYHOLOGICAL CONTRIBUTORS /INDIVIDUAL EXPERIENCE (F) “you keep going as best you can” p1176 KEEPING GOING/INTERNAL DRIVE (F/OP) “becoming “old” was a complex process and not always readily accepted, compounded when the experience of transition appeared to be sudden or chaotic” p8		but I have fallen five times and… I’ve broken everything” p10	

	(OP) "tended to evoke a strong and often emotional reaction, particularly older men… Several… participants expressed incredulity or offence" p10 EMOTIONAL CONSEQUENCE "fear of what might happen" p1429 UNCERTAINTY/EMOTIONAL CONSEQUENCE (OP) "frail elders themselves differentiate between being and feeling frail" p1427 PHYSICAL				(OP) "fear of further decline, loss of independence and separation from society" p1430 PSYCHOLOGICAL CONSEQUENCE/SOCIAL CONSEQUENCE/ LOSS – INDEPENDENCE (OP) "become a burden" 14 LOSS - IDENTITY	ACCEPTANCE/ TRAJECTORY/ ADJUSTMENT (OP) re: ED admissions with no treatment given "sense of abandonment" p1430 EMOTIONAL EXPERIENCE/VALUE (NCHP/OP) "although professionals discussed a wide range of relevant local services… the majority of older people rarely discussed or accessed these. Several paid for			

	CONSEQUENCES/EMOTIONAL EXPERIENCE (OP) "sense of change… living with the loss of whom and how one is in the world… evoking… anger and resistance" p1428 CHANGE/LOSS/EMOTIONAL EXPERIENCE (OP) "whole self was imbalanced" p1428 CHANGE/IDENTITY (F) "challenges and changes to social identity and positions in the world… were perceived differently by friends and family				(OP/IC/NHCP) "Disabilities arising from physical health conditions or frailty" p396 PHYSICAL CONSEQUENCES - DISABILITY (OP/IC/NHCP) "low mood was not a barrier to, but a result of, being unable to continue valued activities" p397 PSYCHOLOGICAL	private assistance, mainly cleaners, although these arrangements were not discussed by many professionals" p396 SPECIALIST INPUT/ADAPTATION - DELEGATION (OP) "seemed to struggle to allow herself to feel dependency and accept appropriate aids to mobilise" p1429 ACCEPTANCE/ADAPTATION - COMPENSATION (R:Warmouth/OP) "most participants			

	following a period of physical vulnerability" p1176 IDENTITY/ CHANGE/SOCIAL CONSEQUENCES (F) "feeling invisible, talked about and talked over" p1176 EMOTIONAL EXPERIENCE/LOSS OF AUTONOMY (F/OP) "they appeared vulnerable as their sense of self was threatened" p8 IDENTITY/VULNERABILITY (F) "uncertainty of being imbalanced seemed to				CONSEQUENCES/LOSS – MEANINGFUL ACTIVITY	actively resented the identity, even those who could be classifies as frail using objective criteria" p350 RESISTANCE (OP) "many obstacles in my life that I've had to overcome… it comes from an inner strength" p1389 INNER STRENGTH (R/F) "not that they deny (accumulation of deficits) but that their health and well-being is defined by what they can, as much as what they			

	precipitate unease." P1176 UNCERTAINTY/EMOTIONAL CONSEQUENCE (F) "expressed a sense of shame at being seen with a walking aid, or wheelchair" p1176 VISIBILITY/EMOTIONAL CONSEQUENCE/FAILURE (F) "the loss of physical function evoked a loss of certainty about how the world was" p1176 UNCERTAINTY (R:Nicholson/F) "Participants used frailty as a term of separation – given to others who					cannot, do" p350 FOCUS ON ABILITIES (OP) "In the context of a chronic condition, understanding that the condition will fluctuate and that there will be 'good days and bad days'… is also part of keeping going" p1391 KNOWLEDGE/INNER STRENGTH (OP) "participants like Lewis have successfully adapted to their symptoms that this results in			

	were seen to be more unwell and needing more care than themselves" p350 DIVIDING (OP) "a distinction between feeling frail… and being labelled as frail… thus frailty connotes a sense of nihilism and is used as a term of separation, used about others but not about oneself" p510 DIVIDING (R/F) "participants recognised their bio/psycho/social vulnerabilities. However, frailty was associated					their downplaying the adversity of these… are they demonstrating resilience?" p1387 ADAPTATION/ RESILIENCE (OP) "a new health service to address current challenges was not always seen as appropriate" p399 PROVISION OF SERVICES (F/OP) "resisted the offer of a stick as it represented getting older" p8 RESISTANCE/VISIBILITY			

	with giving up.” P350 PHYSICAL/SOCIAL/ PSYCHOLOGICAL CONSEQUENCES/VULNE RABILITY/ PSYCHOLOGICAL CONTIBUTORS (OP) “frailty may represent a personal failure” p510 FAILURE/PERSONAL (F) “the frail have few or no… validated identities or empowering self-narratives” p485 IDENTITY/AUTONOMY (R:BGS) “older people and their carers associated the term with					(F/OP) “lowering her expectations” p8 ACCEPTANCE (F/OP) “when I adjust I will be alright” p8 ADJUSTMENT/ ACCEPTANCE (F/OP) “adaptive responses… evidence of maintained perceived balance and resilience in the context of physical impacts” p10 ADAPTATION/ RESILIENCE (F/OP) “acceptance of new conditions			

	end-of-life, cancer syndromes and high degrees of functional dependency. Respondents usually regarded “frail” as a negative label” p349 DEPENDENCY/END OF LIFE (OP) “sense of fear, depression and vulnerability” p1492 LOSS OF CONTROL/EMOTIONAL CONSEQUENCES/PSYCHOLOGICAL CONSEQUENCES (F/OP) “increasingly overwhelmed and distressed by the					and devices to cope was also key to coping” p10 ACCEPTANCE/ COPING STRATEGIES (F/OP) “maintaining routine… contribute(s) to preserving identity” p11 MAINTAINING ROUTINE/ MAINTAINING IDENTITY (F/OP) “significance of respectful relationships” p11 RESPECT/QUALITIES OF PROFESSIONAL – RESPECTFUL/VALUE			

	changes in her health" p8 EMOTIONAL CONSEQUENCES/CHANGE/ ACCEPTANCE (F/OP) "for some, situations that signalled that their health was worsening caused anxiety and distress" p7 ACCEPTANCE/ADJUSTMENT/ EMOTIONAL CONSEQUENCES (F/OP) "frightened of falling again" p7 PSYCHOLOGICAL CONSEQUENCES (F/OP) "Where bodily changes made it difficult to negotiate daily living,					(F/FF) "wanted to feel included in decision making" p11 AUTONOMY/AGENCY Re: what should be prioritised: ((F/OP) "autonomy and protection", (FF) "safety, finances… value of living at home" (NHCPs) "safety, autonomy and personal care" p12 AUTONOMY (NFP/OP) "aim to keep frailty at a distance or control it" p9 RESISTANCE			

	previously taken-for-granted activities were perceived as risky" p7 RISKY/PHYSICAL CONSEQUENCES (F/OP) "low mood… appeared to intensify the effects of physical impairment" p6 MOOD/EMOTIONAL CONTRIBUTORS (F/OP) "loss… for many this was not being able to go out and maintain social relationships" p6 LOSS/SOCIAL CONSEQUENCES (F/OP) "(loss) was associated with not					(NFP/OP) "strategies include adaptive coping such as optimisation, maintaining social connections, and psychological and physical strategies to prevent or manage frailty… preference for services that would enable them to maintain their independence" p9 ADAPTATION/COPING STRATEGIES/CONNECTIONS/ INDEPENDENCE (OP) "disbelief of the potential success of			

	being able to manage the home environment" p6 LOSS/MAINTENANCE OF IDENTITY/HOME (OW) "referred to frailty in various ways, ranging from an observable physical state, through the experience of vulnerability and negative social assumptions, to its association with crisis events… physical appearance related to… being small or skinny… " p433 VISIBILITY/VULNERABILITY/ PHYSICALLY DIMINISHED					frailty interventions" p7 UNDERLYING BELIEF (F)" a relationship centred approach to care is critical to… realise their goals beyond functional capacity" p1173 QUALITIES OF PROFESSIONAL - RELATIONSHIP (OP) "(some people) wallow in it… even act in a 'frail manner' in order to secure support… perhaps 'wallowing' is a way for people to cope" p1491 ADAPTATION			

	(F/OP) "the experience of frailty was understood through… four themes… Fluctuating ill-health and the disruption of daily living…patterns of transition… Change in the management of daily living… made adjustments… continue to manage daily living… taking control… keeping going… Frailty as anxiety, fear and uncertainty… feeling frail… episodes of uncertainty challenge identity… Making sense of changes… come to terms with their current situation" p4 UNCERTAINTY/CHANGE/					– IDENTITY/ COPING STRATEGIES (OP) "process of identifying as frail (is) transitional… had control over how they thought about being frail… key determinant of whether an individual adopted a frailty identity was disengagement – socially or physically – and not their physical impairments" p1492 AGENCY/ MAINTENANCE OF IDENTITY/ ADAPTATION –			

	TRAJECTORY/ CONTROL/WILLPOWER /PSYCHOLOGICAL CONSEQUENCES/ADJUSTMENT (OW) "withdrawn" p433 WITHDRAWAL (F/OP) "Frail older people experience episodic moments of frailty in their daily lives where daily living becomes precarious" p2 UNCERTAINTY/RISKY (OW) "value statements of pity, shame or disgust… not in charge" p433 VALUE/FAILURE/ LOSS OF AGENCY					CHANGE/ENGAGEMENT (OP) "most… did not identify as frail, suggesting people may have the ability to resist this process" p1494 RESISTANCE/ MAINTAINING IDENTITY (OP) "strategies to resist frailty… first, being active… 'Doing things' was (used) to 'fight against frailty'… second… relating their experiences to a particular limitation, part of the body, or… to a			

	(OW) “isn’t strong… doesn’t have a lot of emotional resources… needs to be taken care of… they don’ have the resources themselves, they haven’t found the resources themselves… dependent… at risk… deteriorating... more and more isolated” p434 EMOTIONAL RESILIENCE/DEPENDENCE/ TRAJECTORY/SOCIAL CONSEQUENCES (F/OP) “a sense of loss… loneliness as a consequence of increasing physical impairment” p2 SOCIAL					specific, isolated event… third… social comparisons with others they consider to be frailer” p1494 RESISTANCE (OP) “highlighted the preventative actions they take to delay frailty… healthy diet, exercising and ‘staying active’” p1495 PREVENTATIVE/ LIFESTYLE MODIFICATION (OP) “drawing on the past to make sense of the present. This increased their			

	CONSEQUENCE/PHYCHOLOGICAL CONSEQUENCE/LOSS (OP) "when others considered them frail they were avoided and excluded from social activities" p1493 EXCLUSION/IDENTITY/SOCIAL CONSEQUENCES (OP) "(some people) wallow in it… even act in a 'frail manner' in order to secure support… perhaps 'wallowing' is a way for people to cope" p1491 IDENTITY/SICK ROLE					optimism about the future and helped create a sense of self as resilient" p1388 MAINTAINING IDENTITY/ RESILIENCE (OW) "you have to be ambulant to enjoy life" p434 MOBILITY/PLEASURE (OP) "an occasional and temporary sense of despair when he first wakes with a diminished sense of motivation, which is restored as everyday routine kicks in" p1389 MOTIVATION			

	(OP) classed as frail on self-reported CFS but "stated he was not in 'frailty mode', which he described as 'sitting down' and 'wasting time'" p1492 PSYCHOLOGICAL CONTRIBUTORS/BEHAVIOURAL CONTRIBUTORS (OW) "frailty may be about preparing for death" p434 MORTALITY (OW) "building on their descriptions of physical frailty… narratives turned to social experiences… everyday struggles… a link not with age but with					(OP) "he might not always be able to rely on his daughter to… continue living at home… a less transient sense of vulnerability… countered by… inner strength and the acceptance that he will probably have to make a difficult decision about where to live in the future" p1389 (expectation of control and autonomy) AUTONOMY/LEVELS OF INTER-			

	particular experienced such as illness" p434 PHYSICAL CONSEQUENCES/SOCIAL CONSEQUENCES (OP) "Conversely, for the majority… the presence of health conditions or physical decline did not result in self-identifying as frail" p1491 IDENTITY SEPARATE TO PHYSICAL CONTRIBUTORS (OP) "acknowledgement of their limitations and impairments resulted in the adoption of a frailty identity" p1491 ACCEPTANCE/IDENTITY					DEPENDENCE/PLANNING (OP) "still doing all of these activities with an underlying continuity of self) p1390 MAINTAINING IDENTITY/ MAINTAINING ROUTINES "daily routine was an important anchorage" p1177 MAINTAINING ROUTINES/ANCHORAGE "sustaining connections" p1177 CONNECTIONS			

	(OP) “expected physical decline with increased age… acceptance of this natural process” p1491 ACCEPTANCE/LOSS OF CONTROL/INEVITABILITY (OP) “the three participants who identified as frail believed that frailty was due to factors beyond their personal control” p1491 IDENTITY/LOSS OF CONTROL (OP) “associated with physical appearance and emotional experiences” p20 VISIBLE/EMOTIONAL EXPERIENCE					(F) “increasing bodily capacity through exercise and adaptations… for some were welcomed… for others… seen in a more ambiguous light… learning something new or meeting new people was difficult” p1177 ADAPTATION/ EXERCISE (F) “new connections were created by allowing a level of inter-dependency on others” p1177 CONNECTIONS/			

	(OP) “Being frail’ was related to the objective classifications of frailty… but identifying as frail incorporated the negative and feared views about old people as feeble, dependent and vulnerable” p1490 OBJECTIVE/IDENTITY (OW) “instead of rejecting the concept of frailty, the women tended to speak of moments when they ‘felt’ frail… (different from) the earlier physical descriptions… in all cases… loss of control” p434					INTER-DEPENDENCY LEVELS (F) “although physically almost totally dependent, she retained enormous capacity to do things differently and thus to develop new connections” p1177 CONNECTIONS/ ADAPTATIONS “a relational creativity underpinned by the capacity to connect to their changing circumstances and adapt within the			

	EMOTIONAL EXPERIENCE/ LOSS OF CONTROL (OP) "three different points of gradations of physical frailty: intermittent dependency and interdependence…; continuing stable housebound dependence…; and highly escalating morbidity" p1428 DEPENDENCE/MORBIDITY (OW) "not only a physical description and an emotional experience but also a socially-					ambiguity and disconnections of being frail" p1178 ADAPTATION - CHANGE "Avoiding using the term 'frail'… use specific examples of living with frailty in order to drive self-identification" p7 LINGUISTICS/ MAINTAINING IDENTITY "Using language that resonates with OPs desire to maintain or return to a level of independent living" p7 LINGUISTICS			

	constructed concept… a way of talking… not something you say about yourself" p435 PHYSICAL CONSEQUENCES/ EMOTIONAL EXPERIENCE/ SOCIAL CONSTRUCTION/ IDENTITY (F/OP/FF/NHCPs) "becoming frail was not universally perceived as preventable and amenable to change" p14 IRREVERSIBLE/LOSS OF CONTROL (OP) "being identified as living with frailty is associated with loss of					"Medical professionals are not seen by OP as their first port of call for receiving help with everyday challenges" p8 SPECIALIST INPUT (OP/IC) "information about accessing preventative strategies and frailty services are received in the context of… attitudinal barriers that OP have to engaging with strategies and services" p8 OVERCOMING ATTIUDINAL			

	self-determination and self-efficacy" p1 LOSS OF CONTROL/WILLPOWER /FAILURE (OP) "most older persons do not expect to achieve the model of successful ageing where high cognitive and physical functioning is maintained until death… illness and frailty were seen not only as inevitable signs of old age, but also as the very essence of old age" p26 INEVITABILITY/ LOSS OF CONTROL/ ACCEPTANCE (OP) "more uncertainties (than NHCPs) and					BARRIERS/ KNOWLEDGE "provide intensive support at times of particular vulnerability and to prevent or minimize hospitalisation" p1437 SERVICE PROVISION – TIMELY SUPPORT/INTENSITY OF SUPPORT/COMMUNITY BASED "Being at home was important… brought feelings of control and anchorage… to previously frequently habituated places…			

	thought frailty was… inevitable and inherent to old age" p7 UNCERTAINTY/LOSS OF CONTROL (OW) "it's a description… (like) a very fat person, she's very frail… I can point out to you all the frail people when you see them" p435 VISIBILITY (F/OP) "a constant process characterised by a gradual decrease in their ability to manage daily living and routines over a period of time" p6 TRAJECTORY – GRADUAL					provide meaning and cohesion" p1429 HOME/COMMUNITY BASED/AUTONOMY/ MAINTAINING IDENTITY/ANCHORAGE "to see, be seen and remain connected to the outside world" p1429 MAINTAINING IDENTITY/AGENCY/CONNECTION (F/OP) "coping strategies" p7 COPING STRATEGIES (F/OP) "being supported in varying degrees by informal			

	(OP/HS) “a major concern… on the one hand, frailty interferes with the way old people like to live ad feel, and on the other hand, it substantially adds to the rise of health and care costs” p3 AUTONOMY/LIFE CHOICES/MEANINGFUL ACTIVITY (OP) “a spectrum of physical and mental health states…” p3 PHYSICAL AND MENTAL CONTRIBUTORS/SPECTRUM					and formal social support networks) p7 SOCIAL SUPPORT/COMMUNITY BASED (F/OP) “Reappraisal of ongoing changes… enabled the older participants to further redefine their problems and accommodate changes to daily routines” p8 ADAPTATION – ROUTINES/ MANAGING CHANGE (F/OP) “modifying existing patterns of daily living and			

	(OP) “slight gender bias… ‘little old lady’” p10 GENDER (F) “pain, increasing tiredness and lack of strength” p1177 PHYSICAL SYMPTOMS/CONSEQUENCES (OP/IC/GP) “Helpless, doddery, bony, shrivelled, wasting away, shaky, thin, horrible, weak bones, can’t do anything, old, little old lady, not me, small, tiny” p10 PHYSCALLY SMALL/LOSS OF CONTROL/LOSS OF IDENTITY/DIMINISHED					creating new ways of managing” p9 ADAPTATION – ROUTINES (F/OP) “Making choices in day-to-day living enabled (OP)… to continue to engage with life, providing a counterpoint to the idea that the visibility of agency decreases, as (OP) enter the fourth age” p9 AGENCY/ AUTONOMY/ DOING TO V DOING WITH “Daily routines… ground participants			

	VERSION/PHYSICAL SYMPTOMS "useless" p21 VALUE (OP) Independence scale: 2 "Getting slower… Feeling tired… Lacking in strength…" 3 "Struggling…frustrate… low… tough" 4 "losing control… not coping… feeling vulnerable… feeling weak" 4 "giving up" p17 "consistency in the language… OP used to… talk about the 'trigger point' (stage 2-3)… typically centred on words and phrases that referred to their mood and state of mind" p17					in the present and in a wider continuity of social relations… connected… to the… rhythm of work and rest practiced in wider society… for some, routine kept unwanted thoughts of dependency or decline at bay" p1429 MAINTAIN ROUTINES/ MAINTAIN IDENTITY (OP) "Paradoxically, connections with welfare services seemed to exacerbate imbalance… routines were often			

	NEGATIVE EMOTIONAL EXPERIENCE/LOSS OF CONTROL/SLOWING/PSYCHOLOGICAL CONTRIBUTORS/RISKY/BALANCE (OP/Puts) "described frailty both as a state of general physical impairment and disease, and as a condition with delineable social and psychological ill-effects" p1484 PHYSICAL/SOCIAL/PSYCHOLOGICAL (OP/Puts) "reduced ability to cope with their physical limitations, negative emotions,					disrupted" p1429 MAINTAIN ROUTINES (OP) "Particularly for those living on their own, a network of neighbours and friends predominated over family to provide this daily social 'glue'" (to be at home) p1429 COMMUNITY BASED/ SOCIAL SUPPORT (OP) barriers to accessing support: "limited understanding of what 'support' might look like… a belief that clinical			

	impaired cognitive functioning and poor social interactions" p1484 NEGATIVE EMOTIONAL/PHYSICAL/SOCIAL (OW/Grenier) "described frailty in relation to emotional responses and in the context of their functional limitations and physical changes" p1484 NEGATIVE EMOTIONAL/FUNCTIONAL/PHYSICAL (OP/Grenier) "not only an association with physical capacity but… powerlessness,					conditions take precedence over general physical and mental wellbeing" p19 KNOWLEDGE/ ACCESS (OP/IC) rename CGA to "be positive and position the service as something that an OP is shaping and driving, rather than being a passive participant" p24 DOING TO V DOING WITH/ LINGUISTICS (OP) "medical consultants… tended to be received more favourably (than)			

	dependency, cognitive decline, reflecting feared aspects of ageing" p1484 PHYSICAL/NEGATIVE EMOTIONAL/LOSS OF CONTROL (OP) "they depicted them as hunched over, grey-haired, wobbly and slow (physically and mentally" p1490 VISIBLE/PHYSICAL/MENTAL (OP) "poor health, mobility issues… functional impairments" p1490 PHYSICAL/FUNCTIONAL					specialists in support (e.g.) geriatricians, OTs and DNs" p24 SPECIALIST INPUT (OP) "unaware of CGA" p8 KNOWLEDGE/ DOING TO V DOING WITH (OP) "with mild frailty reported… purposeful or incidental health behaviours… exercise, paying attention to diet, socialising, activities to enhance mood and memory, and creating occupational			

	(OP) “negative thoughts and attitudes (e.g. Thinking you ‘weren’t good enough to do something’) … trepidation and vulnerability, inability to cope… common negative old-age stereotypes” p1490 NEGATIVE EMOTIONAL/VALUE/UN SUCCESSFUL (OP) “cycle of decline… became progressively more inactive” p1490 TRAJECTORY - CYCLE Att3:					activities” p396 BEHAVIOURAL/ BIOPSYCHOSOCIAL (OP) “assistive devices… modifying activities around frailty symptoms” p396 ADAPTATION - ENVIRONMENTAL (OP) “a network of social support” p397 COMMUNITY BASED/ SOURCES OF SUPPORT (OP/NHCP/IC) “Knowledge of local services and the skills to access them were considered			

	"OP articulate their physical and mental wellbeing in terms of being able to complete everyday tasks… do not primarily define themselves in terms of an overall state of frailty" p7 LINGUISTIC (A/OP)" For critical gerontologists and older people, questions remain about whose interests are being served by the social constructions of frailty" p123 SKEPTICAL – WHOSE INTERESTS Frailty as a concept presented as useful,					important" p397 KNOWLEDGE/ COMMUNITY BASED (OP) "Behaviours associated with independence and a sense of self developed over a lifetime were… more likely to be undertaken than those associated with "being elderly"" p397 BEHAVIOURAL/ INDEPENDENCE/ MAINTENANCE OF IDENTITY (OP/NHCP/IC) Domains to address health promotion:			

	however term is problematic. Focus is on significance of resonance of term with patients. SKEPTICAL - RESONANCE (SH) "stakeholders are less clear about the benefits of the concept of frailty and that a more nuanced dialogue about what frailty means is probably required" p349 SKEPTICAL – UNCLEAR BENEFITS "need to be aware of the unintended negative consequences of the constructs of frailty… labelling someone as					"mobility and exercise, socialising, finance and paperwork, computing skills, mood, memory, environmental adjustments, nutrition, medications management, personal hygiene, carer education" p398… "recommended addressing these domains through providing information… psychological support and practical support" p399			

	frail can lead to the stereotyping of an older person as failing to age well, which can be internalised by older people and cause unnecessary suffering… the very term used clinically to identify people for whom health can be optimised, is experienced by many as a term that labels people as failing" p350 NEGATIVE – LABELLING "it can describe the 'glass half empty', but not the ways in which the glass is half full" p350 NEGATIVE – DEFICIT FOCUS					HEALTH PROMOTION/ BIOPSTCHOSOCIAL/PRACTICAL/ INFORMATION PROVISION (OP/NHCP/IC) "Motivating people to change behaviour was viewed as…important… encouraging choice… and providing support over time" p399 MOTIVATING/ BEHAVIOUR CHANGE/ SERVICE DELIVERY - DURATION			

	(G/NHCPS/OP) "Concerns have been raised that ignoring the differences between (G/NHCPs/OP) in how frailty is understood might alienate the very people that interventions for frailty are designed to support" p1 SKEPTICAL – VARIOUS UNDERSTANDINGS (OP) "Consequences of seeing oneself as frail would become physical manifestations that furthered decline… identifying as frail led not only to frailty but… ultimately death" p1490					(NCHP/OP) "home based service was largely acceptable" p399 LOCATION (OP/IC/NHCP) "appointment frequency and duration should be individually tailored" p399 SERVICE DELIVERY - DURATION (IC/NHCP/some OP) "continuity of worker" p399 CONTINUITY (OP) "mostly preferred a mature person with life			

	NEGATIVE – IDENTITY/LABEL (OP) "frailty is a generalization and I don't think it has really any place in the medical conversation" p20 NEGATIVE – NON-MEDICAL "The linguistic connotation of the terminology has resulted in rejection from older people… contested biomedical utility and unclear management pathways have created resistance amongst some (HCPs)" p703					experience" p399 QUALITIES OF PROFESSIONAL - AGE (OP/IC) "communication skills… considered paramount, and professional qualifications, though favoured by carers, were seen by most OP and NHCPs as unnecessary and potentially detrimental (e.g. Appearing too extreme for their current issues, encouraging dependency) p399 PROFESSIONAL			

	NEGATIVE – CONNOTATIONS (NHCPS/PM/OP) "can have negative associations" p2 NEGATIVE – CONNOTATIONS (R:Warmouth/OP) "most participants actively resented the identity, even those who could be classifies as frail using objective criteria" p350 NEGATIVE – IDENTITY/ RESISTANCE (OP/NHCPs/PM) "There is growing evidence of antipathy to the term from older people, from					INPUT/ QUALITIES OF PROFESSIONAL - COMMUNICATION/ DEPENDANT ON LEVEL (OP) "shopping or socialising were not matters that could be addressed by healthcare services… suggested… overcoming this negative perception… included advertising in local non-health settings… using word of mouth and communicating a positive focus on maintaining health			

	non-specialist clinicians and from policy makers" p349 NEGATIVE (F) (Becker; Kaufman) "the label is often actively resisted by older people themselves, who distinguish the body one is (self-identity) from the body one has – a physically vulnerable object" p1173 NEGATIVE – IDENTITY/RESISTANCE (OP) The label of frailty is actively resisted as elders distinguish between the body one is (self-identity) and the body one has – a physical, vulnerable and					and independence rather than frailty or decline" p400 COMMUNITY BASED (OP) "new services for mild frailty should be personalised and focus on maintaining independence" p400 PERSONALISED/INDEPENDENCE (OP) "prefer a non-specialist trained worker to provide this low-level support, ideally over a sustained period of time" p400 SPECIALIST INPUT/			

	objectified social identity" p1427 NEGATIVE – IDENTITY/RESISTANCE / OBJECTIFICATION (R:Grenier/OP/F) "differentiate between being and feeling frail… actively resisted as older people distinguish between the body one is (self-identity) and the body one has – a physical, vulnerable and objectified social identity" p350 NEGATIVE – IDENTITY/RESISTANCE/ OBJECTIFICATION					SERVICE DELIEVERY - DURATION (OP) "specific professional skills were considered inappropriate for low-level support in health promotion in mild frailty" p400 SPECIALIST INPUT/ DEPENDENT ON LEVEL			

	"'frailty' does not resonate with older people nor is it something they identify with" p3 NEGATIVE – IDENTITY/ RESISTANCE/LINGUISTICS (OP) "some seniors might not prefer the term "frail" … Interviewees might be unwilling to consider and rate themselves frail." p4 NEGATIVE - IDENTITY								

Appendix 9: Concept Analysis - Sample of thematic analysis for 'The people being described as frail' category of concept analysis. Completed for all 7 categories in Appendix 7

Data Recording Sheet							
Discipline/population group	Attributes	Identification	Antecedents	Consequences	Management	Model case/ References	Philosophical view
	Att1: Has Frailty been operationalised, defined or conceptualised? **Att2:** Presents key characteristics, qualities or features inherent to Frailty? **Att3:** Is Frailty a useful concept?	**Ide1:** A specific means to identify or assess frailty is recommended and commented on?	**Ant1:** Events or phenomena preceding Frailty	**Con1:** Occurrences that follow Frailty defined	**Man1:** A specific management approach or intervention is recommended for frailty?	**Mod1:** Provides a clear example of Frailty **Ref1**: Identifies situations, incidents or phenomena in which Frailty can be considered.	**Phi1:** Entity, dispositional or evolutionary view of Frailty concept?
The people being described as frail	**Att1:** END OF LIFE "older people and their carers associated the term with end-of-life, cancer syndromes and high degrees of functional dependency"	**Ide1:** FUNCTIONAL THRESHOLD • TRIGGER POINT VISIBILITY • PHYSICALLY SMALL • OBJECTIVE	**Ant1:** POTENTIAL FOR CHANGE • VULNERABILITY • CHANGE • RISK • UNCERTAINTY PATTERNS	**Con1:** PHYSICAL CONSEQUENCES • MORTALITY • SLOWING • DEPENDENCY • HOSPITAL ADMISSION • DISABILITY	**Man1:** MODIFIABLE FACTORS • BEHAVIOURAL CONTRIBUTORS • PREVENTATIVE • LIFESTYLE MODIFICATION • OVERCOMING ATTIUDINAL BARRIERS • HEALTH PROMOTION	**Mod1:** "nothing wrong with my health but I have fallen five times and… I've broken everything"	**Phi1:** Dispositional: 8 Entity: 1 Evolutionary: 1

	LACKING - WELLBEING "requiring the mobilisation of resources to create wellbeing" **Att2:** SENSE OF SELF • UNSUCCESSFUL • VALUE • FAILURE • AUTONOMY • MAINTENANCE OF IDENTITY • THREAT • DIMINISHED VERSION • ACCEPTANCE • IDENTITY • LOSS OF AGENCY DEFICIT • LACKING LIVED EXPERIENCE • EMOTIONAL EXPERIENCE • INDIVIDUAL EXPERIENCE	• GESTALT	• TRAJECTORY – GRADUAL • SPECTRUM • TRAJECTORY – CYCLE PSYCHOLOGICAL CONTRIBUTORS • STATE OF MIND KNOWLEDGE • REDUCED AWARENESS OF RISK PHYSICAL SYMPTOMS • PAIN • FATIGUE	PSYCHOLOGICAL CONSEQUENCE • SICK ROLE • NEGATIVE EMOTIONAL • LACK OF DIGNITY SOCIAL CONSEQUENCES • WITHDRAWN • DEPENDENCY • EXCLUSION LOSS • LOSS OF CONTROL • LOSS OF AUTONOMY • LOSS OF IDENTITY • LOSS OF INDEPENDENCE • LOSS OF CONNECTIONS • LOSS OF MEANINGFUL ACTIVITY	PERMANENCE • PERMANENCE • INEVITABILITY MAINTAINING IDENTITY • CHOICE • ROUTINE • AUTONOMY • CONTROL • AGENCY • INDIVIDUAL EXPERIENCE • PERSONAL TRAJECTORY • ANCHORAGE • DOING TO V DOING WITH COPING STRATEGIES • RESISTANCE • LEVELS OF INTER-DEPENDENCE • PLANNING BELIEFS • REWARD/MOTIVATION • PERCEPTION ADAPTATION • ACCEPTANCE • ADJUSTMENT	"for some a gradual decline and for others a sudden and shocking rupture which they related to a specific event, for example a fall" "a person that's sitting in the armchair all the time" "losing independence, dignity and control" "isn't strong… doesn't have a lot of emotional	

	• CONTEXTUAL • BALANCE • DEPENDENCE • MEANINGFUL ACTIVITY • HOME • PERSONAL BIOLOGICAL • MORTALITY • PHYSICAL CONSEQUENCES • PHYSICALLY DIMINISHED • SLOWING • GENDER PSYCHOLOGICAL • PSYCHOLOGCIAL CONDITION • PSYCHOLOGICAL CONTRIBUTORS • EMOTIONAL RESILIENCE • SICK ROLE • NEGATIVE EMOTIONAL • WILLPOWER SOCIAL • SOCIAL CONSEQUENCES				• DELEGATION • COMPENSATION • MANAGING CHANGE • ENVIRONMENTAL POSITIVITY • FOCUS ON ABILITY • FOCUS ON INDEPENDENCE PSYCHOLOGICAL CONTRIBUTORS • KEEPING GOING • INTERNAL DRIVE • EMOTIONAL EXPERIENCE • PERSONAL SENSE OF VALUE • INNER STRENGTH • KNOWLEDGE • RESILIENCE • RESPECT • ENGAGEMENT • MOTIVATION QUALITIES OF PROFESSIONAL • RESPECTFUL • RELATIONSHIP CENTRED • AGE	resources… needs to be taken care of… they don' have the resources themselves, they haven't found the resources themselves… dependent… at risk… deteriorating... more and more isolated"	

	• WITHDRAWAL • DIVIDING • SOCIAL CONSTRUCTION **Att3:** NEGATIVE • LINGUISTIC • LABELLING • DEFICIT FOCUS • IDENTITY • NON-MEDICAL • CONNOTATIONS • RESISTANCE • OBJECTIFICATION SKEPTICAL • WHOSE INTERESTS • RESONANCE • UNCLEAR BENEFITS • VARIOUS UNDERSTANDINGS				• NON-SPECIALIST • COMMUNICATION SERVICE PROVISION • SPECIALIST INPUT • CONSIDERATION OF LINGUISTICS • TIMELY SUPPORT • INTENSITY OF SUPPORT • COMMUNITY BASED • NON-MEDICALISED PREFERRED • ACCESS • KNOWLEDGE • HOLISTIC • PERSONALISED • PRACTICAL • DURATION • CONTINUITY • FLEXIBLE • INFORMATION PROVISION SOCIAL SUPPORT • MAINTAIN CONNECTIONS PHYSICAL • MAINTAINING MOBILITY • EXERCISE		

Appendix 10: Concept Analysis - Concept analysis summary

People with frailty	Informal carers	Non-healthcare public	Non-specialist health professionals	Clinical experts	Professional and governing bodies
Frailty is…					
…an end to life and absence of wellbeing…	…serious and related to end of life…	…a visible part of the feared ageing process…	…vulnerability to change, complex system failure…	…susceptibility to adverse outcomes…	…extreme vulnerability to internal and external stressors…
…it is…					
…permanent and inevitable, broadly considered negative with uncertainty around the benefits and understandings (label, non-medical, deficit focus, objectified, stigma) …	-	…permanent and impersonal…	…preventable or reversible only to a certain threshold, viewed as both positive (anticipate needs, tailored care, unifying, holistic, risk management, aids decisions) and negative (scepticism around	…broadly viewed positively (clinical tool, manage economic risk, care planning) but with linguistic ambiguity…	…preventable, and broadly viewed positively for its potential to prevent admissions, reduce service use and costs, improve patient outcomes, encourage a holistic approach and legitimise clinicians…

			meaning, label, harmful to identify, non-individual, lack of dignity, non-specific, management unclear) in equal measure		
…preceded by…					
…state of mind, reduced awareness of risk, pain, fatigue, uncertainty and vulnerability…	-	…inactivity…	…physical (dementia, falls risk, comorbidity, weakening, ageing) …social (overprotective families) …psychological (bereavement, reduced engagement) …acute episodes (mental or physical) …functional (environmental changes, dependence)	…socioeconomic deprivation…	…medical interventions such as prescription medications or surgery…

…and presents as…					
…social (division, withdrawal, dependence) …psychological (threat to identity, loss of agency and control, feeling of failure, loss of dignity) …biological (slowing down, being female, being physically diminished, weakness)	…change to identity …a transition …visible signifiers …gendered (female) …physical …lower independence	…something that happens in care homes …visible …change in character …physical (weak, fragile) …change in social role …ageing process …functional dependence …psychological (helplessness, worry, fear, humiliation)	…identity change (lacking purpose, weak personality) …psychological (negative emotions, anxiety, low mood, low self-esteem, cognitive decline) …gendered (female) …objective (visible, thin, small) …functional change (reduced coping, reduced independence) …subjective …physical (end of life, thin, weak, poor mobility, malnourished, resus-order) …complex (cumulative, changeable, uncertain, dynamic)	…risk (*from* polypharmacy, *of* medical complications), psychological (fear of falls), cognitive, physical, multifactorial	…a gradual/progressive deterioration …physical (such as reduced mobility, urinary incontinence or side effects from medications) or cognitive …vulnerability

			…trajectories (scale)		
…identified by…					
…visible signifiers, and a functional threshold or “trigger point” …	-	-	…intuition (feeling, judgement, instinct) …assessment (advanced skills) …visible indicators (environmental clues) …assessment tools (Rockwood, Timed-Up-And-Go, standardised, simple score)	-	…assessment tools (standardised, objectifiable, deficit focus, electronic frailty scale), proactive screening (65+ years, electronic frailty scale) …
…and results in…					
…loss of independence, loss of control, loss of connection, loss of identity, acute admission, disability, dependency, exclusion, mortality…	…psychological consequence …disability …end of life	…disability, dependency, decrepitude, death…	…physical (death, injury, illness, falls, infection, pressure sores, reduced mobility) …use of services (admission) …dependence (institutionalisation) …psychological	-	…risk of negative health outcomes, substantial care needs…

…and can be managed by…					
…adaptation (resilience, acceptance, environmental) …positivity …psychological contributions …behavioural changes …lifestyle modifications …health promotion …physical intervention …maintaining identity …qualities of professionals …personal belief …adopting coping strategies …social support	…clinician skill …interventions (health behaviours, social, psychological, practical, knowledge increase, medications) …positive language …support at home …patient centred approach …service design	…controlling progression …social connectedness …maintaining independence …use of technology …exercise …activity …adaptation (personal and environmental) …psychological strategies	…service design (long term approach, reviews, information sharing) …support at home …interventions (mobility, nutrition, medication management, health promotion, coping, environmental modifications, falls recovery, muscle strength) …patient empowerment …psychological intervention …resilience …clinician training	…modifying health behaviours …considering whose responsibility ethically	…social engagement …falls assessment …ACP …dietary change …personalised care (patient lead) …effective service design (coordination and information sharing, monitoring, long term input) …proactive prevention (early identification and intervention) …support at home …health behaviours …education …resistance exercise

Appendix 11: Literature review - Inclusion and Exclusion criteria applied to scoping review of the literature

	Inclusion	Exclusion	Rationale
1	"Frail" or "Frailty" included in title	"Frail" or "Frailty" included in title	Frailty to be primary focus of paper in order to capture most significant evidence
2	Terminology used by people with frailty in existing literature or used by UK clinical guidelines, to refer to psychological aspects of frailty	Papers not using this terminology will not have been captured	Broad use of known clinical and lay perspectives to maximise breadth of sample
3	Terminology which describes a change in status or an active influence on the progression of frailty	Studies which do not refer to change in frailty *or* psychological status among people with frailty	Aiming to include all studies which offer insight into the relationship between changing frailty status and psychological or social factors, without limiting included methodologies or approaches
4	Studies of UK based cohorts, or predominantly UK based cohorts only	Studies predominantly or solely using participants outside the UK	To maximise transferability of known evidence to proposed study setting and identify gaps in current evidence base relevant to proposed setting
5	Peer reviewed articles only	Non peer reviewed	Capturing higher quality evidence
6	Articles published within the date range 2011-2021 (second search updated to 2021-2023)	Articles published prior to 2011	To reflect the most contemporary evidence base
7	Results refined to primary health and social care databases	Articles published in databases related to other disciplines	To capture the most relevant evidence to inform a health and social care study
8	Studies presenting empirical research	Opinion pieces, literature reviews and proposed studies	To identify and critique the existing evidence around frailty transitions and psychological or social influences

9	Frailty levels measured either objectively or subjectively	Frailty level not indicated at any time during the study	Extent and approach to frailty measurement is relevant to critical analysis of quality of evidence. Some indication of extent of frailty needed as basic requirement of subject area

Appendix 12: Literature review - Sample of the inclusion/exclusion criteria application process

	A	B	C	D	E	F
1	Gen area					
2	Title	Abstract	UK based	Empirical research	Frailty measured	Article Title
1561			non specific	review		Social frailty in older adults: a scoping review.
1562			china			Social Frailty is Associated with Physical Functioning, Cognition, and Depression, and Predicts Mortality.
1563			japan			Social Frailty Predicts Incident Disability and Mortality Among Community-Dwelling Japanese Older Adults
1564			non specific	review		Social frailty: the importance of social and environmental factors in predicting frailty in older adults.
1565						Social interactions, body image and oral health among institutionalised frail elders: an unexplored relationship.
1566			no UK cohort			Social isolation and loneliness as related to progression and reversion of frailty in the Survey of Health Aging Re
1567						Social isolation and loneliness as risk factors for the progression of frailty: the English Longitudinal Study of Age
1568			canada			Social Position and Frailty.
1569			america			Social Support, Stressors, and Frailty Among Older Mexican American Adults.
1570			no UK cohort			Socio-demographic determinants of worsening in frailty among community-dwelling older people in 11 Europea
1571						Socio-demographic Profile of Frail Institutionalized Elderly in Juiz de Fora - Minas Gerais.
1572			netherlands			Socioeconomic inequalities in frailty and frailty components among community-dwelling older citizens.
1573			china			Socioeconomic Inequalities in Frailty in Hong Kong, China: A 14-Year Longitudinal Cohort Study
1574			china			Socioeconomic status as a moderator between frailty and mortality at old ages.
1575			china			Socioeconomic status, frailty, and subjective well-being: A moderated mediation analysis in elderly Chinese.
1576						Soins des personnes fragiles: Des compétences professionnelles à celles plus profanes des aidants familiaux, qu
1577						Soluble ICAM-1, Independent of IL-6, Is Associated with Prevalent Frailty in Community-Dwelling Elderly Taiwan
1578						Spatial and temporal gait characteristics in pre-frail community-dwelling older adults.
1579						Special considerations for the treatment of multiple myeloma according to advanced age, comorbidities, frailty
1580				review		Specifying the content of home-based health behaviour change interventions for older people with frailty or at
1581			america			Spirituality, quality of life and frailty in community-dwelling adults ≥ 50 years.
1582						Split-course hypofractionated radiotherapy for aged and frail patients with head and neck cancers. A retrospect

Appendix 13: Literature review - Review strategy 21/03/21 What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in community settings?		
Reasoning	Search terms	Results
Primary subject of focus	**TITLE ONLY:** frail OR frailty	N = 82, 764
	AND	
Language taken from perspective of person with frailty in existing papers, and from NHS frailty toolkit and comprehensive geriatric assessment (CGA) template psychology section	**ALL FIELDS:** agency OR control OR preference* OR psychosocial OR dignity OR identity OR failure OR uncertainty OR coping OR behav* OR resilience OR belief OR acceptance OR lifestyle OR featur* OR mindset OR psychol* OR social*	N = 16, 024
	AND	
Language to represent the influence on change in frailty status	**ALL FIELDS:** contribu* OR influen* OR incidence OR decline OR effect OR prevent* OR meaningful OR significant OR trajector* OR intervention OR impact OR manage* OR pattern OR treat* OR transitions OR change OR progress* OR differen*	N = 12, 365
	AND	
Language to capture community-based locations in the UK	**ALL FIELDS:** discharge OR centre OR clinic OR "out patient" OR out-patient OR home OR rural OR urban OR community OR primary-care OR "primary care" OR housing OR "stay-at-home" OR social or community-dwelling OR remote	N = 8, 363

	AND	
	Peer reviewed articles only (higher quality evidence)	N = 7, 600
	AND	
	Date range: 2011-2021 (contemporary evidence)	N = 6, 027
	AND	
	Most relevant health and social care databases: MEDLINE complete (1384), Academic Search Complete (1024), CINAHL Complete (765), ScienceDirect (251), APA PsychInfo (240), Directory of Open Access Journals (238), Scopus (158), Social Sciences Citation Index (94)	N = 4, 154
	AND	
	Duplicates removed	N = 1, 871

Appendix 14: Literature review - Review strategy for updated review 19/02/23 **What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in community settings?**		
Reasoning	**Search terms**	**Results**
Primary subject of focus	**TITLE ONLY:** frail OR frailty	N = 140,546
	AND	
Language taken from perspective of person with frailty in existing papers, and from NHS frailty toolkit and comprehensive geriatric assessment (CGA) template psychology section	**ALL FIELDS:** agency OR control OR preference* OR psychosocial OR dignity OR identity OR failure OR uncertainty OR coping OR behav* OR resilience OR belief OR acceptance OR lifestyle OR featur* OR mindset OR psychol*	N = 36,882
	AND	
Language to represent the influence on change in frailty status	**ALL FIELDS:** contribu* OR influen* OR incidence OR decline OR effect OR prevent* OR meaningful OR significant OR trajector* OR intervention OR impact OR manage* OR pattern OR treat* OR transitions OR change OR progress* OR differen*	N = 29,070
	AND	
Language to capture community-based locations in the UK	**ALL FIELDS:** discharge OR centre OR clinic OR "out patient" OR out-patient OR home OR rural OR urban OR community OR primary-care OR "primary care" OR housing OR "stay-at-home" OR social or community-dwelling OR remote	N = 20,009
	AND	

	Peer reviewed articles only (higher quality evidence)	N = 18,894
	AND	
	Date range: 2021-2023 (updated search range)	N = 5,148
	AND	
	Most relevant health and social care databases: MEDLINE complete (1182), CINAHL Complete (394), ScienceDirect (155), Directory of Open Access Journals (246), Scopus (178)	N = 2,551
	AND	
	Duplicates removed	N = 1,484

Appendix 15: Literature review - Review strategy for updated review 19/02/23 - additional search term **Scoping literature review strategy – updated review 26/02/23** **What is known in the existing literature about the influence of psychosocial factors on changes in frailty status in community settings?**		
Reasoning	**Search terms**	**Results**
Primary subject of focus	**TITLE ONLY:** frail OR frailty	N = 140,598
	AND	
Language taken from perspective of person with frailty in existing papers, and from NHS frailty toolkit and comprehensive geriatric assessment (CGA) template psychology section	**ALL FIELDS:** social*	N = 14,835
	AND	
Language to represent the influence on change in frailty status	**ALL FIELDS:** contribu* OR influen* OR incidence OR decline OR effect OR prevent* OR meaningful OR significant OR trajector* OR intervention OR impact OR manage* OR pattern OR treat* OR transitions OR change OR progress* OR differen*	N = 11,307
	AND	
Language to capture community-based locations in the UK	**ALL FIELDS:** discharge OR centre OR clinic OR "out patient" OR out-patient OR home OR rural OR urban OR community OR primary-care OR "primary care" OR housing OR "stay-at-home" OR social or community-dwelling OR remote	N = 11,226
	AND	

	Peer reviewed articles only (higher quality evidence)	N = 10,529
	AND	
	Date range: 2011-2023 (replicating combined date ranges of two previous searches)	N = 8,812
	AND	
	Most relevant health and social care databases: MEDLINE complete (1635), CINAHL Complete (693), ScienceDirect (301), Directory of Open Access Journals (380), Scopus (465), APA PsychInfo (394), Social Sciences Citation Index (237), Journals@OVID (87), AMED (13)	N = 4,198
	AND	
	Duplicates removed	N = 3,698

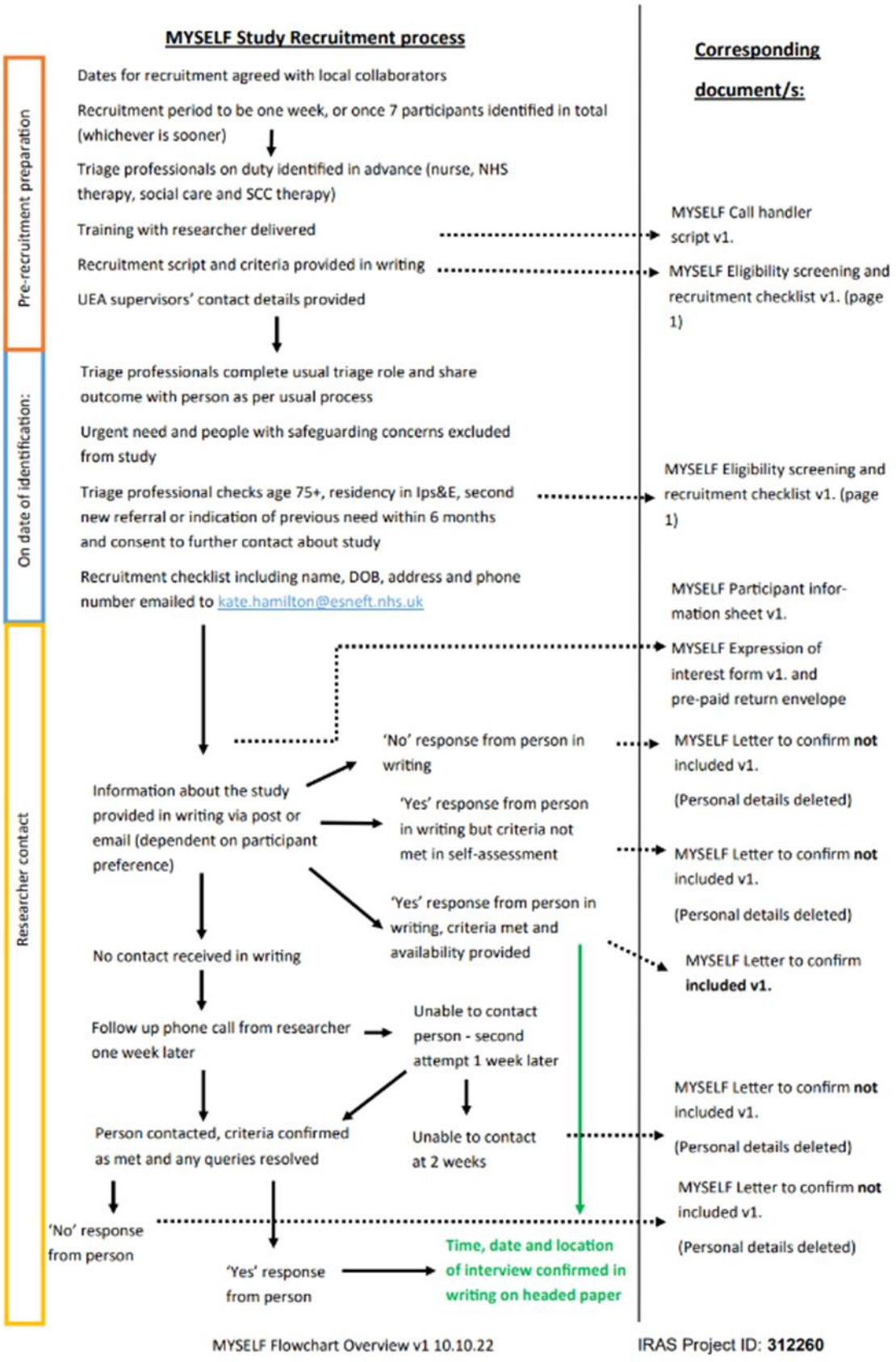
Appendix 16: MYSELF research study - Inclusion/exclusion criteria and rationale - recruitment wave 1 (3 pages)

	Inclusion	Exclusion	Rationale
1.	Age ≥75	Age ≤74	• Increased likelihood of identifying people living with frailty in comparison to including age 65+ (age which most frailty tools are validated for) • Includes a cohort likely to have expectations of an independent and well fulfilled lifestyle, as well as older cohorts
2.	≥3 'yes' response on self-assessment questions	≤3 'yes' response on self-assessment questions	• Questions are derived from the PRISAM-7 self-assessment frailty measure • Devised by the PRISMA group (Programme of Research to Integrate Services for the Maintenance of Autonomy) – an ethos aligned with this study's aims • Appropriate for completion verbally or by post • Appropriate for use if a person is unwell and use of physical assessments such as 'Timed Up and Go' might place the person at risk • Based on the individual's functional autonomy rather than adopting a medicalised model • Recommended by NICE and the British Geriatric Society as appropriate to identify frailty, and people who may benefit from an integrated service delivery model • Other commonly used assessment tools such as Clinical Frailty Scale can only be applied after a Comprehensive Geriatric Assessment (CGA) which will not be feasible to complete for the purpose of this study or accessible to the researcher if already completed
3.	One or more separate referrals before this one in the last 6 months, related to one of the 5 frailty syndromes: • Falls (e.g. collapse, legs gave way, 'found lying on floor'). • Immobility (e.g. sudden change in mobility, 'gone off legs' 'stuck in toilet').	• Previous referral but not related to the frailty syndromes • Duplicate referrals for same event or current involvement eg. GP and ambulance crew both refer following a fall	• Repeated referrals may indicate susceptibility to sudden deterioration as described by Clegg et al 2013 • Maximum 6 month period between referrals more likely to identify period of active change • PRISMA-7 has very good sensitivity but only moderate specificity for identifying frailty. Frailty syndromes can also be present without frailty. Combining PRISMA-7 and recent presence of frailty syndrome will increase accuracy in identifying frailty.

	• Delirium (e.g. acute confusion, 'muddledness', sudden worsening of confusion in someone with previous dementia or known memory loss). • Incontinence (e.g. change in continence – new onset or worsening of urine or faecal incontinence). • Susceptibility to side effects of medication (e.g. confusion with codeine, hypotension with antidepressants). Or indication that previous referrals were advised but declined	• Previous referral but ≥6 months ago • No previous referrals	
4	• Permanent home address in Ipswich or East Suffolk	• Temporary address eg. holidaymaker • Intention to move out of area within 12 months	• Within geographical areas of sponsor organisations • Reduce potential for participant drop-outs • Inclusion of both urban and rural areas within sample, representing different levels of access to public transport and amenities
5	• Self-referral and third party referrals	-	• Broad range of experiences of coming into contact with formal services • Intention to include people with different levels of autonomy, activation and ability to access services
6	• Telephone, written and online referrals	-	• Reduce potential bias in sample resulting from access to any particular referral method eg. only online referrals might favour more affluent or urban cohorts whereas only telephone might favour those with a more traditional outlook or with no verbal or hearing impairments
7	• People in receipt of formal care or personal budgets • People with informal care and support arrangements • People with no existing care or support arrangements	-	• Initial broad sample exploring a range of lived experiences • Avoid any assumptions about 'coping' or 'not coping'
8	• People with no known risks recorded on the records system	• People with known risks recorded on the records system	• The call handler will not be asked to make decisions about whether an specific risk would warrant exclusion from the study therefore any recorded risk will be treated as an exclusion criteria

			• Examples of risks recorded may include history of domestic violence, weapons in the property, need to visit in pairs or pets in the property. Access to this prior information or the need to take additional precautions may hinder a neutral relationship between the researcher and the person or lead to potential bias • This exclusion criteria may risk less representation of some 'hard to reach' groups however researcher safety must remain the priority

Appendix 17: MYSELF Study Recruitment process - flow chart



Appendix 18: MYSELF - Triage professional's script v1 10.10.22 (1 page)

MYSELF research study – *Triage professional's script*

(Once all aspects of processing referral complete and triage role has otherwise ended)

Estimated time: 1 ½ mins

Triage professional:

"Before you go, we are currently working with a student called Kate Hamilton from the University of East Anglia, who has asked me to invite you to take part in a research study.

Kate is looking for people to take part in a series of interviews to find out what helps people get back to normal after changes in their health or day to day life. Taking part is voluntary and is separate from the reason you have been in touch with us today. We won't be sharing any information from your records with Kate as the study is entirely separate. You are not being asked to commit to anything right now and would be able to leave the study at any time in future.

Would you be interested in finding out more about the study and whether you might be eligible?"

Person:

"Yes please"

Triage professional:

"Ok, great. Kate would like to send you some information about the study to have a look at. Would you prefer Kate to send you the information by post or by email?"

Person: states contact preference

Triage professional:

"Is there anything Kate needs to know to make it easier for you to read the study information, for instance do you prefer a larger text or a language other than English?"

"Are you happy for Kate to call you after she's sent the information in case you have any questions?"

Person: Yes/No

"And finally, can I please check you're happy for me to share your name and [preferred contact details] with Kate? [confirms correct details]"

"Thank you for your time"

End – estimated time 1 ½ mins

Person:

"Maybe/not sure"

Triage professional:

"There is absolutely no obligation Mr/Mrs X. Would you be interested in receiving an information pack either by post or email and some time to think about it? Alternatively I can ask Kate to call you over the next few days to talk about the study before you decide?"

Person:

"Yes please"

Triage professional:

"No problem. Can I please confirm I have your consent to share your name and [preferred contact details] with Kate? [confirms correct details]"

"Thank you for your time"

End – estimated time 1 ½ mins

Person:

"No"

Triage professional:

"Ok, that's no problem at all. Thank you for your time."

End – estimated time 1 min

Person:

"No thank you"

Triage professional:

"Ok, that's no problem at all. Thank you for your time."

End – estimated time 1 min

Appendix 19: MYSELF Eligibility and recruitment checklist v2 02.12.22 (2 pages)

MYSELF Eligibility screening/recruitment checklist v2

	Participant name:	**Age:**
	Address:	**Gender:** *M / F / prefer not to say*
Sections 1-5: call handler to please complete:		
		Please circle/delete as appropriate:
1.	Is the individual aged 75 or over?	Yes No
2	Is the individual a permanent resident in the Ipswich or East Suffolk area?	Yes No
3	Is this the second new referral for this person over the last 6 months, or has a previous referral been discussed/recommended and not completed for any reason e.g. person declined at the time?	Yes No
4	Does the individual consent to sharing their name, age and contact details with the researcher for the purpose of follow up contact from the researcher to learn more about the study without obligation to join the study?	Yes No
5	Are there **no** known hazards or safety alerts formally highlighted, for example as an alert to other professionals on the home screen?	Yes No
6	Does the person have sufficient English language skills to participate in an interview?	Yes No

If yes to all the above, please indicate preferred contact method and contact details:

Post ☐ Phone ☐ Skype/Zoom ☐

Form to be emailed to kate.hamilton@esneft.nhs.uk Thank you.

Sections 6-10 for researcher to complete:		
	Post/email	
6	Individual sent Participant Information Sheet, Expression of Interest Form x2, and return envelope if postal?	☐ Date sent …… Follow up call 1 week later ☐ No contact within 2 weeks? ☐ - letter/email sent confirming not included in study
7	Expression of Interest form returned indicating a positive response to 3 or more of the 5 self-assessment questions?	Yes No
8	Expression of Interest form received with availability indicated?	☐
9	Interview date/time posted/emailed to individual?	☐
10	Capacity demonstrated and written consent to participate received at first face to face visit	☐
Or	**Phone / Teams / Skype**	
6	Consent for call confirmed and gatekeeper questions 1-5 checked?	Yes No
7	Self-assessment questions completed verbally with 3 or more positive responses indicated?	Yes No
8	Participant Information Sheet read to individually verbally or posted as per individual preference?	☐ read ☐ posted
9	Interview date and time confirmed?	☐
10	Capacity demonstrated and written consent to participate obtained at first face to face visit	☐

Appendix 20: MYSELF Participant Information Sheet (PIS) v2 02.11.22 (8 pages)

Mrs Kate Hamilton
Professional Doctorate student

Faculty of Medicine &
Health Sciences

School of Health Sciences

University of East Anglia

December 2022

The 'MYSELF' study: The (M)echanisms of destabilisation in older people living with frailt(Y): understanding social influences on frailty trajectory, (SELF)-management and personal responses to change

PARTICIPANT INFORMATION SHEET v2

(1) Summary

You are invited to take part in a research study about the experience of managing at home for people aged over 75 living across Ipswich and East Suffolk. You have been invited to participate in this study because you are a resident within the Ipswich and East Suffolk area and have recently had more than one contact with a health or social care service. This Participant Information Sheet tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it or for future research.

We will make sure no-one can work out who you are from the reports we write.

Participation in this research study is voluntary. By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.
- ✓ Have received a copy of this Participant Information Sheet to keep.

(2) Who is running the study?

The study is being carried out by the following researcher:

Mrs Kate Hamilton - Student on the Professional Doctorate in Health and Social Care programme at the University of East Anglia.

This will take place under the supervision of Prof Fiona Poland - Professor of Social Research Methodology at the University of East Anglia, and Dr Linda Birt - Senior Research Associate at the University of East Anglia.

The term 'we' in this information sheet refers to the sponsor organisation, the University of East Anglia. The terms 'I', 'you', 'me' or 'my' refer to you as the person who may wish to participate.

(3) What will the study involve for me?

As a participant in this study you will be asked to take part in a maximum of three interviews over the course of a year. Interviews will take place at your home or another location of your choosing where you are comfortable. If you would prefer not to meet in person a virtual interview can be arranged online via zoom or teams. Interviews will take up to an hour at most and will be arranged on a date that suits you. You will be asked to write down what you consider to be important things that happen in your life from month to month, and to talk about these during each interview. Interview discussions will be audio recorded and transcribed whether face to face or virtual, and any details from which you might be identified will be removed for confidentiality. No images will be recorded.

At each interview you will be asked to reflect on the previous few months, discussing how you have been managing at home. General topics for discussion will have been prepared by the researcher, however you will be asked open questions such as 'how have you been managing at home since we last met?' or 'how would you describe the level of support you have available?'.

Your name and contact details have been shared as per the consent you gave when you discussed the study with the call handler from the health or social care team. The researcher will not have access to any information about you beyond what you choose to share. Any notes you may share about important life events, or anything disclosed during interviews will only be used for the purposes of this study and will not be shared with any third parties.

During the interview an audio recording of the conversation will be made. After the interview the researcher will turn this recording into a written record of the conversation. Once the written transcript is compete the researcher will delete the audio recording.

At the start of your second or third interview the researcher will talk to you about the main focus/es of the previous interview to make sure what you have said has been understood accurately. You will have the opportunity to see a summary of the findings of this study once it is complete.

(4) How much of my time will the study take?

Each interview will take a maximum of one hour, or a duration comfortable for you. Ideally we would like to interview you three times in total over a period of up to 12 months, but if you would prefer to only do 2 interviews this can also be accommodated. A small amount of note making between interviews is suggested to record key events for discussion. You will be given a diary to make these notes in.

(5) Do I have to be in the study?

Being in this study is completely voluntary and you do not have to take part. If you do choose to take part you may choose not to answer any questions that you do not wish to answer during the interview. You may also choose to have someone else with you during the interview if you would like to.

Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of East Anglia, East Suffolk and North Essex NHS Foundation Trust (ESNEFT) or Suffolk County Council (Social Care) now or in the future.

If you decide to take part in the study, you can withdraw at any time. You can do this by stating this intention either verbally or in writing to the lead researcher.

(6) What are the consequences if I withdraw from the study?

Even if you agree to participate now, you are free to leave the study at any time without consequences of any kind. You may choose not to answer any of the interview questions, or to end an interview at any time without consequences of any kind. You may withdraw permission to use data from your interview within 2 weeks after the interview, in which case the material will be deleted.

(7) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any particular risks or costs associated with taking part in this study. If you would prefer to have someone with you during the interview such as a friend or family member or a carer you are entirely free to do so.

(8) Are there any benefits associated with being in the study?

This study is entirely separate from any other contact you may be having with health or social care services, but offers an opportunity to share your experiences of managing at home in older age.

We anticipate learning from this study will help shape and inform community health and social care services across Ipswich and East Suffolk. Research based on lived experience helps develop high quality services that meet the needs of older people.

(9) How will we use information about you?

We will need to use your contact details and information from you for this research project.

This information will include your:

- Name
- Address
- Phone number
- Age
- Any information you provide during interviews
- Anything you write down in the research diary provided

People will use this information to do the research or to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

(10) What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

(11) Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/

- from the Health Research Authority's information leaflet available from http://www.hra.nhs.uk/patientdataandresearch
- by asking the researcher Kate Hamilton - 07926 074 725, or
- by emailing the University of East Anglia's Data Protection Officer Ellen Paterson - **dataprotection@uea.ac.uk**

(12) What if I would like further information about the study?

When you have read this information, Mrs Kate Hamilton (kate.hamilton@uea.ac.uk, 07926074725) will be available to discuss it with you further and answer any questions you may have.

(13) What if I have a complaint or any concerns about the study?

If there is a problem please let the researcher know using the contact details above. If you would prefer, you can contact the primary supervisor for the study via the University of East Anglia at the following address:

Prof. Fiona Poland

School of Health Sciences

University of East Anglia

NORWICH NR4 7TJ

F.poland@uea.ac.uk

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact:

Dr. Nicola Spalding - Deputy Head of School of Health Sciences University of East Anglia

NORWICH, NR4 7TJ

N.Spalding@uea.ac.uk.

(13) How do I know that this study has been approved to take place?

To protect your safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research has been approved by the UK wide Research Ethics Service managed by the Health Research Authority.

(15) OK, I want to take part – what do I do next?

You need to fill in one copy of the expression of interest form and return using the enclosed stamped addressed envelope to:

Kate Hamilton - Doctoral Student,

c/o East Suffolk and North Essex Foundation Trust,

Constantine House, 5 Constantine Road, Ipswich, IP1 2DH.

Please return the expression of interest form within 2 weeks if you are interested in taking part. You should keep the letter, information sheet and the second copy of the consent form for your information.

The researcher will also call you 1 week after sending you this study information just in case you have any questions. You do not need to answer this call if you do not wish to. You may also use the phone numbers included in this information sheet Monday-Fri 8.30-4.30 should you wish to discuss anything related to this study. If you call outside these hours please leave a message and the researcher will call you back as promptly as possible.

Appendix 21: MYSELF research study - Expression of interest form (1 page)

MYSELF research study - *Expression of interest form*

I ..... would like to express my interest in participating in the MYSELF research study.

I can confirm that (please tick):

I have read and understood the Participant Information Sheets and am aware that the study has inclusion criteria. As such I am aware that I may not be selected to participate in the study.	☐
I have completed the self-assessment questions below: I have a health problem/s that require me to limit my activities YES ☐ NO ☐ I need someone to help me on a regular basis YES ☐ NO ☐ I have a health problem that requires me to stay at home YES ☐ NO ☐ I regularly use a stick, walker or wheelchair to get about YES ☐ NO ☐ I have someone close to me i could count on in a time of need YES ☐ NO ☐ I understand that my responses to these questions will help determine whether I will be invited to take part in the study	☐
I have provided my preferred contact details below to enable the researcher to contact me:	☐
Address: Phone number: Email address: Other: Communication needs: Availability:	

Please return this form within 14 days using the enclosed envelope to: **Kate Hamilton c/o ESNEFT community teams, Constantine House, 5 Constantine Road, Ipswich, IP1 2DH.**

MYSELF Expression of interest form v1 10.10.22 IRAS Project ID: **312260**

Appendix 22: MYSELF Letter to advise inclusion criteria NOT met v1 10.10.22 (1 page)

Mrs Kate Hamilton
Professional Doctorate student

Faculty of Medicine & Health Sciences
School of Health Sciences

University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
United Kingdom

(Date) 2022

Re: MYSELF study: personal responses to change

Dear [name],

Thank you for completing and returning the Expression of Interest form and self-assessment questions.

Unfortunately, as explained in the original paperwork you received, I am unable to involve everyone who has expressed an interest in taking part in this study. On this occasion, you have not been selected to be interviewed about your experiences as your self-assessment responses did not match the criteria we were focussing on for this study.

If you have any questions regarding this, please do not hesitate to contact me.
May I take this opportunity to thank you very much for your interest in this project.

With kindest regards

Kate Hamilton
Professional Doctoral Student

kate.hamilton@uea.ac.uk

07926 074 725

Appendix 23: MYSELF Letter to confirm inclusion criteria met v1 10.10.22 (1 page)

Mrs Kate Hamilton
Professional Doctorate student

Faculty of Medicine & Health Sciences
School of Health Sciences

University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
United Kingdom

(Date) 2022

Re: MYSELF study: personal responses to change

Dear [name],

Thank you for your interest in the MYSELF study and for completing and completing the self-assessment questions.

I would like to invite you to participate in this study and be interviewed by myself as the researcher. Based on the availability you indicated on the Expression of Interest Form, I would like to visit you at your home on:

Xxxxxxxx the xxxxxth of xxxxxxxxx at xxxxxxxx

If this is not convenient or you have any questions in the meantime, please don't hesitate to contact me.

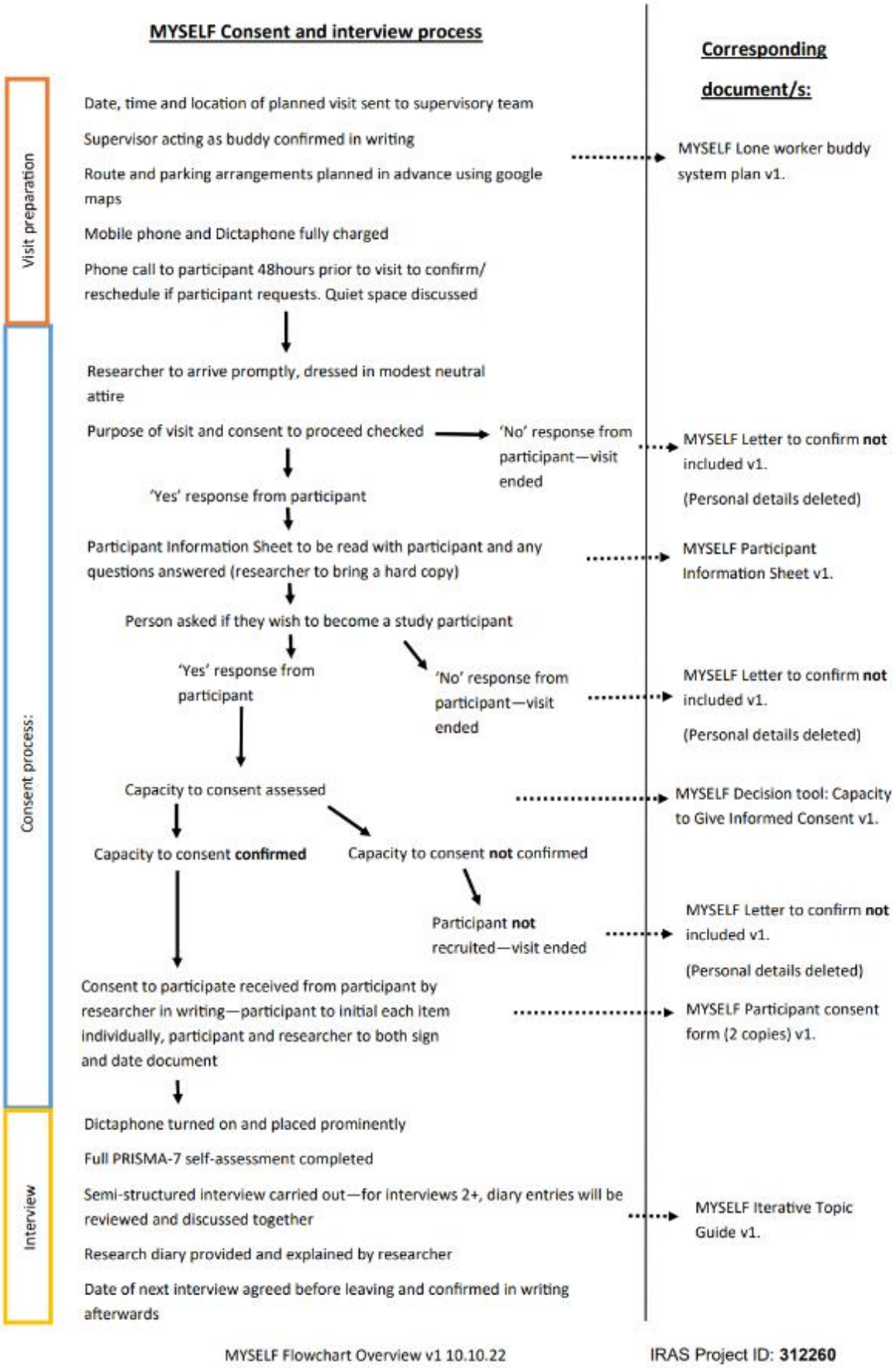
With kindest regards

Kate Hamilton
Professional Doctoral Student

kate.hamilton@uea.ac.uk

07926 074 725

Appendix 24: MYSELF Consent and interview process flowchart



Appendix 25: MYSELF Decision tool - capacity to give informed consent - Version 1 10.10.22 (2 pages)

MYSELF research project

***Assessment of capacity to provide informed consent to participate in the MYSELF research project* – for completion by researcher prior to starting the consent process**

Potential participant name	
Researcher name	
Researcher signature	
Date	

Capacity should be assumed unless otherwise proven. Practical steps to increase understanding should be taken. Considerations may include:

1. Does the person have all the relevant information they need? Y/N
2. Could information be explained or presented in a way that's easier for them to understand (for example, by using simple language or visual aids)? Y/N
3. Have different methods of communication been explored, such as non-verbal communication? Y/N
4. Could anyone else help with communication, such as a family member, carer or advocate? Y/N
5. Are there particular times of day when the person's understanding is better? Y/N
6. Are there particular locations where the person may feel more at ease? Y/N
7. Could the decision be delayed until the person might be better able to make the decision? Y/N

The potential participant must have received the Participant Information Sheet and discussed it verbally with the researcher before carrying out this assessment.

The Mental Capacity Act requires that in order to demonstrate capacity an individual should:

A. Understand the purpose of this research
B. Understand what is expected of them if they take part
C. Retain the information long enough to weigh up risk and benefits to them
D. Be able to identify any consequences of their taking part or refusing to take part
E. Communicate their decision.

The researcher should now ask the following questions.

Question to be asked	Indicative reply showing potential participant understood this question	Ability (A-E) being assessed	Did the person reply appropriately?
Can you tell me what the study is about?	Mention: managing at home, important changes in my life, how much support I need, what I do when things change, how happy I am with my life	A	YES / NO
If you take part in the research do you know what it will involve?	Mention: talking to researcher more than once and/or being asked questions and/or talking in own home and/or keeping track of important events	B	YES / NO
If you take part in the research will there be any benefits to you or others?	No Yes (ask person to describe)	C	YES / NO
If you take part in the research do you think there will be any problems for you?	No Yes (ask person to describe)	C/D	YES / NO
If you decide not to take part in the research will it affect your care?	No Yes (ask the person to describe)	C/D	YES / NO
Would you like to take part in this study?	Yes/No	E	YES / NO

If all questions are answered appropriately the person has demonstrated they have capacity to consent. Move to the consent process.

If the above considerations have been made and the person remains unable to answer appropriately to 1 or more questions they will not have demonstrated their capacity to consent, so that the consent process cannot be started.

Appendix 26: MYSELF Participant Consent Form v2 02.12.22 (6 pages)

MYSELF research study

PARTICIPANT CONSENT FORM v2 (First Copy to Researcher)

I, ... [PRINT NAME], **am** willing to participate in this research study.

In giving my consent I state that:

	Participant's Initials:
I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.	
I have had the purpose and nature of the study explained to me in writing (Participant Information Sheet v2 02/12/22) and I have had the opportunity to ask questions about the study.	
I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia, East Suffolk and North Essex NHS Foundation Trust (ESNEFT) or Suffolk County Council (Social Care) now or in the future.	
I understand that I can stop being part of the study at any time, without giving a reason.	
I understand that I can withdraw permission to use data from my interview within 2 weeks after the interview, in which case the material will be deleted.	

I understand that I may choose to end an interview at any time, and/or not to respond to any interview questions I would prefer not to answer.	
I understand that the results of this study may be published but that I will not be identifiable in any publications.	
My non-identifiable data will be stored in the University of East Anglia's data repository after the study for the purposes of supporting future studies or checking the findings of this study.	
I understand that my personal details will only be shared with people who need to know who I am as part of the study, unless I give my express permission.	
I understand that interviews will be **audio recorded**	
I understand that I will be asked to use a **research diary** in between interviews and that these will be kept by the researcher and replaced at each interview	

Participant's name (PRINT):

Participant's signature:

Date:

Researcher's name (PRINT):

Researcher's signature:

Date:

In the event of any emergency, is there anyone you would like the researcher to contact?:

In the event of an emergency, do you have any advance decisions in place which you would like the researcher to be aware of?

Researcher to complete:

Consent received: ... Face to face ☐

Virtually (transcript of conversation included) ☐

MYSELF research study

PARTICIPANT CONSENT FORM v2 (Second copy to participant)

I, ... [PRINT NAME], **am** willing to participate in this research study.

In giving my consent, I state that:

	Participant's Initials:
I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.	
I have had the purpose and nature of the study explained to me in writing (Participant Information Sheet v2 02/12/22) and I have had the opportunity to ask questions about the study.	
I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia, East Suffolk and North Essex NHS Foundation Trust (ESNEFT) or Suffolk County Council (Social Care) now or in the future.	
I understand that I can stop being part of the study at any time, without giving a reason.	
I understand that I can withdraw permission to use data from my interview within 2 weeks after the interview, in which case the material will be deleted.	

I understand that I may choose to end an interview at any time, and/or not to respond to any interview questions I would prefer not to answer.	
I understand that the results of this study may be published but that I will not be identifiable in any publications.	
My non-identifiable data will be stored in the University of East Anglia's data repository after the study for the purposes of supporting future studies or checking the findings of this study.	
I understand that my personal details will only be shared with people who need to know who I am as part of the study, unless I give my express permission.	
I understand that interviews will be **audio recorded**	
I understand that I will be asked to use a **research diary** in between interviews and that these will be kept by the researcher and replaced at each interview	

Participant's name (PRINT):

Participant's signature:

Date:

Researcher's name (PRINT):

Researcher's signature:

Date:

In the event of any emergency, is there anyone you would like the researcher to contact?

In the event of an emergency, do you have any advance decisions in place which you would like the researcher to be aware of?

Researcher to complete:

Consent received: ... Face to face ☐

Virtually (transcript of conversation included) ☐

Appendix 27: MYSELF Iterative Topic Guide - Version 1 10.10.22 (4 pages)

MYSELF research study – *Iterative Topic Guide*

Note: Participant Information Sheet (PIS) to be read with participant prior to interview, and capacity to consent decision tool to be used. Subject to capacity being confirmed, the participant should complete the consent form themselves prior to starting the interview. Recording may then start.

Introduction

- I realise we've just covered this Mrs X, but as we've just starting recording I'd like to start by confirming with you please that we have read through the participant information sheet again together, that you are aware that the purpose of this research study is to understand more about how older people across East Suffolk manage at home and respond to changes. Are you happy to continue with the interview today Mrs X?
- If you would like to stop or take a pause at any time please let me know
- I have planned to spend up to an hour with you today but if you would like to stop sooner we can
- I will be recording our conversation today on this Dictaphone (prominently placed and pointed out), but I'll be transferring this into a written version of the conversation and deleting the recording as soon as I've done that – this normally takes me around 4 weeks
- As we've talked about before, you are welcome to leave the study at any time.
- There are no right or wrong answers, and all your views have value here
- Please ask me to clarify if the question isn't clear
- The only other thing I need to remind you of before we start is that although this is a confidential space, if you tell me anything that suggests you or someone else is at risk of harm or that a law has been broken I may need to share this information further. We would talk this through first if it came up.
- Are you happy to continue?

Indicative topics

Focus areas for interview 1:

Building rapport

Wider context – connections to community, getting out

Getting on at home – recent changes

Reason for referral/'tipping point'

Decision making – seeking support versus self-management

Interview 1

Broad context about life at home: 'I'd like to understand a little bit about living in X'

- *Can you tell me a little bit about what it's like for you living in X?*
  - How long have you lived here?
  - How did you come to live here?
  - Can you tell me what you particularly like about living here?
  - And can you tell me anything you particularly dislike about living here?

Getting out and about:

- *Can you tell me about getting out and about in X?*
  - How do you feel about going out in X?
  - Can you tell me what comes to mind when you think about going out in X?
  - Consider PRISMA 7 response to related question

Managing at home: 'and just shifting our focus now to life at home'

- *How have you been getting on at home recently*?
  - How do you feel when you're at home?
  - Who would you say takes part in the running of your home day to day?
  - *How do you feel about day to day life at the moment?*
  - *What parts of your life are going well for you at the moment?*
    - How can you tell if something is 'going well'??

- Consider PRISMA 7 response to related question
- *Are there any parts of your life you feel less satisfied with?*
- Why do you think that is?
- How do you feel about the amount of support you have around you?

The 'tipping point': The reason we have ended up sat here today is because X referred you to X service (specific detail for individual participant).

- *Can you tell me in your own words about how you came to be referred to X please?*
  - Why did it happen?
  - Looking back, to what extent were you expecting this to happen do you think?

Decision making: 'I'd like to understand more about the decisions involved in getting in touch with X service'

- *Whose decision was it to get in touch with X?*
- How did you feel about the referral?
- Can you tell me about any previous contact you've had with health and care services?
- What were your expectations of what might happen after this referral was made?
- *Can you tell me about a time recently when you have asked for help from someone else?*
- How do you feel about asking for help?
- Consider PRISMA 7 response to related question
- *Can you tell me about a time recently when you could have asked for help with something but chose not to?*
- How did you deal with the situation yourself? What went well? Is there anything you wish you had done but didn't do?
- *What are your thoughts on getting back to normal when something like this has happened?*
- What do you feel is important in that process?

Do you have any further thoughts you would like to share about our conversation today?

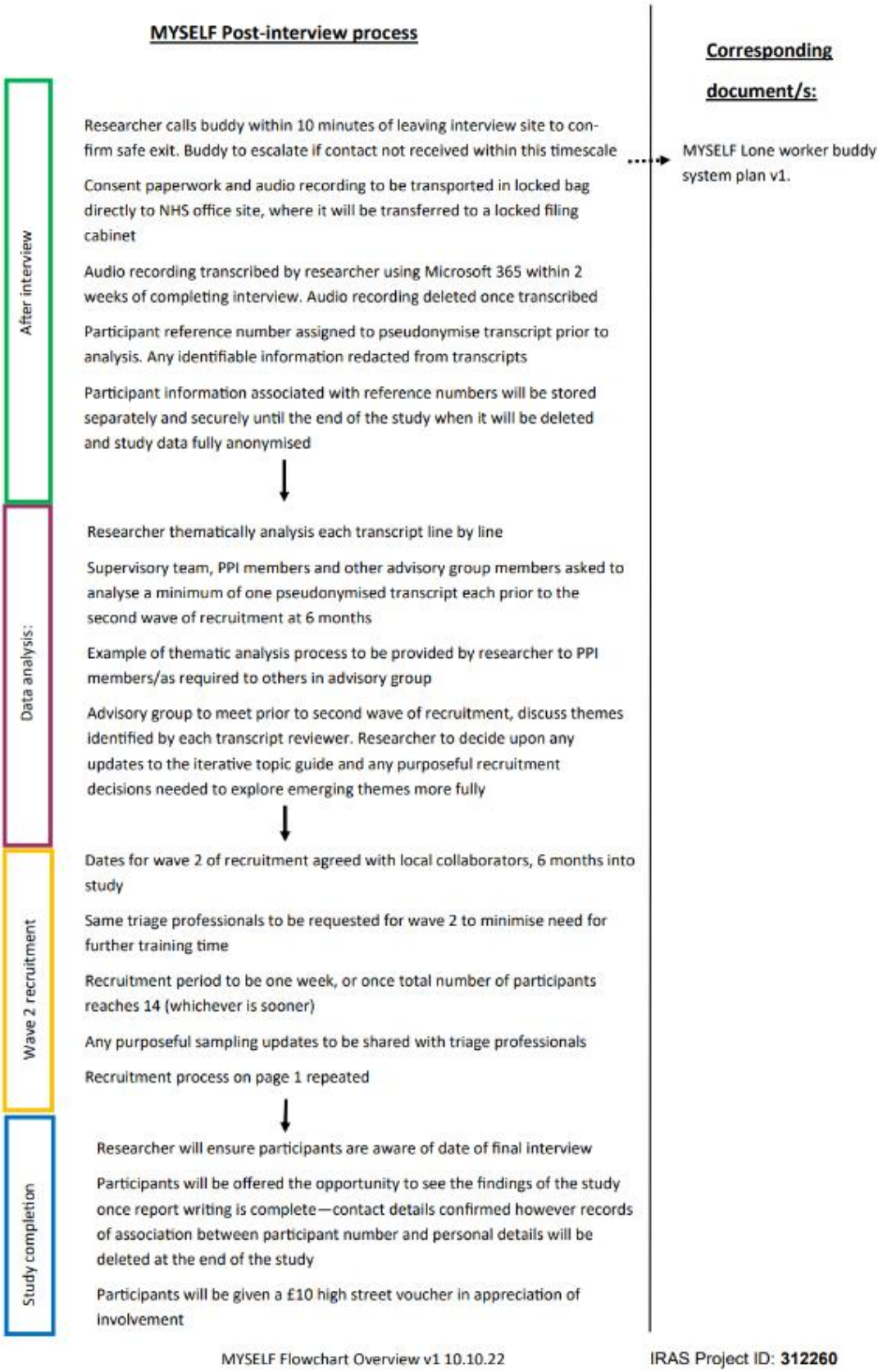
Conclusion: Thank you for your time and for sharing your thoughts with me. Our conversation today has been really valuable.

As I said earlier, I will take the recording with me and transcribe it before I delete it. Once I have read through it again I would really like to come back and talk to you again with some more questions if that's ok? Are you happy to book a date in now for three month's time? I will call you before then to confirm, so if you change your mind at all or need to change the date that's no problem.

In the meantime, can I please ask you to complete this diary? This will help our discussion next time we meet as we will be able to look in more detail at how you are over the next 3 months. If you are able to complete this once per week that would be great, but even once per month would be helpful. As you can see, there is some guidance right at the front, and there is a double page spread for each week with 6 questions to answer. Do you have any questions about the diary or what will happen next?

Once again Mrs X, thank you for your time.

Appendix 28: MYSELF post-interview process flowchart



Appendix 29: MYSELF research study - Participant Diary sample of Diary 1 v1 10.10.22 - Cover and p2-4. Subsequent content for weeks 2-20 provides identical content to week 1 (p3-4)

MYSELF research study

Participant diary 1

V1 10.10.22

IRAS Project ID: **312260**

What is this diary for?

This diary has been designed by the researcher to help you keep track of the things going on in your life from week to week, what is going well for you and how you feel about dealing with challenges. We will look back at it during our interview conversations and use it to help explore how the previous few months have been for you.

Why are there only 20 weeks in the diary?

The researcher will collect this diary at the end of each interview and you will be given a fresh diary for next time. The pages are likely to look very similar but the questions may change slightly to help focus on different parts of life.

What if I don't have time to fill out the diary or I forget?

Please don't worry. The more you are able to fill out the more we will have to discuss together at the next interview, however any time you give to this study including filling out this diary is entirely voluntary and is appreciated. Please try to aim for at least four diary entries between each interview if you can.

How do I answer the questions on the right hand page?

Write one X on each line. Placing it closer to the end of the line shows you strongly agree or disagree with the statement. Placing it somewhere nearer the middle shows you don't feel as strongly one way or the other. Here is an example:



1

Date .....

Three things that have happened this week:

This could be good things, bad things, things you do every week or things that have happened for the first time

-
-
-

How have you been getting on at home this week?

What's going well?

Please draw an X on the line below to show how much you agree with these 3 statements today

I am confident I can figure out solutions when new problems come up in my life



Strongly disagree Strongly agree

I am confident that I can tell when I need support from someone else and when I can take care of a problem myself



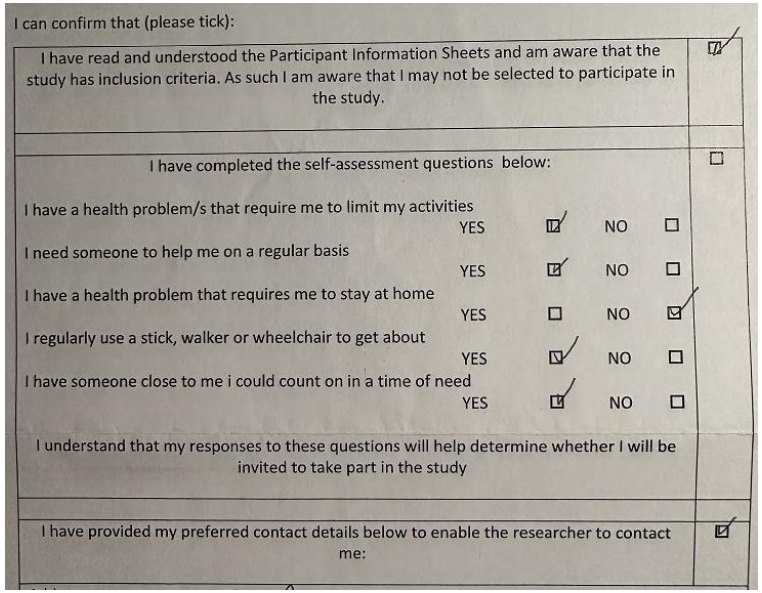
Strongly disagree Strongly agree

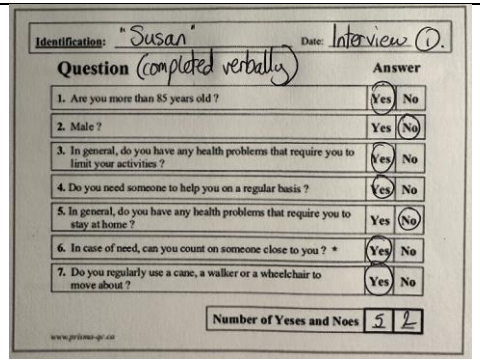
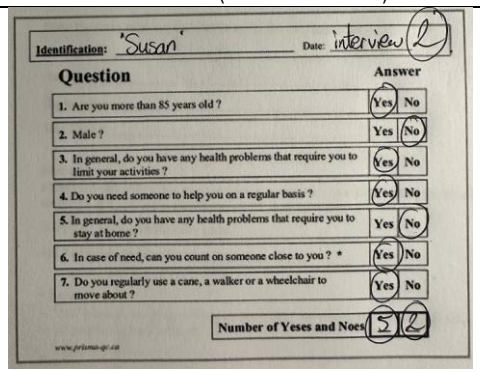
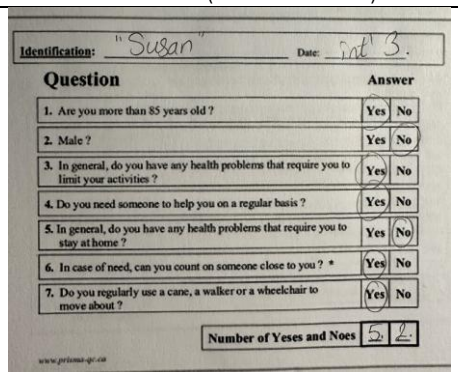
I am confident that I can prevent or reduce problems with my health

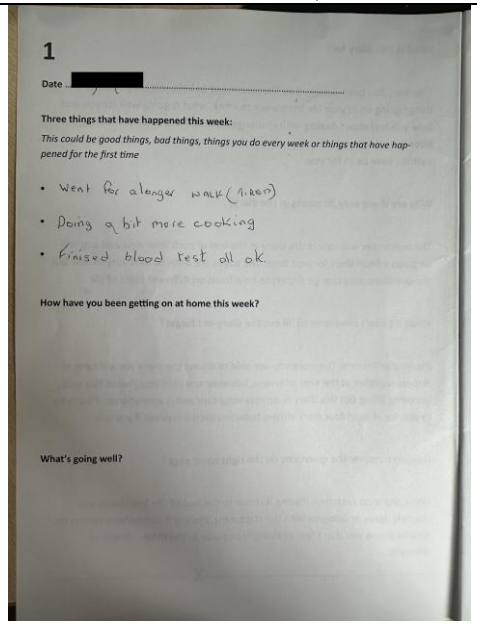


Strongly disagree Strongly agree

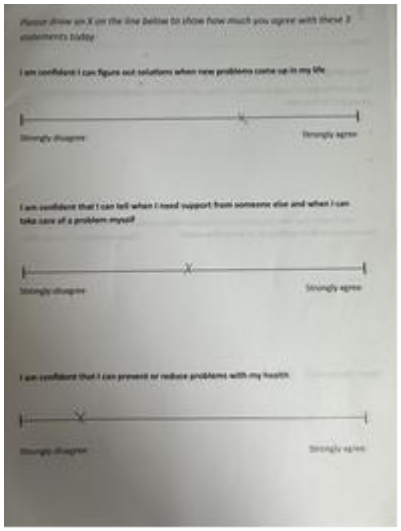
Appendix 30: Analysis of interviews against CFS scoring and frailty fulcrum domains - Susan

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
Recruitment checklist (cropped to redact participant indentifiable information)	 I can confirm that (please tick): I have read and understood the Participant Information Sheets and am aware that the study has inclusion criteria. As such I am aware that I may not be selected to participate in the study. ☑ I have completed the self-assessment questions below: ☐ I have a health problem/s that require me to limit my activities YES ☑ NO ☐ I need someone to help me on a regular basis YES ☑ NO ☐ I have a health problem that requires me to stay at home YES ☐ NO ☑ I regularly use a stick, walker or wheelchair to get about YES ☑ NO ☐ I have someone close to me i could count on in a time of need YES ☑ NO ☐ I understand that my responses to these questions will help determine whether I will be invited to take part in the study I have provided my preferred contact details below to enable the researcher to contact me: ☑		
PRISMA 7 responses			

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
			
Participant diary	N/a – first diary issued	<u>Activity log:</u> "[J]ust a few words. Yeah, I was tired" **Susan** [describing single diary entry] "I went for a longer walk, can't remember where now but I was tired at the end of it. Doing a bit cooking and finishing blood test I was on, and they were all ok…. That's as far as I got" **Susan** <u>Activity log (completed 4 days after interview 1):</u>	<u>From researcher notes:</u> Pre-interview: During the consent process prior to interview 3, whilst talking through the right to pull out at any time during the study, Susan responds with word to the effect of 'I pulled out of that bit' and indicated the participant diary. She then hands the diary back to me, with no further entries included. Wishing to respect this I did not attempt to complete the diary content with Susan during interview 3. Post-interview: Brief discussion of next steps of the course and part of outcomes will be to reflect on what's worked well from a study design perspective and what didn't, giving the example of the diaries. Susan laughs and comments that she

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
		 1 Date [redacted] Three things that have happened this week: *This could be good things, bad things, things you do every week or things that have happened for the first time* • Went for a longer walk (1.2km) • Doing a bit more cooking • Finised blood test all ok How have you been getting on at home this week? What's going well? <u>Visual analogue scales (completed during interview 2):</u> "And where on that line did you put your little cross for that first questions on the right-hand page? Where you'd scored yourself on that line for how confident you felt with problem solving things" **Researcher [following on from discussion about activity log entries]** "I am confident I could figure out, yeah. The first one there [indicates where the cross has been placed towards the right hand end of the scale]. It's out… that way" **Susan** "There… so that's towards the… strongly agree…" **Researcher**	didn't have the patience. I acknowledge that as Susan has commented on energy levels becoming lower, the diary may be 'too much of an ask' to which Susan replies 'definitely', and that 'it's bad enough some nights deciding what we're gonna have for dinner!'. I comment that Susan and Jim may wish to put their feet up and rest for a bit after I leave, to which Susan says they'll probably go out to the conservatory for half an hour.

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
		"Well then I did but… not now . And then the next one's there [indicates placement of next cross]." Susan "In terms of the problem solving, I suppose just to pick up on what you've just said there about possibly feeling as though if you did that scoring at the moment, you might get a slightly different picture… Can you tell me any more about why that might be different for you at the moment?" Researcher "That one [indicates diary page again and reads prompt statement aloud], 'I'm confident I can prevent or reduce problems with my health'. I haven't. Strongly disagree, I can't. I'm not confident." Susan "And what did you put at the at that point for that question? Had you put it down at that level at that stage as well?" Researcher "Yeah. That's the cross… strongly disagree [points to diary page response] I don't think we've got any further than that" Susan "…so you feel you feel less able to prevent and control health changes than you did…?" Researcher "Only the falling. I feel as though I've got no control over that whatsoever. I mean i hold on when I'm walking. Get up in the night, i hold on. Not much else I can do…" Susan "And what about other aspects of your health? Your day-to-day life? Do you feel that there are other aspects of your life that you feel any more able to control? Or to prevent change with?" Researcher "No, I think it's about the same. Just plodding on. Get on with what you've got… I feel as though it's all slowing me down… the walking, you know. I can't get on… Frustrated really, yeah. It can't be helped" Susan "What about the question about knowing when you feel confident to manage a problem yourself and when it feels like something that someone else needs to come and help	

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
		with? How confident do you feel in judging that?" **Researcher** "You just know when it's the right time to do something… I know when I need help from other people you know, so I ask for it… you know if I, if Jim's not around I have got the neighbours who I can get in contact with, except Christmas Day we won't have anyone. They're all going away" **Susan** 	
Social Environment • Main carer & carer network • Next of kin & wider family • Friends & community • Preferred methods of interaction	"Yeah, so does [Jim] [gets tired]. [laughs] two old cronies walking along together." **Susan 4 [Jim 4]** "Erm, we used to go out with a group '[organised groups name], which [Jim] belonged to, but can't do that now. It's a	"I've got support with the neighbours. They're very good. I've only got to ask for anything. And then I'll get passed on to another one if that one can't do it. But yeah, no we're not, not, er… I mean Jim's er, he can get out, so I say to Jim 'you go'. A, it gives us both a break, and b, I think it's good for him to carry on as normal. Like Jim's gone out this morning. He said 'aren't you coming?'. I said 'no'" **Susan 4**	"Yeah, she parks up here… we said park in the middle. We're not worried. We're not going to use it" **Susan** [describing arrangement with neighbours to use their driveway]

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	coach… And it's up about four or five steps. And I can't get upstairs and [Jim] can't really… we have done [their activities] but I can't do them now" **Susan 6** *"We haven't got the access to get to them"* **Jim 6** "I get in and out [of a taxi] don't I to go to the [to Jim]... We've been out for a couple of meals with different people. Takes a time. Our daughter comes up and go out with them. Which is not very often cos they live [180 miles away]" **Susan 4** *"And our son lives in [another country]"* **Jim** *"*So we see even less of him. But err, he does phone twice a week doesn't he [to Jim]." **Susan** "The neighbours come. You know, [neighbour's name] came night before last didn't she? Lady up there." **Susan** [when asked if anyone comes to visit them at home] "Yeah, that's when I first went down [fell] and then the neighbours were good… [didn't know them previously] We don't see a lot of them now... When I fell the second time [Jim] phoned [neighbour] up… he came over and err put me in a chair cos I was just on the floor and that floor's hard. They put me in a chair called the ambulance and that was it… it was	**[not dependent for daily help but identifying resources to seek nearby help]** [when asked 'have there been any changes since we last spoke about the amount of support you've got at home or that you're needing with going out?'] "I've pulled back like this morning I said to Jim, you go. Because I mean anything happened to me, he's got to do it, for himself" **Susan 5 [impairs going out - reason becomes complex and entwined with Jim's needs but has same outcome]** [talking about going out with Jim less often since interview 1] "some people are very helpful… just lifted me up!... I don't know who he was got me, me walker, gave me that. And they watched me walk. 'Yeah, you're alright'. And the man had gone! Just disappeared. I couldn't turn around quick enough to see and say – I did call out thank you but whether he heard me I'm not sure" **Susan 5 [impaired walking outside/fall]** [assisted up by a member of the public after a fall] "I mean the man who lives next door, erm, I can't remember his name… [name] and… [name] and [name]. Er, he went down. I was in the car driving then and I saw him go so I stopped. Got out . At the time he wasn't talking to the neighbours - all the neighbours had upset him… I said do you need a hand because I was going to work, half past five in the morning would you believe. And er, 'no' he said 'I'll get up myself'. Oh he was a grumpy old so and so… I mean I did help him up in the end because he couldn't get up" **Susan** [talking about a previous older neighbour who fell on the slippery path]	"[Referring to rumbling noise outside] That's [another neighbour's name], that's our bin going up [laughs]." **Susan 5** "[W]e've got good neighbours round here… We know they're there" **Susan** *"I mean, [couples names] over there have told us to call them if there's anything…."* **Jim** "Well, [one of couple] took me yesterday, didn't he? [to Jim]… Round [supermarket name]" **Susan 5** *"They've been moaning, because we've not used them"* Jim "We've been going on the busses so I thought this time we would ask [the neighbours]. 'Right' he said, 'I'll sit in the car park and wait for you'. I said, 'no', because we don't know how long we're going to be. We wanted to go over to [another shop] as well, so we sent him home [laughs]" **Susan 5** "They're there if I need them… Well, just our little group around us. I mean, all right, they go out. I don't know when they're going. Some of them let us know, don't they? [to spouse]" **Susan** [when asked what it is about the relationship with neighbours that works well for her] "When we're out there they might say, you know, we're going, do you want the lift or anything? But normally it's up to us if we want it, to ask for it… not *pushed* in any way" **Susan 5**

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	neighbours first and then I got carted up to the hospital" **Susan 4 [falls – *should* symptoms be limiting activities?]** "I've got a loud voice… and I've got a whistle" **Susan 5 [plan and practical steps in place to seek help]** [preferred way to seek urgent help] "I fell out there [indicates back garden]… I had me whistle and I blew it… [neighbour] must have been in the conservatory…" **Susan 5 [impairs walking outside alone]** *"We had about seventeen people coming in!"* **Jim** "[Neighbour responding to whistle] she was an ex-carer so she knew what she was about and what she was doing" **Susan 4 [not dependent for daily help but identifying resources to seek nearby help]** *"We're not, in each other's pockets. If you need help just say"* **Jim** "Yeah, just pick the phone up. Any of them will come over. They can't get in cos we lock the front door" **Susan 4 [not dependent for daily help but identifying resources to seek nearby help]** "[Shop] put their prices up and it all got a bit too much and then I met [name] didn't I, a lady that lived over on the estate across the road. We knew her for years.	"[T]hat was one of our Thursday nights. We sit out the front on a Thursday night. We were sitting there one day recently, and er it started to rain. So I said to Jim, we were gonna have to take them in - I didn't mean we *want* them all in cos they all had muddy shoes on. Anyway, we came out here [conservatory], and we put some more chairs out here and we sat out here. For two and a half hours and they've done their game" **Susan** [neighbourhood continuing Thursday night gatherings after 'clap for carers'] "Yeah started off as that [clap for carers] – it's just neighbours now. Yeah. We've had a few new couples come. A couple more die cos it's quite elderly up here. We've got new house to sell over the road" **Susan** "Only a bit of shopping. [Name] across the road does my…. I mean, I think Jim tripped the other day and he broke one of these glass tops [indicates wicker side tables with glass on top]… [Neighbour] took it across the road, to a shop round the corner, and she says she'll pick it out when we get a phone call." **Susan 5 [not just planning support, now using it – ad hoc need indicates transition into CFS 5]** [when asked about help from neighbours since last interview] "If Jim doesn't want to spend or Jim doesn't want *me* to spend hours in the kitchen cooking. Jim'd much rather phone up and get fish and chips or ready meals which we've got [ready meals] we have, and I keep them as back up. Cos if anything happens and I can't do any cooking. At least I know Jim's got some meals… I don't mind them when Jim's tired and I know he's tired or been doing… I mean Jim's been doing all this paperwork for the blummin bank and erm, Jim sort of comes out of the room [indicates a tired	"*They're not necessarily intrusive*" **Jim** "Jim takes [the bins] down and [neighbour] brings them back, erm, and *little* things" **Susan** *"We've never asked her to"* **Jim 5** "[A]fter the gathering out there last week, I couldn't do much, so I came in out the way , and then [name] and… they cleared the table, and all took their own bits back, and then what was ours they put in me fridge" **Susan 6 [help with outdoor activities and keeping house]** [describing how the unsolicited support of neighbours enabled her to join and contribute to the Thursday street party] "Not so much, because, like Jim was saying about [alarm company], don't react as quick as we'd like, erm, but neighbours, yeah, they're pretty good, aren't they [to Jim]? **Susan** [when asked if support to get back to normal after something like a fall has happened is as significant as at interview 2] "[name] would help us next door, but we don't…" **Jim** "We don't like him. We've had a few run ins with him… Friction" **Susan** [reflecting on available support in the event of an emergency] "We'll go back. Maybe next Christmas…" **Susan** *"Depends…"* **Jim** "Depends on us both… Thursday nights, they've taken over" **Susan 5 [but perhaps anticipating 6**

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	And then we went on holiday and she died… £2 for a pair of trousers, and it didn't matter what you offered her, she wouldn't have it" **Susan** [loss of affordable clothing adjustment/repair services] [long standing use of local, but not necessarily doorstep, local resources] <u>From researcher notes:</u> (Pre-interview) Susan states they have lived there for 35 years but only just got to know the neighbours more recently. They state it started with the 'clap for carers' during COVID, and the road have continued to gather outside on a Thursday night and sit out with their chairs, 'although the clapping has stopped'. **Summary: CFS 4** **On balance predominantly CFS 4 but environmental factors outside the home e.g. steps might increase this to elements of CFS 6. Evidence of scoping available skills and resources in anticipation of CFS 5+. Parallels drawn with Jim when using language to indicate perceptions of others – perhaps a protective mechanism. Reduced access to community and social activity due to difficulty with environmental features. Access to wider neighbourhood continues. Aware of lack of proximity of family and infrequency of visit. Relationship with core neighbourhood developed when**	expression], so I think 'what should we have tonight', you know?" **Susan** "We are doing our own Christmas meal. Yeah, Jim'll have to do the lifting. Er, I've already ordered the turkey and all the trimmings with that… My butcher'll fetch them. We've known him years and he drops them off. He doesn't deliver for everyone, but as I say we've known him years so…" **Susan 5 [help with heavy lifting]** "But you *know*… I push Jim, I do push Jim… You think how long we've been married and that, you *should* know each other" **Susan** [when asked about knowing when to push through and when to hold back] *"Jim's not walking very well"* **Susan [Jim 5 – evident change in walking]** *"Cos Jim's diabetic I have to watch him. I mean, I have to watch his tablets… Jim does it all himself. I have to remind him later on today, teatime I'll say 'did you have your, err, medication before dinner'? 'Oh no, I'll go and do it'. Little things like that… just looking out for each other"* **Susan [Jim 5 – assistance with medication management]** "Probably, but they don't talk about it a lot. [Friend] definitely don't talk… well, he don't talk… No, [friend]'s very private on that. She, she does everything. She does all the cooking, the computer… but they've got a big family around them. They've got three. Yes, three children and grandchildren. And they're all [local town]" **Susan** [when asked whether there's anything that friends in a similar position have done that helps them]	**due to stairs]** [talking about making adjustments to social activities] *"Our neighbour over there has got a key to the [alarm company] box"* **Jim** "She's got a spare door key an' all, hasn't she? [to spouse]" **Susan 6 [practical actions in anticipation of further standby for basic needs indoors]** *"No, she's got the number to the box"* **Jim** "Oh…" **Susan** "Yeah, yeah, it still is now but few and far between innit? [to Jim]" **Susan** *"Yeah [pause] I mean they're all getting older and dying off as well"* **Jim** [when asked about the move towards telephone contact with friends described by Susan during interview 2] [when asked to what extent telephone contact with friends impacts from a support perspective] *"Erm, [pause] that support doesn't exist"* **Jim** "No, not anymore" **Susan** *"[Friend]'s finally realized that she can no longer drive… So she's in exactly the same boat as we are"* **Jim** "We're all in the same boat" **Susan 5** [When asked what it's like having people around that are in the same boat] *"Well they're not!"* **Jim** "They're not here, they're all round [town name]" **Susan** *"So, you just lose them"* **Jim**

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	transitioned to CFS 4, previously did not know neighbours. Started from a place of need but on a background of social capital invested. Preference for support from people in close proximity even if not previously known. Not drawing on support day to day, but evidence of scoping available resources and skills around. Having space from others is valued, with choice and control over when support is requested. A long-standing behaviour of using skills and resource in the wider neighbourhood to problem solve.	"Well, because of COVID and everything we've not done it - we used to meet up about once a month and used to go to different pubs and that for a lunch thing - can't do that anymore… Because you couldn't meet up from different areas… Well we kept all the, all the phone calls going" Susan 5 [COVID accelerated CFS 4 into CFS 5 and hasn't reverted for social activity] [reflecting on lasting changes to social connections post-COVID] "You know, you get a phone call 'oh, hello'. I mean, one couple, he was a [sportsman] – they're all blimmin' [sportsmen] – erm, and he, he's not been well. He had a fall in the garden, in the shed or out the shed, I can't remember which way round and he has blackouts now and everything. He's not at all well" Susan From researcher notes: On the table by the front door I notice a chocolate bar. I joke that Jim has been 'caught out' buying snacks whilst out and about. Susan responds that this is actually a bar she puts in Jim's pocket when he goes out alone in case he needs it to manage his diabetes. Summary: CFS 5 Overall a clearer picture of CFS 5 or the early transition stages of CFS 5. Clear evidence of not just planning support resources but drawing on them on an ad hoc basis and a satisfaction with the availability of support. Choice and control over how and when this support is accessed is valued. Support beyond core roles is a theme, and appears in long standing relationships such as the gardener and the butcher. Susan is also planning ahead for the impact on Jim if her needs change, not just how she will meet her own needs. Spousal support is a protective and proactive	*"We used to go on holidays with [charity name]… And those people now no longer exist"* Jim "Some of them don't [pause] all older than us who were on it weren't they? [to spouse]" Susan "Well we've got [name] our daughter" Susan *"Yeah. She's worried about us"* Jim "She worries because she lives in [place name] and our son is in [another country], but he phones… twice a week, really, from [another country]" Susan [when asked if they have someone to talk to if they have any worries] *"Mmmm, my daughter works [in the health system] anyway, she's fairly high up, so she knows a lot [pause]… She's in [place name]. She can't really..."* Jim [when asked 'so family are worrying about you?' whilst Susan was in the bathroom] *"You can see too much of people… If you're too much in each other's pockets. You annoy each other"* Jim [while Susan is in the bathroom] *"We used to go on the bus to [place]… we used to go by bus there with our friends, catch last back at four o'clock, and there you are."* Jim "Not now… It's virtually always practical… This year? [pauses and looks at Jim] Yeah, I think it started changing last year" Susan

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
		viewpoint from outside self (bidirectional), and balances waiting to be asked with just stepping in and acting. Retaining independence from each other is valued, even if that means reducing individual activity to allow the other to be independent. Motivation for limited activity becomes blurred. Susan denies her own ability being a reason, but does reflect on a friend's situation of fit to falls to being more unwell. Perhaps an unconscious parallel indicating expectation of the future. Ultimately perhaps not an entirely selfless act. By acting as support for each other, treatment burden of long-term conditions is shared/experienced by both Susan and Jim. Wider neighbourhood responses to Susan's fall are noted and there is a sense that Susan feels she hasn't balanced this relationship as unsure whether the stranger who helped her heard her thanks. The idea of social capital is a theme, with Susan reflecting on a previous elderly neighbour who fell but had not built good relationships with his immediate neighbours. She supported him because of her own good will rather than a sense that he deserved her help. When thinking about support of others in similar situations, proximity of family is perceived as a key factor which Susan and Jim lack. The expansion of Jim's role to include carer in interview 1 is preferred over paid care. With family not proximal other expansions of close relationships are less possible. This is echoed later when daughter is described as worried but what can she do. In describing Thursday nights Susan indicates building social capital by inviting neighbours in even when she didn't really want to. A sense of 'paying into the pot'. Thursday night gatherings act as a mechanism to continue to grow and maintain social capital despite turnover of neighbours. The impact of COVID is shared and social connectedness was accelerated into CFS 5 whereas practical tasks such as shopping returned to CFS 4.	*"You always have to think of err, the transport"* Jim "It's connections on the bus and things like that. If you go a way by taxi it costs you a bomb. Couldn't afford it could we [to Jim] all that" Susan *"We afford the taxis, carefully"* Jim "Don't go out as frequently as we'd like" Susan 5 *"We don't go out really, very often for pleasure. We go out for shopping."* Jim [talking about not going out for pleasure/socially anymore] *"Strengths. I think so yes"* Jim "Yeah, I'm just working it out, but i think so too yeah… It just works, just if I wobble a bit, he'll stick an arm out and just grab the arm and then I've got the door [referring to getting across the living room]" Susan 6 [when asked whether they felt facing their separate changes was a source of strength or an additional challenge] *"She was pregnant, and she called me in work. I had a bike then I just got on and came home. I was the first person there"* Jim [describing a history of supporting Susan] "Well having someone to listen really" Susan [describing a neighbour who continued to drive a bus after she felt he was unsafe – asked what she felt helps make what you'd consider the right decisions when these things come up] Summary: CFS 6

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
			Clear evidence of CFS 5 with multiple instances of transition into CFS 6. There are some activities which have been reduced or not yet repeated, but would likely indicate CFS 6 if attempted. In other areas Jim indicates only behaving as per CFS 5 to humour neighbours or perhaps accepting the support is part of paying into social capital. This may be a protective mechanism. Susan and Jim are more definite about support no longer existing from friends or the loss of people previously in their lives compared to previous interviews. Sense of loss/bereavement. There is a sense that people in the immediate vicinity are the focus as the source of support. Susan retains her attendance at the street parties, but is reliant on practical help to fully participate. Neighbours begin to take a more proactive role, supporting with some practical tasks without waiting to be asked – accepted perhaps because a respectful relationship has built over time first. Trusted boundaries and demonstrated this. Alarm company unsatisfactory but neighbours respond quickly. Real sense of reflectiveness and practicality in planning for the future, and compromises such as allowing neighbours to access controlled space of home in an emergency. Access to social activity and wider community spaces has reduced, but neighbours play a key role in continuing access. Choice and control, and maintaining personal space and independence remain key themes. No changes to support 'on paper' – Jim and Susan are codependent. Frailty level on paper is

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
			influenced significantly by the environment so Susan and Jim avoid some activities, e.g. any places with steps/stairs.
	"I think we're very lucky to be honest, you know, with the neighbours and everything. We've got buses up the road, erm, to take a different way into [town], we've got other buses further. Yeah, connections, got good connections. Got the hospital [indicates distance from home], erm, doctors are that way." **Susan 3** "Yeah, we just have a walk along the front and look at the shops, and… have something to eat usually and come back." **Susan 3** *"…we're both from [UK city] and you used to go around and find what you could to make use of it because of all the bombs etcetera"* **Jim** "I mean, you go in the garage, if you're lucky to get in…" **Susan** *"You can walk round"* **Jim** "I can't, not with all the bits of wire and stuff around" **Susan** *"Where I've worked, because [company name] was just recovering from the war we had to make do. That also helps"* **Jim**	*"Today he's got an appointment at the bank. Otherwise he wouldn't have gone… Oh he'll be alright… once he's down there and on his way. He's got all his papers so he knows where he's going and what he's doing"* **Susan** [about Jim needing to go out despite losing paperwork for the and missing the bus due to time taking searching for it with Susan's help] **Jim 4** "Yeah, still going. Yeah we do. I mean, we're going this week, only up to [Another town name] - it's not far. But, er, that's where I fell last time [laughs]. Get the bus from here up to the top of main road, and we have to change and when we change that's where I fell down" **Susan 3 [after a period of 4 following fall outdoors]** [asked about continuing to go out on the bus] "I am slow. I mean, especially up this road at the end where the [local building] is, all the leaves are coming off the trees like everywhere, and the pavement is covered. Well when they get wet they are very very slippery" **Susan 4 [slowing up, limiting activity]** "It looks a straight road. But it's not. And the underfoot is terrible. The pavements are rough and broken. And you've got to watch where you're going. I've seen many people trip . Well when my brother-in-law come down oh years ago, I	<u>From researcher notes:</u> We sat in the living room, Susan in the recliner chair she indicated was her regular seat. Coffee table moved to the centre of the room for the Dictaphone. "Went to the opticians yesterday, and there's only one chair there for customers… we didn't want to go in, because we knew we had to go that way... So [Jim] sat on the chair and sit up on board [on the walker seat]. No problem" **Susan 5** [describing the need for her new walker's features] **Jim 5** "Still accessible. If you've got busses up there, [medical access], and we used to have a shop over there, but just up the road, they've got a shop. So if you've got a car, it's no problem. But err, you know, we've got good neighbours round here." **Susan 5** *"Because there's no car, no freedom . You could just go in get anything you want. Now it has to be planned, and you have to look after out for the busses"* **Jim** "Busses, or taxis or…" **Susan**

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	[describing practical resources that help/hinder keeping going day to day] <u>From researcher notes:</u> (Pre-interview) Whilst consent paperwork is being signed there is some small talk about the location of the property and other buildings and business in the immediate surroundings. The site is in an urban location but somewhat tucked away. Susan states they have lived there for 35 years but only just got to know the neighbours more recently. (Post interview) On the way back through the house Jim directed me to open one of the closed doors in the hallway. Inside was a room containing two slightly cluttered desks, and up every wall and inside several built-in cupboards was shelving filled with what can only be described as 'potentially useful items'. Tools, glue, multiplugs, books, boxes, paperwork. Most items had a handwritten label with its contents, and much of this appeared to have been there for a number of years. This seemed to be a source of some pride and satisfaction for Jim and a source of mild annoyance to Susan, who stated that the labelling did not help with finding items. Summary: CFS 3 **Susan and Jim describe a well connected and practical wider physical environment and being able to access this for routine**	mean, he's been dead for seven, eight years. He used to come down after his wife died. And he nearly fell over! Cos the pavements are so bad" **Susan** "We've got the meeting on Friday, erm, at the local hall. [MP name] I think his name is, one of the MPs is coming down to talk about different things. I'd like to go I won't go out in the dark… No, no. I don't feel confident to walk up the road in the dark. I mean, I haven't got the best eyesight anyway, which doesn't help. No, I shan't go to that but I'm pushing Jim to go" **Susan 5 [impaired walking outdoors]** "There's so much more traffic. We asked for… they put new traffic lights and new layout up at the church or up the top, and er, we asked 'Could we not have the traffic lights in this road, so that when we come out, they change?'. 'No, too expensive' they said and wouldn't do it. But, y'know, I mean you can sit up there for 5, 10 minutes and you can't get out" **Susan** "I had a lightbulb go in the bathroom. Well Jim wasn't up to getting the ladders up and going in the loft, so I didn't say anything to him. Well course [son] comes in and says 'What's the matter with yer light?'. I says 'it's blown, needs someone to go up there'. Oh, he said, you got any? I said 'Yeah', showed him when they were. He got one out, went up in the loft, changed it and it was done. And then from there on he was looking around. He found umpteen things he said was… I mean, we had a crack in our bedroom. We know it's there. But we can't get up. We can't do it so, leave it…. I didn't want Jim to go up there. I didn't think Jim was safe" **Susan 5 [help with heavy housework]** [talking about son's visit 3-4 weeks previously] **Jim 5**	*"We're using more taxis than we've ever used… even when I first didn't have the car"* **Jim** *"I said, 'Come on then, we're going for a drive'. And went over to [car dealership], and the young lady called a taxi for us to come back [laughs]. And Susan didn't realise what we were doing… I knew I had to get rid of it… I had realized I was going..."* **Jim** "A liability" **Susan** *"Yeah, a liability"* **Jim** "[the safety of] Others, yeah… Yes, *hard* change that was" **Susan** *"It'll be, in both of us walking up there to get the bus"* **Jim 5** [when asked what's changed that means less bus use and more taxis "Yeah, you don't realize how long this road is until you have to walk it" **Susan 5** *"Well, I was born in [place name] during the war and we had a seven-room house, and there were about 14 people living in it. And anything you needed if it was lying around on the bomb site and that, you used it… [and then later in the workplace] you had to scrounge everything, even there, to make things work"* **Jim** [talking about his storage room whilst Susan is in the bathroom] [on returning] "Jim's a very handy person" **Susan** [Jim demonstrates lighting system he installed and describes having laid the driveway]

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	walks. Within the home they have physical resources to make do and mend and describe this as a long-standing behaviour. Although general tiredness is mentioned during this interview, physical environment is framed as the wider local area, which Susan and Jim are able to access.	"[T]here's some other bits up there that have gotta come down. We've got to get rid of… We're getting older, we won't be here forever. And it's gonna fall on them to who are over here to sort it all out. So I'm just trying to break it down a bit" Susan 5 [but planning for 7+] [talking about jobs in the loft that need doing] "[W]e went out for a meal - used to be about eight of us but one died so seven. And we went out, would have been a few weeks ago now – only fish and chips, nothing… Because it's trying to get people from different areas into [place]. And, yeah, none of us have got cars. It's all gotta be bus or taxi. I mean we're the side of [place], one couple's the other side of [place], err, [name] is way out of [place]… So you know, we're not too bad for buses because we can, we've got different ways we can go. But one of them she has to get a bus oh, about 10 o'clock – only the one bus. And one bus back." Susan 4 [on differences in how her friends are managing] From researcher notes: On the way out Susan did not use her walker but 'furniture walked' through the property, pointing out to me that she knew exactly where to place her hands. 'I've even got him trained to keep things away from the edge of surfaces so I've got a clear edge running around'. I say, I can't help but look around with my OT brain and wonder if there's anywhere an additional rail or two could go. Susan says no there's not – that they've looked at it before, and I have to agree I can't see any obvious spaces at first glance. 5 Summary: CFS 4 There are a range of possible CFS levels indicated. Susan initially paints a picture of managing well and going out to	*"…what we've got is old [referring to possessions]..."* Jim "We'll replace them when we use them. Or, I don't know…" Susan "This one is not as high as that one [other riser recliner] or the settee. Cos I've got short legs and they never touch the floor." Susan 4 [furniture purchased to meet individual needs] Summary: CFS 5 Almost totally complete picture of CFS 5. Chair purchase for fatigue management was some time ago so not indicative of a new change. Susan and Jim both need to sit whilst out so benefit from taking a walker with a seat with them. The wider neighbourhood continues to be accessed, and the neighbours are referenced as a resource in this. The switch to using buses has progressed to more taxi use due to limited mobility walking to the bus stop. Susan and Jim describe increased cognitive demand in planning taxi use and a reduced freedom compared to when they had a car.

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
		walk for pleasure but describes not going far on the b. Following a fall on the way to the bus stop Susan indicates a period of more limited going out activity but planning trip out again this week, indicating reverse from 4 back to 3. Similarly, Jim goes to an appointment independently but wouldn't otherwise have gone out – the appointment is a mechanism which maintains CFS at 3 and prevents limiting of activity. Susan sees the ability to go out alone as a benchmark worth protecting and as a significant ability for Jim should anything happen to her. Susan continues to go out but is consciously mindful of the features of her environment, the slippery pavement, the lighting at night, the uneven pavement on her street. Susan draws parallels between her own experiences of falling on the pavement and anxiety around slips and low lighting and narratives of ageing in place that she has observed during the history of her relationship with place. Susan has optimised the home environment for furniture walking, and has stopped accessing some areas of her home.	

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	"I don't want full time carer in or anything, I can manage without…" **Susan** *"Which you do need, you do need help"* **Jim** "I do need help, yeah, that's what you're here for [laughs]" **Susan 5** **"**Yeah, [Jim's] done [the cooking] for the first six months when I couldn't do anything. When I couldn't lift anything. If I, even now I can't lift anything out the oven… so I have to call [Jim]." **Susan 5** "We've got a cleaner who comes. She's new, we've only had her two, three times now. So we really don't know how it's gonna work. It looks all right. Fingers crossed. We have a gardener, erm, [gardener's name]. Is there three? There's another one somewhere along the line. We've just lost our cleaner. We've got this new one. Oh, and we've gotta have someone who cleans the windows, things like that, cos [Jim's] not stable on a ladder or anything." **Susan 6** "I mean, if I want anything I can phone her up and she'll get it" **Susan 6** [about the gardener]	"No nothing. Nothing at all… I don't know what, but yes, I think they should be" **Susan** [when asked whether she had any more appointments to look into her falls, or whether she felt there was any more that could be done] "GP. Not interested though - they haven't got time. I do feel that is half of it. Whereas you could sit and talk to them at one time, now… it's like a conveyor belt." **Susan** [when asked 'have you spoken to anyone about feeling more could be done to address falls?'] **Summary: CFS 6** **Susan continues to fund support with keeping house. No changes or additional support indicated. There is an indication that Susan is dissatisfied with elements of the health system and the absence of further follow up on her falls, perhaps indicating a sense of vulnerability to further crisis events. Susan says her GP is not interested and interactions don't feel personal. This is in contrast to descriptions in interview 1 where the GP is presented as reliable with no complaints.**	"I mean our GP's alright, isn't it [to Jim]… it's quite good" **Susan** [when asked how she felt about contact with health services after previous comments about a conveyor belt and Jim's description today of his long-term condition review] *"I think we can get to the doctors, and the doctors will respond"* **Jim** "They're pretty good" **Susan** [when asked about the role healthcare services play in providing support when there are changes or a concern to raise] *"[B]ut [personal alarm company] is which we're on, are bloody useless"* **Jim** "Me, I've got it on [pulls alarm on string around neck out from under clothing to demonstrate wearing it] but he don't wear his" **Susan 6 [practical measures to access help for needs inside the home]** *"Well, you've phoned up once [to Susan], and 'Oh, sorry, we haven't got anyone here'…. 'You'll have to phone 119'"* **Jim** "Something like that, yeah. And yeah, nothing… [the responder's voice] came through and said they didn't have anyone available" **Susan**

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	"…after I fell with me shoulder… [t]he carers came regular… [every day] to start with, and then they dropped, they had to cut back… they said you're getting on alright, you don't need us. So I said 'fair enough'" **Susan 6 [temporary period previously, then reverted to 5 with Jim's support instead]** "Yes, only the last couple of years because of these falls. Didn't at home. I mean, my mum done everything. It was her who took us to the doctor, and we had a very good doctor. He was good." **Susan 6 [community team visits triggered by CFS 6 need/crisis events]** [confirming involvement of community health teams and how needs had been managed previously] *"…the doctor is good in that when she says something, something's done"* **Jim** "She, she acts on it. So we get on very well so we've got no complaints or anything" **Susan** "I said, 'no way am I going to [another hospital]'. I said we don't know anybody, Jim's got no car, can't drive" **Susan** [after fall and paramedic recommendation] "…like four or five days yeah, not long… It was all right, but it was a bit quick coming out I thought… I couldn't walk, I… I don't		"I do like to do me own shopping but… we get…" **Susan** *"We do an order"* **Jim** "Online now… They bring it in, put it on the table, and we put it away" **Susan 6 [help with outdoor activities – shopping delivered and brought in]** "Don't think so? [to Jim]" **Susan** *"No, we've had people come in for a limited period after a fall and things like that"* **Jim** "It's like that [falls alarm company] eh?" **Susan** *"Yeah, they soon stop"* **Jim** "I think they do about six weeks or something like that" **Susan 5/6 [temporary fluctuations between levels of support]** [when asked if there have been any changes in the types of support she has around her since interview 2] "We've got the gardener, but she isn't very well with… what's today?... Thursday, she might come. She comes sometimes. She's not. She's under the hospital at the moment, but she comes when she can. So, it suits us. She keeps the grass short" **Susan** *"We both got allowance for each other – attendant's allowance"* **Jim** "Yeah you won't have that much longer" **Susan** *"No, that's being taken away"* **Jim** "The government" **Susan** *"They're cutting back, on everything."* **Jim** "Well, we don't know yet, we're waiting" **Susan**

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	know if I came out with sticks or… I came out with something, but erm… no, I didn't like that bit… next thing I knew they were getting all my bits together putting them in a sack or something. Err, Jim appeared on the scene, and we were out" Susan 6 [talking about hospital stay after fractured hip "I mean the carers who came home and helped me in the bathroom, that sort of thing, they were good" Susan 6 [short term support after hip fracture] "I don't know, it was so many people coming in and out at that time. I couldn't honestly say who was what" Susan [unsure which professions visited after hip fracture] "Someone would come in and help me wash if I wanted it, which I didn't really did I [to Jim]? I think one person… they helped and I done the rest" Susan 6 [short term support after hip fracture] *"Within reason we've got enough money"* Jim [asked what helps keep going day to day] **Summary: CFS 6** **Much of the discussion focussed on previous crisis event (falls, fracture, admission) and period of CFS 6 with short**		*"We've still got it at the moment… they're talking about allowances – old age allowances"* Jim "It's gonna hit a lot of people… We won't eat so well! [laughs]" Susan *"[smiles briefly] Yeah. We should be able to keep going with a cleaner and a gardener"* Jim "We *should* be alright" **Susan 6 [anticipating reduction in resource to mitigate against changes. Will continue to prioritise support as necessary not nicety]** *"But it's… a bit tighter"* Jim [on the subject of any changes in support] "Fortnightly" Susan 6 [when asked how often the cleaner is coming in] [on the subject of changes in support – falls alarm] *"After two years, we've given it back"* Jim "I think we must be nearly our two years up, we'll have to check up on it. We're not using it, and then when we did need them and they didn't really respond" Susan "Rely on each other [laughs]" Susan [when asked what they will do instead] *"And neighbours"* Jim "We'll get by" **Susan 6 [testing out additional/improved support but dissatisfied]** "Whatever 'normal' is!... What's 'normal', yeah? What's in your 'normal' is, get up, go to work and, you know, come home. But ours is a different normal. We just get up, take our time,

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	term care support. Although Susan regained independence with personal care she describes ongoing support from Jim instead of having care. There's some suggestion Jim is dissatisfied with this solution. Privately funded support with keeping house.		get washed, dressed. I mean, I was always dressed by seven. Now it can be 10 o'clock. You just accept it [pause] I mean, not got much choice have we?" Susan 6 [would be 6 if continuing task like for like] [when asked about 'getting back to normal' after something like a fall] "Yeah we haven't done this that and the other. I've accepted it more than [Jim] has" Susan *[Doesn't respond verbally but makes a face to suggest conversation is difficult]* Jim "I know [gently to Jim] [both laugh]… Being in the house more and not getting out so much" Susan *"Yeah… yeah"* Jim "But you're now catching me up [to Jim]. Jim doesn't want to come for a walk up the road or anything" Susan 6 [not getting out as much] [when asked how important is it for their 'normal' to stay as it is now] "No, i don't anymore" Susan 6 [help with all outside activities] *"I might go out occasionally to go to a shops and that, but I don't normally"* Jim [when asked about going out by themselves now] "No, we haven't got your clubs to go to what you belong to" Susan *"No [sadly]"* Jim *"…taxis are going up"* Jim "Yeah taxis, everything will go up. So we just got to accept it" Susan

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
			"I haven't been there for five years. I had one call because I made a comment about it" Jim [describing absence of regular reviews for long term health condition] Researcher notes: *Stepping away from the Dictaphone, Jim shows me through to the next room where his CPAP machine is. Jim explains how the machine tracks the number of instances per minute that the user stops breathing for 10 seconds or more, and that he has noted an increase in the frequency of these episodes. Jim also reports he was told when first receiving the machine that it had the ability to be monitored remotely, however as this was very expensive the service was not using this function. Jim talks about a previous consultant who was very good but had long waiting lists, but is now no longer at the same hospital. Jim demonstrates what appears to be an SD/memory card in the device and how to take this in/out. When I ask whether he has to take the card in with him for reviews, Jim responds that he has only been in once, during which the medical professional dismissed symptoms which Jim disagreed with. Jim reports not being asked to take the data card to any appointments to review the data, and that the expectation is to monitor any changes yourself* *"I mentioned it to the Secretary, that I hadn't had a visit or anything for so many years, and I was told, I could phone in"* Jim [describing how

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
			his condition review was initiated – previously only had a phone number for spare parts] **Summary: CFS 6** Susan talks positively about GP responsiveness however had felt negatively about lack of proactive intervention at interview 2. Jim talks about specialist services negatively, also suggesting an absence of proactive monitoring. Falls alarm trialled as a practical plan to support current needs. Dissatisfied with responsiveness. Changes made to food delivery, bringing in rather than to doorstep. Short term periods of increased support following crisis events but returning to previous support level each time. Anticipating a reduction in resource to mitigate against impact of frailty. Planning to prioritise support with keeping house even if food level impacted. Neighbours and each other described as reliable. Independent with personal care, but by adjusting the task rather than compensating with additional support. Could classify as 5 as a result. Describes acceptance of not going out as much, even into the immediate neighbourhood now. Neither going out alone normally. Reduced mechanisms to counteract changes (loss of clubs).

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
 • Recognised conditions or symptoms • Motivation & confidence • Emotional wellbeing • Spiritual & cultural fulfilment	"We were shaken up, but, you know, we overcome it. Went up the road for a walk and that when we both felt like it. Then we got a bus. Oh I think we had a hospital appointment, and so forth to get on with life." **Susan 5-4 Transitioning back after an acute episode** [responding to Jim's fall] "I did in the beginning when one after the other come but now. I mean, they're only the major ones what I've said to you. I've had others, haven't I [to Jim]" **Susan 4 Change of mindset to avoid 5** [describing initial fear of falls]	"Just plodding on day to day the same, you know anything crops up, you cope with it. All we do" **Susan - language of movement, action, steady, continuity, not looking far ahead - reactive** "I've just got no confidence to go from, well here to the bird table. Whereas i used to fill it up. Change the water" **Susan 5 Reduced mobility outdoors. Interview 1 had overcome reduced confidence.** [no longer going into garden without the walker] "Well since the falls. I think I've just lost confidence… and I've also got Jim. He's not, he's not brilliant. He's got, erm, Alzheimer's" **Susan - sense of wellness linked to the wellness of others** [when asked what's changed to reduce confidence]	"I wasn't up to it. I'd had more falls, and…" **Susan 5 but perhaps 6 – stopping activity to avoid emotional response to change?** *"You just didn't want the embarrassment [to Susan]"* **Jim** "I just didn't just want… just couldn't be bothered" **Susan** [when asked why they hadn't gone back to the theatre this Christmas] "Just getting out, isn't it?" **Susan 6 – reason doesn't matter, but continuing to go out together is important** [when asked what are the things that are important enough to keep doing but in a different way rather than to do less of?]

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	"I don't like it. To be honest. I prefer to do me own. But, you do what you can, you know... it's hard to know what you want done. You do it automatically. And that is a problem I think. With a bit more time she'd do a lot more, but [pause] that comes down to finances." **Susan 4-5 Help with heavy housework. Availability of other options/resources** [asked 'how do you feel about having help with the house?] "I just don't fancy I mean we're not doing the same things we used to, or I'm not. Going to work, coming home, house and children. That's all, gone. But yeah. I'm not independent anymore. I've gotta rely on [Jim] all the time. Yeah." **Susan 5 Language of loss. Reduced appetite. Relying on others** [asked why she did not enjoy food like she used to] "Glad [when short term care support ended]. [The house] was ours you know. It was an open house [with carers coming in]." **Susan 6 back to 4/5. Protected space.5 might be acceptable if support is from spouse.** *"we go to anything that we're told to"* **Jim** "I do now, yeah… we didn't really have a lot of choice, I mean. When I was flat on me back" **Susan 4 with acknowledgement of increased vulnerability** [asked 'how	"It's come at the wrong time, for him and for me. But we'll get over it. We'll work through it" **Susan – language of active role/response. Joint resilience** [reflecting on the timing of Jim's Alzheimer's diagnosis] "I get very frustrated when I can't do what I want to" **Susan 5/6 more evident slowing. Help outside and keeping house** [when asked 'how are you feeling about day to day life generally at the moment?] "It is hard. You know some things I think 'I could do that quicker'. But I can't do it quicker" **Susan** [reflecting on her efforts to keep Jim independent] **5/6 More evident slowing – disparity between thoughts and reality** "Shouldn't laugh really, could have been nasty" **Susan 5 Comedy as coping. Acknowledging possible outcomes – 6?** [laughing about falls] "Oh no, it won't stop me. No way. No. Just, we just have to walk slow. I am slow." **Susan 5 resisting 6 – continue to go outdoors but not alone, maintaining independence by adjusting** [when asked if the fall on the way to the bus stop had any affect on going out since] "You get on with it. I've got me, erm, whistles [referring to whistle on string around neck]." **Susan 5 vulnerability to 6 – strategy to call help if/when need arises** [when asked for her thoughts on managing frequent falls] "Well, if that's what I've got, that's what I've got" **Susan 5 acceptance of not going outside alone, no sense of hope of**	"He's just got to sit back and let the world go by" **Susan** [talking about **Jim 5** getting someone else to do DIY tasks now – accepting change with heavy tasks] *"Yeah [deep breath whilst considering] yes, because you get on each other's nerves too much"* **Jim** [impact on relationship dynamic] "I don't think it's the going out, it's going out when you *want* to, instead of having to wait for a bus or wait for a taxi to pick you up. You know, get washed, dressed, ready, we'll go" **Susan** [when asked what affect it's having for going out to have become more difficult] – loss of what going out spontaneously represents, loss of freedom and choice means reliance on others and autonomy (CFS 6+) "Well we just do things differently. We shop differently" **Susan 5 using strategies of compensation and adaptation to staithe off 6** [when asked what's going really well for them at the moment] *"Arguing!"* **Jim** "It's when you sing, when you're in the bathroom!... You accept what's, you accept what's there. You don't compare it, do you? [to Jim]" **Susan 4/5 accepting limitation to activity and help of others. Protective strategy.** *"No... I [pause] [unintelligible] that billiards, snooker. I've not played that for twenty odd years"* **Jim**

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	confident she felt that if she needed support it would be there and she would know who to go to] "I'll never be free of it… I mean, i don't know that I'll be able to go out in the street without the walker. That's the bit I don't like. Not being free" **Susan 5 Loss of freedom, constraint, permanence** "We keep each other going" **Susan** [asked what helps you keep going day to day] **Summary: CFS 4/5 with strategies to resist 5** **Susan describes the onset of falls as recurrent crisis events, but falls becoming a new normal with less fear attached, and 'overcoming it' psychologically. Going out when we both felt like it indicates sense of not being dependent on others. Having a reason to go out (hospital appointment) after a fall is a practical mechanism to resist dependence, however Susan states she is now reliant on Jim. Loss of freedom and of a previous lifestyle is repeated. Needing help with some tasks but navigating the detail of tasks and autonomy over who's coming into the home are significant.**	**reversal** [when asked how she felt about losing confidence walking without her walker short distances] "No [quite definite], cos I know where the shops are, and I've got plenty of protection and that, so... It did at first, but I said to [spouse], 'I'm not sitting in because of that'. I just went out up to the road and then I got a doctor's appointment and other things, so I had to get out - you know? Yeah…" **Susan 4 resisting 5 – reason to go out, expectation of someone respected** [when asked whether incontinence affects going out] "No, no. I don't feel confident to walk up the road in the dark…. No, I shan't go to that but I'm pushing Jim to go" **Susan 5 impaired walking outside alone** "[A] friend of ours who's got dementia and is so changed it's unbelievable. So, we know a little bit of what we're in for… He won't come over here. Yet, he was always over here, or we was always out together" **Susan - mirrored experience with others, anticipating change, practical language** [when asked how she felt about dealing with her falls and Jim's Alzheimer's moving forwards] "For us? I think it's possible. I think one or the other, or both will go downhill as they say. [pause] But we'll cross it when it comes. I mean [daughter]'s down, not far. If we have to go into an old people's home we'll have to go… Oh yeah, we've spoken about it because we've got various friends our age and some are, sort of moving in that direction so yeah… [pause] Might not… might work out…" **Susan – vulnerability, options but focus on here and now, mirroring of other experience** [when asked if she thinks there's likely to be more change ahead for herself and Jim]	"It's like a garden. You don't do that anymore… I do a little bit, but then you're out of breath, and that's it! That's why we hang on to [gardener]… She would do the shopping and, you know, pick any bits up. Well, they all would" **Susan** [when asked about sources of pleasure now Susan and Jim report not going out for pleasure anymore] **Summary: CFS 6** Outdoor activities have stopped, or are only completed together. Acceptance of limitation and adjustment of activities are protective mechanisms to reduce emotional impact. Reliance on domestic support continues, both formal and ad hoc from others.

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
		"What we've got now I suppose. We can get out and about and do things. Can't go to the theatre or the pictures. Went last Christmas - went to the [local theatre name]." **Susan – leisure activity not essential to decent QOL, focus on day to day** [when asked what was important to keep doing, what a decent quality of life looks or feels like] "He sits there 'what we doing watching this for? '… there's no point in him going" **Susan – anticipating leisure activity further impacted** [describing changes in friend with dementia, having attended theatre visit for 20 years] "We're anxious. Well I mean it's me and the theatre; I think Jim'd probably go to the show but… [at this point Jim arrives home]" **Susan – language of joint response, activities limited by each other** [when asked what's putting Jim off going to the theatre this year] **Summary: CFS 5 with evidence of resisting 6** **Dependent on Jim and privately funded support. Evident impact on outdoor mobility and high order IADLs. Again, practical mechanism to return to going out (appointment). Greater anxiety around going outside whereas in interview 1 Susan described overcoming this fear of falls. Frustration with accepting physical reality as it doesn't correspond with mental picture of ability. Less sense of reversibility in condition. Sense of primary focus on the day to day, continuing to move forward steadily with some horizon scanning. Wellbeing and confidence linked to that of others in close proximity – language of we. Anticipating further change by observing experiences of others. Anticipating reduced leisure activity but decent QOL indicated as simply going out.**	

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
 Conditions disclosed during interviews: **Susan:** Reduced shoulder ROM following a fall, Urinary incontinence, frequent falls, mild visual impairment, frequent falls of unknown cause, long standing in-turning foot **Jim:** Sleep apnoea, Cardiac condition, Deaf/Hearing aid user, Narcolepsy, Diabetes	"Yeah, when I'm fit and well [laughs]. I've got a walker, which [Jim] has to put on the bus cos I can't lift it cos this [indicates left shoulder] plays up too much. Erm, and I do get very tired, don't I [to Jim]." **Susan 6 - needs help with outdoor activities** "Oh, [spouse] has to come because as I say i can't lift it on and off [the walker on the bus]. Err, I mean at one time I'd pick that table up and move it from there to there. Because this [shoulder] has packed up I can't. I was told I was gonna have a [surgery]. That's not come to anything. I don't think it will now." **Susan 6 - needs help with outdoor activities. Shoulder injury from fall, plus need for a walker. Frailty trajectory – recovery but not quite as before.** "It's not worth it [surgery]. I mean, when I first [fell and injured my shoulder] I couldn't lift my arm… But I've been doing exercises and I can [move it more] but it's going down that way and lifting anything heavy." **Susan 5 – Help with heavy lifting, improvement with exercises** "I didn't realise that was broken [indicates wrist]. Erm, but if you look at it now [it's misshapen] … I don't think there's anything they can, there look [pauses] I mean, I can move this and I can pick a glass	"I just get on with it. They can't do anything or they're not doing anything. I mean, I was told two years for this to be done [indicates left shoulder] me arm reversed. So I can't see that happening. Not with me age and the national health the way it is. Now I've got a hernia, and they've said well you're on the list. I don't hold out much hope for that… But I'll live… til I die [laughs]" **Susan 5 – continued shoulder issue, help with heavy work needed, increase in comorbidity, no sense of expected reversal** "Since you came out, I'm on the walker. I don't go out without it. I don't even go down the garden without it" **Susan 5-6 deterioration in mobility, indicates increased use of walking aid** [had previously been going out without the walker] "I look all the time, where can I hold on. I mean, get up in the night. I know exactly where I get if I sit here I can get out that way, hold there, hold there and get round" **Susan 6 – mobility impairment affecting indoor mobility** "'bout the same I'm not eating as much as I did when I was at work say, nowhere near it" **Susan 4 – vulnerable, frailty syndrome** [asked how her appetite compared to at interview 1] "No, I don't think so… I think Jim's noticed that I'm doing all right and I am eating" **Susan** [when asked if she thinks Jim is as concerned about her appetite] "I feel as though it's all slowing me down… the walking, you know. I can't get on. I mean, this morning – what did i… - In the utility we keep the washing baskets on top of the freezer and that. I can't reach them. And I can't stand on the stool to	From researcher notes: Pre-interview: Susan answered the door and greeted me, directing me towards the living room as advised the conservatory was too hot this time of year. Susan held on to door frames and walls continuously whilst walking and appeared unsteady and unconfident on her feet. 6 Mid-interview: Susan stands from armchair independently with some effort and without using the riser function, but adopts a stooped posture once stood and shuffles to the living room door close to furniture with hands hovering near the surfaces. The toilet is immediately outside living room door. As Susan reaches the living room door – next to where I am sat - her forearms are at my head height and a large dark bruise is visible along the underside of her forearm, consistent with having fallen heavily against her forearm. I comment on the bruise, and that Susan had mentioned bruising more often. Susan checks her arm and laughs – "Oh yeah, full of bruises me!" 6 [brief pre-recording conversation about changes in mobility since interview 2] "Using [the walker] a lot more" **Susan 6 balance affecting indoor mobility, increased reliance on walking aid and additional seating** "Got a *new* walker… The old one had two wheels on the front and erm just the stand on

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	up, but I'm a bit… wobbly with it." Susan 5 – help with heavy tasks "It's like me foot. I've got a funny leg. That foot turns in [indicates left foot]. When I walk it's like that [turns foot in]. So that is what I'm tripping over. Stop it [to foot – laughs]. It's nothing to do, that foot is nothing to do with these falls." Susan – long standing well managed issue would be excluded from frailty scoring *"We're limited as to what we can do, so we have a short time to actually do anything"* Jim 4 – slowed up, tired "Only my mobility. I can't get out and do anything on my own. I can't go down to town or anything like that. Or even round to Sainsbury's." Susan 5 impairs walking outside alone, shopping [asked about any less satisfying aspects of life] "It's been hard I won't say it hasn't. I mean, you can't get in and out of bed… I can now cos I've got [unintelligible] grab rails, but um, things like that, you go in the bathroom. It's not easy at times getting up off the toilet and down, but… you cope." Susan 5 – not dependent on others but effortful and using compensatory equipment. Use of equipment would indicate more evident slowing [when	get them down because if someone doesn't go up and I just can't get them down which is annoying, so, if I changed the beds or anything. I've got dirty washing in piles waiting to go until Jim's free. You know little… they aggravate… And then I have to stop. And if Jim's tired and don't feel like doing it. Just sits there and it looks ugly… Frustrated really, yeah. It can't be helped" Susan 5 – evident slowing, help with heavy housework [when asked about feeling in control and preventing change] "Oh look after myself and shower and all that. And er, I walk up there [indicates the road outside]. Sometimes I could walk further." Susan 5 – able to walk outside alone but only in immediate local area. No assistance needed with personal care [asked how much she is able to do by herself at the moment] "I haven't got the best eyesight anyway, which doesn't help" Susan [talking about lacking confidence to go out in the dark] 5 – comorbidity affecting walking outside alone "I know the limit. What we can do and what we can't do. I mean I know I can't lift anything hot out the oven. Because I haven't got the control over this arm. So, I won't, I don't lift out. I put it in, and then [spouse] gets it out" Susan 5 "Because a couple, the one who's got dementia, the four of us used to go every year. Anyway, I said to Jim, because we always sat up the top, I said to him 'I'm not sitting up there because of the stairs' and I said we'll sit down the front… I think I had sticks or whatever it was… I couldn't get out. No confidence whatsoever… shaking like a leaf… There was no handrail. So I hung on for dear life" Susan 6 – problems with stairs, needed help with outdoor activity [describing changes	the back. This one is a proper walker with four wheels and you can sit" Jim *"Getting poorer!"* Jim "I keep falling and he's [pause] not too well with his breathing" Susan 6 – recurrent falls despite increased use of walker indoors [asked how things have been since interview 2] "It's not as good, no. I wake up at night to him, like this [indicates shortness of breath]. 'Put your mask on!'" Susan – combined treatment burden, needs interlinked [describing interrupted sleep because of Jim's breathing symptoms] "We just go to sleep if we're tired! [laughs]. He can drop off quite easy. I can drop off if the television's on" Susan 5 – evident slowing, fatigue [asked if sleep disruption affects her day afterwards] *"About six years ago now, it finally came up in the end when I said, I can't drive anymore because she used to nudge me"* Jim "I used to wake him up wait, 'oi, pull over', and I thought, 'We can't do this any longer'" Susan *"I can't think of names, sorry. It's alright, I've got erm Alzheimer's"* Jim "Get by, don't you?" Susan [when researcher asks Jim how he is after diagnosis is disclosed] *"Yeah, I can remember more than you! [to Susan]"* Jim

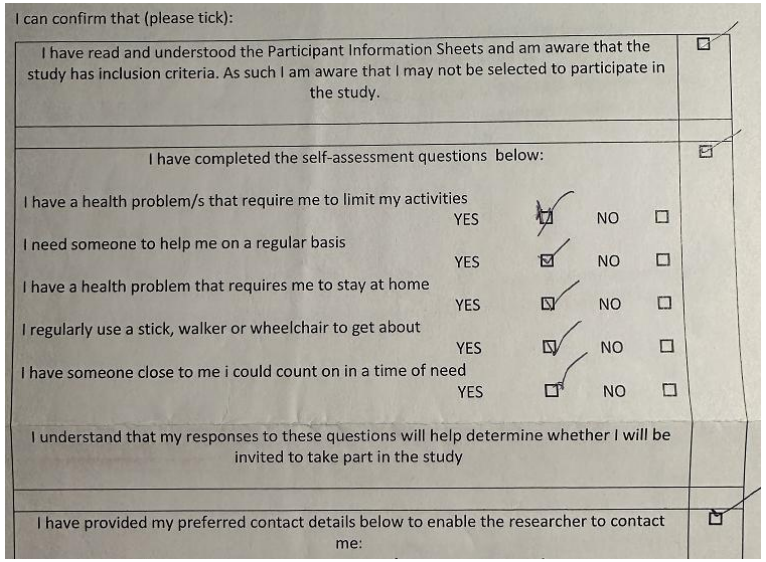
Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	asked 'how have you been managing at home recently?'] *"*Each one you get more [laughs]. I do some of the new ones, well, i do all the new ones. But I refer back to some of the old ones and do them as well [laughs]." **Susan** – repeated episodes, frailty trajectory, continuity versus episodic input [Exercises prescribed by different departments after each fall] *"You're still losing weight"* **Jim** "I'm still eating!" **Susan 4 Frailty Syndromes** "I've had err problems with being incontinent, which, is not very good. But that's been going on for years" **Susan - Frailty Syndromes** *"Susan won't ever be physically able"* **Jim** "I'll never be free of it… I mean, i don't know that I'll be able to go out in the street without the walker. That's the bit I don't like. Not being free" **Susan 5 – Permanent restriction, no sense of expected reversal** <u>From researcher notes:</u> (Pre-interview) Susan answers to door and invites me in, walking without an aid but running her hands along surfaces through the house as she goes. On the way out later Susan	to a regular theatre visit last Christmas once stairs became difficult, and being assisted out by the usherette] "Yeah… got a thing about steps! [laughs]" **Susan 6** "I go out. As I say we go, we go to [another town], we go downtown. But I do have find I have to stop every now and again. I've also got, I'm incontinent as well which does not help. That is a pain" **Susan** [frailty syndromes] **Summary: CFS 5** **Same comorbidities present as in interview 1 affecting daily function– reduced appetite, shoulder issue. Additional comorbidity and deterioration in mobility issue resulting in clear reduction in confidence and reduced activity. Mobility affected indoors now as well as outdoors. Remains unable to go out on transport independently e.g. shopping, but retains independent outdoor mobility with walker up and down the road or in own garden.**	"Yeah, I like to erm, I usually walk with the walker if I'm tired, so…" **Susan 5 – more evident slowing, increased use of mobility aid, tired** [describing being more careful to avoid falls] *"And she does try to use everything to hold on to"* **Jim** "Not really, is there? [to spouse]" **Susan** [when asked if she's had to make any changes to her activities other than moving around more carefully] *"No"* **Jim** "Cooking, I'm a bit wary of lifting heavy dishes out so [spouse] does that. He does most of the cooking at the moment, don't you? [to spouse] err, under guidance [smiles]." **Susan 5 – continuation of previous need, help with heavy housework** "You watch it [to Jim]. He's watching it. I'll go to bed. I get tired, very easy… It's more like the nap wants you! Rather than you want the nap, innit [to Jim]. You can't do anything about it" **Susan 5 – more evident slowing, reduced control over energy levels** [getting tired watching TV] *"Give in!"* **Jim** "you change as you get older" **Susan** **Summary: CFS 6** **Evidence of increased use of walking aid indoors and increased falls despite use of aid. Susan indicates a higher level of fatigue and need to sleep during the day, in part due to the affect of**

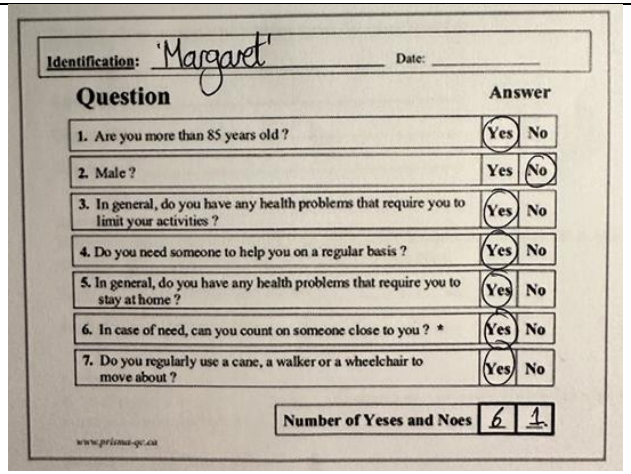
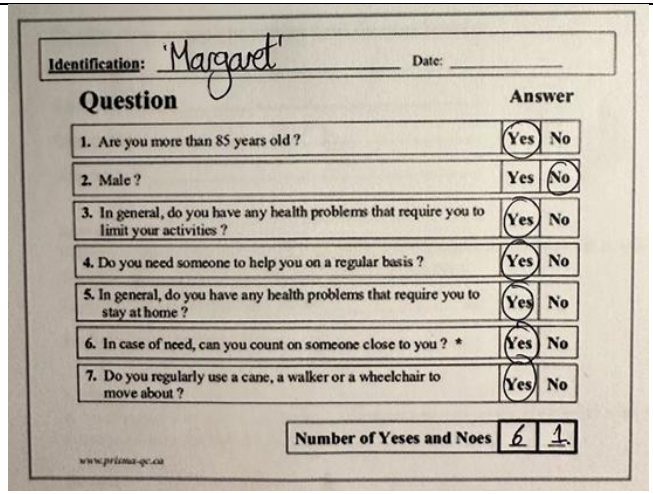
Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	states they have moved items to allow clear hand contact. 4 – independent day to day but vulnerable Jim then reveals he has sleep apnoea and has given up driving as a result. Susan states she knows the warning signs and will let me know if Jim might fall from the chair as I am sitting closer. Summary: CFS 5 Susan has evident slowing up whilst moving around indoors and this impacts going out alone beyond her own street. Susan reports multiple comorbidities and frailty syndromes including weakness, exhaustion, slow gait, incontinence and falls. Susan has repeated health episodes from which she does not return to her previous level of ability – frailty trajectory. Compensatory methods in place to manage symptoms and retain function, e.g. adaptive equipment at home.		Jim's symptoms on night time rest. Continuation of previous symptoms.
	"I mean we went over to Tesco at [place name]. I'd been to the toilet, came out and there was a commotion going on. I thought 'what is it'. [Jim] fell over [laughs]." ***Susan*** *"…me leg's still a bit awkward"* Jim "What, on me own? Well before I started falling… it's a long while. But yeah, I've got	"I mean, alright it was someone's pathway I was crossing. So it went along and down and back up, but… [pause] I don't know" Susan 5 falls outdoors, reduced balance [fell whilst on a sloped path outdoors but not sure what happened] "I lose track of how many there are… I just say 'oh it's another one'." Susan 5 recurrent repeated falls [when asked if she had fallen other than the bus stop incident]	"I had another fall and he didn't hear me" Susan 5 recurrent falls [used pendant alarm but no capacity for assistance to come] "Oh yeah, quite a few haven't I [to Jim]" Susan [when asked about having more falls since interview 2] "Yeah, but there's been nothing major" Jim "I've not gone to hospital through any of them, plenty of bruises! I come up in bruises for no

Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	used to it" **Susan 5 falls outdoors** [asked how long since going out by yourself] "Not this Christmas, yeah the Christmas before that Christmas, whatever that date was two years or some two, three years?... That's when I first went down… too many [since]… Three-month intervals. But I've never passed that three months [laughs]" **Susan 5 recurrent falls** *"When she fell and broke her leg, erm, it was 10 o'clock at night"* **Jim** "That was a nightmare" **Susan 5 – falls with significant injury and acute admission** *"And, I let her lay there cos I didn't really know what damage I would do. So I laid there and it was three hours before an ambulance came. And it was another, four hours [to Susan]"* **Jim** **Summary: CFS 5** **History of recurrent falls with injury and hospital admission.**	"No I don't think so…" **Susan 5 recurrent falls, previously at least three monthly but appears possibly more often now?** [when asked if she felt she was falling more often] From researcher notes: I called to arrange the second interview around a week and a half ago. Talking on the phone Susan described a fall on the way to the bus stop, whereby [spouse], walking a few steps ahead was unaware [they] had fallen. A member of the public assisted Susan up and spouse was unaware of the fall until later. When agreeing to call ahead on the day of the interview, Susan joked 'in case I've fallen again'. On the day of the interview, I called ahead as agreed. Susan confirmed the interview could still go ahead, describing having multiple falls since our last meeting but being 'ok'. **Summary: CFS 5** **Ongoing recurrent falls. Some indication of increased frequency but Susan denies this.**	reason. You know, I don't remember knocking that [looking at bruise on arm], but I must have… in the house, mainly" **Susan 6 recurrent falls within the home, no further admissions but did need to use pendant alarm** "No, yes? [looks to spouse]" **Susan** *"She's more careful [pause] because she can't walk so easily. You just shuffle."* **Jim** "Yeah, I like to erm, I usually walk with the walker if I'm tired, so…" **Susan 6 falls indoors, altering movement to reduce risk** [when asked whether the falls are happening more often] **CFS 6 – appears high risk of further fall with injury as falling regularly, bruising visible and unable to get up independently**
CFS calculated by researcher	CFS 5 Living with mild frailty **Overall CFS 5 using CFS app.** **Evident slowing, help with heavier housework and meal prep.** Susan describes not being able to go out to the shops alone or lift her walker on/off a	CFS 5 Living with mild frailty **Overall CFS 5 using CFS app.** **Evident slowing, help with heavier housework and meal prep.** Susan describes using her walker all the time now, even to access the garden, but remains able to walk up the street	CFS 6 Living with moderate frailty **Overall CFS 6 using CFS app.** **Help with all outside activities and with keeping house. Problems with stairs.** Not dressed until 10. Shopping brought in by driver.

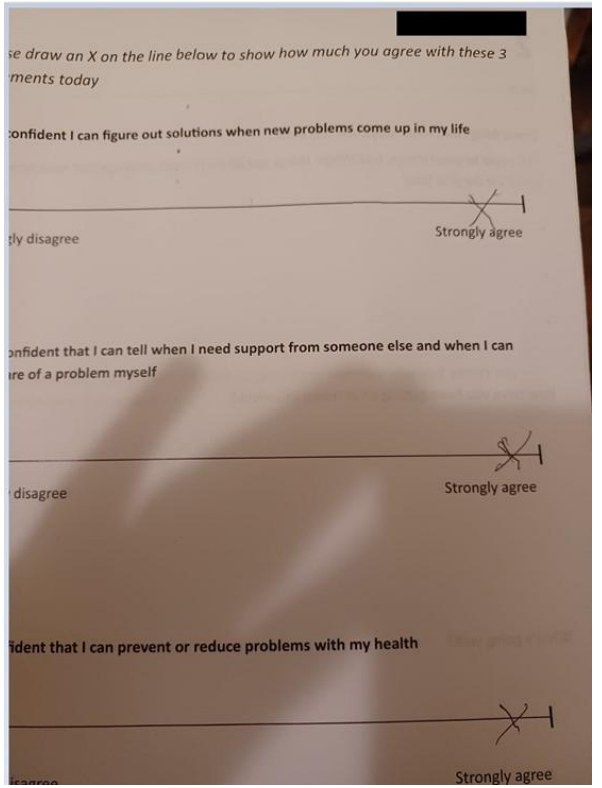
Susan Age 82 *[and Jim]*			
	Interview 1	Interview 2 (13 weeks later)	Interview 3 (40 weeks later)
	bus, but in later interviews states she had been able to walk up and down the street alone at this stage. Susan pays for private support with housework and tries not to attempt this automatically. Jim assists with the heavier aspects of cooking. Jim and Margaret go out shopping together for smaller items and bring their larger shopping deliveries in from the doorstep at home. The couple also go on the bus for leisure – visiting local towns for a coffee and short walk. Susan is independent with all personal care. Susan describes being limited by low energy levels and has experienced multiple falls one of which resulted in a fracture and hospital admission and a short period of reablement at home afterwards, after which she needed no formal care, instead relying on Jim for day-to-day support. Susan has some small equipment items in place to help with getting on/off the toilet and in/.out of bed. Susan has a whistle on a string round her neck in case she falls. Susan has incontinence when initially stopped her going out but no longer limits this.	independently with her walker. Susan describes feeling frustrated by slowing down, particularly being reliant on Jim who is also slowing down. Susan continues to pay for private support with housework, at the same level as interview 1. Susan continues to fall regularly but has had no further fractures or admissions. Susan still has her whistle but has made an appointment to find out about falls alarms.	Susan has trialled a falls alarm but is not satisfied with the response so is going back to using her whistle. Susan and Jim no longer go out for pleasure, only for practical tasks and increasingly this involves Jim going out alone.

Appendix 31: Analysis of interviews against CFS scoring and frailty fulcrum domains - Margaret

Margaret Age 87		
	Interview 1	Interview 2 (8 weeks later)
Recruitment checklist (cropped to redact participant indentifiable information)		
PRISMA 7 responses		

	 Identification: 'Margaret' Date: _____ Question / Answer 1. Are you more than 85 years old ? Yes No 2. Male ? Yes No 3. In general, do you have any health problems that require you to limit your activities ? Yes No 4. Do you need someone to help you on a regular basis ? Yes No 5. In general, do you have any health problems that require you to stay at home ? Yes No 6. In case of need, can you count on someone close to you ? * Yes No 7. Do you regularly use a cane, a walker or a wheelchair to move about ? Yes No Number of Yeses and Noes 6 1 www.prisma-qc.ca	 Identification: 'Margaret' Date: _____ Question / Answer 1. Are you more than 85 years old ? Yes No 2. Male ? Yes No 3. In general, do you have any health problems that require you to limit your activities ? Yes No 4. Do you need someone to help you on a regular basis ? Yes No 5. In general, do you have any health problems that require you to stay at home ? Yes No 6. In case of need, can you count on someone close to you ? * Yes No 7. Do you regularly use a cane, a walker or a wheelchair to move about ? Yes No Number of Yeses and Noes 6 1 www.prisma-qc.ca
Participant diary	N/a – first diary issued	Margaret's diary had not been completed since leaving it at interview 1. Margaret initially explained this had been placed into a pile out of reach by her carers, but when I brought the conversation round to the diary at the end of the interview Margaret then says "Which I chose not to look at…". It is difficult to clearly differentiate between jest and serious comment so it is unclear which is the trues reason behind not completing this. <u>Activity log:</u> We discuss having gathered a reasonable picture of activity since interview 1 [Margaret does not add any additional contributions over and above what's been discussed] and ask whether we could complete the VAS together to complete the interview. Margaret consents to this. I talk through the scales out loud with Margaret. She says "I'm not necessarily always gonna have a load to put in the gap am I?", referring to the activity log on the left page. <u>Visual analogue scales:</u>

		"Right. [reads question aloud] 'I'm confident I can figure out solutions when new problems come up in my life.' Yeah I can, but if I don't figure them out I'll find someone who can!" **Margaret** [on VAS q1] "What is the middle of it? " **Margaret** "The middle of what? " **Researcher** "The line" **Margaret** [I explain the scale again and indicate with my finger the two extremes and sliding scale in between] "Well, to tell the truth I do sort them out meself, but I may ask someone I may not… the next question [Q2] is 'I am confident that I can tell when I need support from someone else and when I can take care of a problem myself'. Well that answers it dun it?" **Margaret** [on VAS q2] "So would you agree with that second one?" **Researcher** [based on Margaret's comment about asking for help sometimes] "Definitely!... Yeah, I definitely strongly agree that…. I mean I suppose… cos that really answers that first one don't it? 'I'm confident I can tell when I need support from someone else and when I can take care of a problem myself'. 'I am confident I can figure out solutions when new problems come in my life'…" **Margaret** "[Pause] Well I suppose the first one's more about working out what the solution might be. The second one is more about deciding whether that solution is something you can do yourself or something you need someone else for." **Researcher** "I'm gonna tell a little fib… ok. I agree. Now, 'I am confident that I can prevent or reduce problems with my health'. Yeah I can, because I'd go about it really finding out. Cos I wouldn't wanna, you know… I wouldn't live with it so I'd find a solution to the experts" **Margaret** [setting the scene for further independent diary use] "So the idea of this diary would be, that at the moment this week that's how you feel about these questions. It might be that another week things happen that make you feel less confident or you've needed to work around" **Researcher** "Yeah, you see… When you have a wobble it's temporary isn't it?... Unless it's a real nasty… [trails off]… See if it's gonna be a 'knock you for six one', it would be something like well the care people said they were no longer gonna come for me but then they're obliged to find you a substitute" **Margaret**

		"Yeah… so it would be a change but not necessarily a complete loss of that support wouldn't it?" Researcher "That's putting it on the err, extreme really… If we're tryin to pick out something that would really do it" Margaret 
Social Environment • Main carer & carer network • Next of kin & wider family • Friends & community • Preferred methods of interaction	"[Friends] were this lovely couple who lived in [another county] and right from there when I had my major surgery for my spine they took me [into their home]… I stayed there in the little snug and did my little bit of exercise" Margaret [describing friends who built her current home]	"Not really no. Cause they're all a long way away, or they're dead. No [POA]'s at [place name] – she had company. You speak to them on the phone and that but you're not really err… You know, I'm not, I had calls." Margaret 4 no support over Christmas therefore not dependent on social support day to day [when asked if she had visitors over Christmas]

	"They'd got a huge garden and watched the wildlife. It was lovely, so I could, you know, enjoy it" Margaret [on what helped her *previous* recovery after surgery] "Their son [name] was adopted. He was a bit of a problem but I got on very well with him" Margaret [describing *previous* ability to make friends easily] "[W]hen I came out with my spinal operation. They said that I had a bath. 'You mustn't bath, you've gotta shower'… then they worked all day and they gutted my bathroom and built me a beautiful shower. And err, I didn't ask them to! I don't know why, I could have had a builder do it but they wouldn't have done it as good as those two did" Margaret 5 – this and previous 3 quotes show dependence on others over Margaret's lifespan, but able to manage PADLs with some adaptation in place [describing support from friends to adapt her home after spinal surgery 50 years *previously*] "And then I'd always end up somewhere or other, in one of my favourite tearooms. And have err, a bacon sandwich and a coffee at lunchtime. Yeah I always, y'know, circulated. I got to know it very very well. I didn't stay in [town name], I used to go to [another town name] which is along the road. He's got a nursery and a little, there was a little cafeteria in there…. And we used to all meet up there, erm usually on a Saturday. A whole crowd of us… locals… There was quite a few – I didn't know their name – people turning up. And took their dogs for a walk so they'd come in for a coffee." Margaret 4 able to go out independently, choice over how to interact with others and maintain connect. Use of language 'circulated' implies continual movement out into the wider community [describing going out prior to COVID] "So, and I had an annex. They always… there's always something for me" Margaret 5 historically able to manage own needs with	"[I]t was a funny Christmas really, very short and sweet. My err, lady who does my housework and my washing and my bed making and all that, she bought me this [indicates diary/organiser] and it's invaluable" Margaret 6 help with heavy housework/keeping the house. Possibly indication of need around memory or cuing? "But I mean, I had that man didn't I, do you remember? I've not seen him since. He was something like, erm, he took pictures and that and he was a freelance man going round to the people if he thought they were on their own and they needed y'know, they were lonely… And the link up is [place] – the bloke down there. Well I know [another person there] because when I used to need an ambulance to go you could borrow or pay for it from them. And he's something to do with that… " Margaret 6 need help with outdoor activity therefore the man visited at home. Sense of reduced choice and control over how the interaction was arranged and took place [describing new contacts made after calling the 'single point of access' community phoneline] "Well it must have been a Monday because my friend [name] was here" Margaret 4 not dependent on this friend daily, but a predictable pattern or routine to visits "Yeah, the only thing is, y'know I've got [friend] who works at [care home]. And I've got [POA friend] – she don't get out that often. I get lots of phone calls but now most of my obviously living friends are not in this area. But now I've got that phone [new mobile]" Margaret 4 not dependent daily but frequent phone contact. Loss due to age. Loss of proximity but video calls have partially mitigated [when asked how she feels about being referred to a befriender without her knowledge – 'She was trying to help me'] "I do get in a bit of a mess with it, but erm [carer name] last week, goes 'go on, press that'. 'Oh Margaret!' she goes. See now she lives in [another part of the UK] and she's a real guardian angel she is. But y'know, she can't make her way down here. I used to have to drive her everywhere. She's only familiar with the bits of road. I used to have to take her to the cemetery for her dad's grave up in [another place]" Margaret 5 need help with high order activity, in this case use of video calls. 'Guardian angel' title not dependent on proximity or on solely

	support of friends in proximity during recovery from planned surgeries [describing friends accommodating her needs in their home] "I got backup in as much as, [another friend], she lives at [another town]. She's my power of attorney. She totally organizes all my money, she's the bank manager at [another town] at [bank] where I used to work. She organizes all my finances together with her mother. I don't have anything to do with it, nothing at all." Margaret 5 support with finances [when asked 'would you have somebody now, if something went wrong, if there was a problem, someone you could call on for help?] "[T]hey started looking around and thinking well they're getting on. And [husband friend] was having [health] problems… She had… the doctor knew she would keep going *cough, cough cough*…. the doctor noticed, supposedly… and then the next thing you know… they [were] tied at the wrist, you couldn't imagine… [husband friend] had to go into a hospice… And he progressed and she… she went poorly. So they ended up sharing a suite together there. I used to speak to her every day. She had a job to breathe, and [husband friend] was progressively getting worse. And I, one day, erm… I phoned up. I said 'I'll ask you questions, don't speak cos you can't speak'. And anyway. She said, what's it, 'this was a good morning, [husband friend] had died'. And… I was gonna phone her but she said 'no, I'll phone you later in the day'... She phoned me and she died at… same day… " Margaret drawing on previous experience of problem solving with support of friends, doesn't comment on or acknowledge not there now- ?defence? Experience of others used as a response. Externalised? [in response to question about having someone to call on for help. Throughout this response Margaret switched between description of their shared home and issues they resolved with it, and the deterioration of her friends]	receiving support from that person, sense of protection [describing help from carers to accept a video call on her new smartphone] "My electric company which is next whatever, well they'd got a lower tariff and when I asked they said I couldn't have it. And [POA friend] said 'don't worry, come with me we'll go in Which'. She said 'we'll go on Octopus'. So that's supposed to be being done." Margaret 5 support with finances. Shared decision making. States not involved at all with own finances, but taking a directive role in advocating own wishes so perhaps not entirely dependent on support [describing support from friend who is POA] "That's a good bloody month or so and she hasn't set a – she's getting these weird and very verbal messages from me she thought, but they were too clever for me. It was me putting them on there. And [other friend] was putting something like, 'I wanna go over to Octopus, can you do it?'. Well I know she's busy at the moment, well she's always busy. Anyway, I don't think she took it that well cos she thought it was me talking. And she sent this bloody 0800 number to do it myself [laughs]." Margaret 5 support with finances but ?some cognitive or behavioural aspect putting strain on relationship. Margaret advocating for own wishes but setting an expectation that friend cannot meet [describing delay in change of utility provider and friend suggesting Margaret does it herself] "Well [POA friend] has always made me very wary about what I do in my phone. A long time ago, I think it's because her sister – she's in the nursing homes – I think she had a bad experience and I think her daughter did as well. Well I know my neighbour did, so then you err on the side of extra caution" Margaret 5 drawing on experiences/observations of others to risk assess and influence self-management behaviour [when asked how she works out which things she can manage herself and which she doesn't feel able to manage eg. calling the number to switch utility provider] "Well my shopping, that's done by [other friend]. She does it once a week – Marks and Spencer's or whatever. And then [POA friend], she might like, she gets me, I don't know – other bits. Like she might say to me, 'I'm going down to Waitrose in my lunch hour, was there anything you wanted?'. Might say 'no

	"They've all kicked the bucket now anyway…" **Margaret – reduced network due to age and bereavement. Loss.** [talking about friends] "Well I think it shows you how... dependent and loyal I am with my friends at the time. And they've always been the best of people haven't they to me" **Margaret 5 friendships as a key resource previously. 'Dependent' and 'best to me' imply friendships may not have been of equal nature in both directions** [reflecting on what her past friendships say about her] "well, here I've got [POA friend], I've got [another friend] – she's young… Finance and all that, or any problem. Takes a bit of a while sometimes for her to get here. She's a very busy lady. [Younger friend], she's in that care home. And she comes here" **Margaret 5 help with finances and problem solving. Not immediately accessible** [when asked what contact with friends and her community looks like now] **Summary: CFS 5** **When talking about her current situation Margaret indicates her friendships also include a degree of practical support, in this case mostly finances. Margaret reflects on her previous experience of support needs after planned surgeries for a spinal condition and typically being able to manage her main care needs with proximal support from friends if needed. Margaret returned to living independently once recovered and talks about going out driving in the local area right up to COVID, indicating CFS 4 approximately 4 years previously. This suggests a history of some vulnerability and periods of increased dependence but no permanent long standing care need.**	thank you, I'm alright'. You know?" **Margaret 5 help with shopping. Choice and control, some degree of autonomy, both planned and ad hoc opportunities** [on deciding what she does and doesn't feel able to manage] "Oh yeah it'll be alright once I get in the swing of it... I couldn't go out in this weather. Somebody said 'oh! We'll go down town!'. I said 'no we bloody well won't, not in this weather!'" **Margaret 6 help with outdoors – offered but declined sue to weather** [on getting her powered wheelchair recharged after a couple of years] "all over the years all my friends in school apart from one, they're dead" **Margaret – loss of networks due to age** [describing history of excelling in entering school early when asked 'What's keeping you going do you think?'] "I mean when I was in the other school, erm, there was a girl in the seniors like, and I was still in the ordinary school, before the grammar school… And she always protected me. Somehow or other as I've gone through class I do seem to have had a little guardian angel. And I had a particular good guardian angel – it was [man's name] – the head boy. Oh, I could get round him to do my bloody homework!... Yeah, I usually had somebody to look after me – not intentionally!" **Margaret Guardian Angel again, this time in past. 'Protected me'. 'Someone to look after me'. Not a planned or requested role.** [when asked 'What's keeping you going do you think?'] **Summary: CFS 6** **Overall Margaret presents a need for support with high order IADLs and with all outdoor activity which would suggest CFS 6. However within this Margaret displays self-advocacy suggesting she is not entirely dependent with these tasks. Her previous friendships appear to have been unequal, with the friends also taking on a support role which Margaret does not indicate needing to reciprocate. It may therefore be the case that Margaret has always blurred friend and carer roles, therefore care support being offered may not indicate a true need but a long standing behaviour or coping strategy. Margaret has no social visitors over Christmas suggesting she is not dependent on friends day to day, but formal care continues. Friendship contacts have become frequent**

		telephone contact and Margaret implies video calls have gone some way to mitigating any sense of reduced contact from this, perhaps something not immediately considered or recognised by others. Social contact appears frequent and for those in close proximity there is some routine and predictability where practical tasks are being undertaken. Gifts are exchanged with privately funded support contacts, suggesting personal relationships have formed. Also an indication of expansion and flexibility of these roles as people privately funded do additional ad hoc tasks. Margaret has both planned and ad hoc support offered. Support to go outdoors is declined although when describing why no to get a dog Margaret implies not going out would ruin a dog's life. There's some indication Margaret may not fully trust those offing support to do a competent job taking her out, perhaps a sense of vulnerability. Idea of a Guardian Angel is raised twice, once in earlier life and once regarding current friend. This appears to be a role of someone looking out for Margaret, doing things to help her even when not asked.
 • Think from the skin outwards • Clothing & footwear • Main daily living areas • Beyond the doorstep & transport	"It was hilarious, this little cottage, my bedroom… erm, when they were getting renovation they put a toilet downstairs, so they put in a little room, a little cupboard with a commode thing in there, but when you go from there, the floor went downhill! So in the middle of the night, I'd come out from there and you'd, I'd get to my bedroom which was just there [gestures] you'd take off at like 90 miles an hour! [laughs] It was lovely!" Margaret 5 previous experience of risk perception [previous experience of using a wheeled commode] "And it was a separate built little house. Attached to theirs, and it got, my own bathroom and toilet, and this lovely bedroom, and French doors that looked out over their garden. But then a total outlook right out over to, I think it must have been [another town], right out. It was lovely!" Margaret previous experience of recovery from ill health – visual connection with nature/outdoors was a key feature that gave pleasure withing the recovery period [describing physical features on her Annexe that gave her pleasure]	From researcher notes: "On arrival I called Margaret as before from the driveway to confirm the key safe number and enter the property" 6 would need assistance to open the front door indicating CFS6+ "I erm, had a little fly we had the other week and couldn't get rid of the pair. Every time the carers came in at night they brought these horrible flying insects in with them. I said 'I never get flies!'" Margaret 7 carers visiting throughout the day (two carers, four time a day). Associated with a loss of control over the home environment. "I've got to change from this very uncomfortable harness which I'm going on now. It really is bad. It cuts in your legs and everything. And the nurses said it's absolutely awful. Well I think they might have stirred it up, I don't know, cos I haven't got a number I could have stirred up. Anyway, he said he's got this new harness and it's, it's amazing. It's like a little padded – you know a baby seat you put in a car. Well, it's a little bit like that. It comes up here [indicates on own body], which is good cos it for the top of my spine, and then it sort of, it's all padded and then, then it just… I don't know it just does up no problem at all. Whereas this one, they have to strap it on and when I can't breathe at all it cuts

	"Well I was still… Oh I'd go out every day driving. I, I was good, I could drive about. I had a new car. I started that when my dad was around." Margaret 4 pre-COVID experience of going out every day independently [when asked whether the fluid in her legs had affected her movement, or whether she was already having some difficulty before this] "And then I'd go out… I discovered everything about this locality and right miles around! I knew more about this, round here, than people who'd been born here and never moved. I just enjoyed it." Margaret 4 pre-COVID independent going out in the local area [describing going out daily pre-COVID] "Yeah I was… get up in the morning, make the bed, tidy up, have me breakfast bout ten o'clock. Go out, get in me car cos it's there [indicates empty driveway outside bungalow]. It's got electric doors so I had that done, and err, everything was easy!" Margaret 4 pre-COVID independent going out in the local area [describing life before COVID] "Yeah! But then we couldn't go out, and cause then you become more dormant don't you?" Margaret COVID lockdown as a point of change [when I clarified that she was going out right up until COVID] "I haven't been out for three years" Margaret indication of timescales of change [when asked if she still goes out now] "They brought the hoist out, but one hoist they brought was so big we couldn't get it through the doorways. Well my doorways are conforming to proper building regulations. It was a bloody, absolute… mess! And i… she's put oh well you've got no confidence in me. And I said well do you blame me?! You've not done anything right." Margaret 7 experience of transition into	my breath off all together. But no, this is very very good." Margaret 7 continued reliance on hoist and carers [describing a recent visit from the community health team to review her hoist slings] "I've got this new phone. And, bloody hell it's so complicated. Yeah, but [friend] upgraded it!" Margaret 5 needing help with higher order IADLs. Technology upgrade with support – complicated. "I get lots of phone calls but now most of my obviously living friends are not in this area. But now I've got that phone [new mobile] we've got the picture on" Margaret – phone upgrade has changed communication with friends "And if it's come… I keep all my stuff in a small place here, cos you see [POA] has to come over and sort it" Margaret 6/7 Micro-environment – needs help with arranging possessions within reach [looking for Participant Diary and explaining how her friend places her post where she can reach it] "Now this chap I've got today, I had him the day before yesterday. Erm, he's got a hacking cough. Now I said to my girl carer…. I said to her 'would you please convey to the people, your office, you've got the phone, that I'm not happy with the fact that he's come here on Wednesday with a bad cough'" Margaret maintaining choice and control over the immediate environment and advocating for her own health within it [talking about the relationship she has with her carers] "See I don't know, and I get it and then they whizz it away…" Margaret 6/7 Micro-environment with reliance on others to set up. Loss of choice and control. [describing how post is moved by her carers] "I folded it up, one copy so that I can take it to bed with me [looking through carrier bag with medications and essential items in] cos it's got all the numbers on it. And this is the one I said it turned up and I thought mmmmmm. Here it is – I've shut it up in my glasses case." Margaret – carrying essential items in a carrier bag to ensure they are accessible to her at all times [searching for the leaflet with the 24/7 support number on it]

	using a hoist at home [describing the new hoist not fitting into her home] "I'm not staying in bed all day. I can't eat laying down, I can't drink laying down, and it plays my back up, I'm not supposed to lay down" Margaret 7 confined to bed or chair, considering risk of bed vs chair. Bed care may mean complete dependence whereas getting out to a chair may facilitate participation in the tasks and reduce assistance [raising concerns to the carers when the hoist broke down] "I said to [POA], 'I've come to the conclusion, I can't enjoy them cos I'm not in that room, it's full up with furniture, and erm, I enjoy what I've got here'. Y'know, that's fine. So err, I decided that I'd phone up the people and ask 'em, would they like their… instead of waiting til I die, have them now…" Margaret 7 focus on now / acceptance of the immediate environment. Not able to access other areas of the home independently [talking about making arrangements for possessions she no longer uses] "Where you came in, go up where my bed is – they haven't made it – and then the door by the phone over that way. There's two doors, one is a walk-in wardrobe and the other is the wetroom. Unfortunately the hoist won't go in there [pointing to bathroom], that's why I have to have a shower…" Margaret 7 hoist with carer assistance for all personal care. Limited choice and control over immediate environment "I was limited in my going from day to day really by the fact that the original Occupational Therapist took away my real good thing which was that Sara Steadi [device to assist with transfers, and requires the user to pull themselves up to standing to allow a perching seat to be placed behind them]" Margaret 6 to 7 use of a steadi indicates reliance on others for all transfers (assistance of two carers needed for steadi), but an active role	"No, not really… Because we're still waiting to put them all into gear. Y'know, like I still have to be taken up to the bed to have my pad changed, and then they're gonna get this business for the toilet... that's where I should go to the toilet, on the toilet. And now I've got me err, [private acupuncturist] charged up me wheelchair I am supposed to be whizzing around on that… Get out of my way, I shall be dangerous – it's so sensitive! And then one of 'em said 'oh, so I can take you out?'. I said 'I doubt it'. I said 'you can't drive my steadi or my hoist, surely you won't drive my wheelchair?'." Margaret 7 dependent for all personal care and toileting in part due to the environment, however not readily taking up use of the powered wheelchair for independent mobility indoors [when asked if there's anything more she is able to do for herself since interview 1] "One of the nurses kept on and on and on and on and on and on, so I just said I'd get [private physio/acupuncturist] to charge it up. Well it was hilarious when I used to be on it around here. He used to make me go up there, down here, in there, out there. Well it was so bloody sensitive I ended up in the bloody wall every time…it'll be alright once I get in the swing of it. It's funny cause, in good weather. I couldn't go out in this weather. Somebody said 'oh! We'll go down town!'. I said 'no we bloody well won't, not in this weather!'" Margaret 7 difficulty adapting to strategies to regain some independence at home [when asked whose idea it was to use the powered wheelchair at home] "The other little chair that I use for my transfers here. That's the other little chair and that's one that I could self-propel but I've never been able to self-propel it. I don't think my arms are bloody long enough! So what they do, they lift me off here onto the wheelchair" Margaret 7 use of an attendant propelled wheelchair Summary: CFS 7 Margarets comments about the physical environment are more focused on the present during interview two, whereas in the first interview she had also reflected on previous aspects of her physical environment at times of previous health recovery and up to the point of the COVID lockdown. Use of the hoist with carers continues, and although Margaret has been using the painful sling for several months she has now been assessed for a more comfortable

	for Margaret, whereas hoisting is a predominantly passive activity for Margaret indicating greater dependence. "Ruined my life in a way she did, she did. She, erm, messed up the bed. My bed, which is it, was too low. And she arranged for it to go up… higher, built up. And she sent two blokes round here and they went according to her measurements, and the bed she made a complete hash of, was so high I was virtually touching the ceiling. It was ludicrous! The blokes said at the time they couldn't understand it. So course, even the carers, the tall ones couldn't reach it. So I ended up bed… having to stay in bed for at least two months, which is so bad because I've got scoliosis of the spine, which I've had major surgery on. She ruined it good and proper. And it took 6 months for that bed to be brought down!" Margaret 6 to 7 completely dependent on others due to changes to the environment. Actions of carers as well as Margaret were impeded by the environment/actions of someone else. Appears to avoid term 'bedbound'. Negative impact of environment on management of long term condition. "[W]hen they knew that report which said I wasn't really coping with you know, bad heart and all that they cut that bit out with the wheelchair. But, it goes against the grain... The Occupational Therapist says we're supposed to do it. I said 'what Occupational Therapist? They don't come" Margaret 7 use of an attendant propelled wheelchair indoors with the carers. Equipment usage determined by others – carers or OT. [describing following a transfer routine that contradicts the OT guidance] "I accept it. I've got my little plants. Got my garden out there for… I don't get a chance to see that because erm, on this hoist you're laid off and you can't have a good look out [indicates reclined position during hoisting rather than upright]" Margeret 7 reliance on hoisting with carers [when asked how she feels about not going out for three years]	alternative sling. Margaret describes a 'micro-environment' arrangement as a result of only being able to access items within immediate reach between carer visits. Essential items are kept in a carrier bag and with Margaret at all times. The actions of others entering the environment are magnified eg. letting a fly in or having a cough. Others around Margaret have taken steps to encourage greater independence through the powered wheelchair however this has been unsuccessful.

	"You've ruined my life really. I said you've taken away what little pleasure I had. I stood up on that Steadi. 'Well no, you were being lifted'. I was not being lifted! You came here in the morning when they left. We swung, I swung my legs round, it went on the steadi. Then I just… they brought the Steadi machine up here, and so I put my arms on it, and I pulled myself up. I did not get lifted. And that's what all the carers said, but she, she'd been new to the job but she was so poor at it… really really poor" Margaret 7 transition from 6 to 7 and using the hoist instead of the steadi [describing the assessment of the steadi and OT decision to stop use] "Friday night we go into the bedroom. I'm on the hoist. We've gone up to the bed to swing me over, put me into the bed, onto the bed to do the nighttime ritual. And the hoist it got stuck up in the top" Margaret 7 dependent for personal care on the bed [use of the hoist to go to bed. Crisis event with equipment] "Swinging away, and it is painful cos this squeezes me here (indicates where the sling edges come in contact with body). And all the legs hurt, so I said 'I can't take much more of this'" Margaret 7 dependent on hoist and slings despite pain associated with use [describing breakdown of hoist and pain associated with sling] "They brought the hoist out, but one hoist they brought was so big we couldn't get it through the doorways. Well my doorways are conforming to proper building regulations. It was a bloody, absolute… mess! And i… she's put oh well you've got no confidence in me. And I said well do you blame me?! You've not done anything right. You've ruined my life really." Margaret 7 dependent on others due to use of hoist. Hoist within home environment creates further restriction to function and satisfaction for Margaret [describing her interaction with one community OT]	

	"Err, yeah… what it does, they fix a harness on you. They get that off the chair and they fix it and tighten it up. Well the thing is, that's not really doing my back a lot of good. That's where an Occupational Therapist would say 'no, you can't have it'. Anyway, that's another obstacle I've got to try and… [trails off]" Margaret 7 dependent on use of a hoist despite considering this contraindicated [in response to a clarification question about which moving and handling device she is using as she continues to refer to the hoist as a stand aid] "So I went into bed after, where they prepare me and thought well tomorrow morning gotta greet the fact we haven't got us one of 'em [indicates hoist]. And the weekend isn't it… 'oh, bloody hell!'" Margaret [describing some care needs being met on the bed] Summary: CFS 7 Prior to COVID, approximately 3 years previously, Margaret describes accessing the local community independently in her car daily (CFS 4). COVID lockdown became a change point after which Margaret did not return to going out. Margaret had been getting around at home with carer assistance and use of a Sara Steadi which she felt was a positive experience and allowed her to stand/perch upright and see out of the window. During the 12 months prior to the interview an OT recommended removing the Steadi and replacing with a hoist. Margaret did not agree with this decision. A Steadi may indicate assistance somewhere between 'minimal assistance' (CFS 6) and 'completely dependent' (CFS 7), however the hoist is a more definite move towards 7. The hoist is also associated with pain and inconsistency having broken down once. Combination of hoist and home environment creates further access restriction and reduced satisfaction for Margaret. Alongside this Margaret describes using an attendant propelled wheelchair with the carers indoors although the carers have stopped using it since	

	her health deteriorated, and being unable to access some areas of her home/possessions that previously gave her pleasure. Margeret is no longer able to access her preferred bathing facilities since the change from stand aid to hoist, but feels the hoist is contraindicated due to her long-standing scoliosis. Overall there is a sense of physical interaction with the immediate environment being dependent on the decisions and actions of others, which is a change from independence over a three-year period.	
 • Health & social care integration • Sharing information & care records • Respite & carer support • Funding & benefits	"I pay for all my support. I pay for my cleaners, the chap who does the garden. Everything you pay for. The carers" **Margaret 7 carers for personal care, plus paid support for outdoor activity and keeping house** "You can't… who's responsible? There was another OT at [place name] and she said, I could do this straight away, but she's made the mistake and she's got to be responsible for putting it right. Well… as I say, godforsaken chore that was. It was virtually, yeah, six months, over six months" **Margaret [describing error in bed raise made by one OT and the challenges and delays in rectifying this]** "It was a bloody, absolute… mess! And i… she's put oh well you've got no confidence in me. And I said well do you blame me?! You've not done anything right. You've ruined my life really. I said you've taken away what little pleasure I had. I stood up on that Steadi. 'Well no, you were being lifted'. I was not being lifted! You came here in the morning when they left." **Margaret 7 Increased dependence on others and reduced pleasure as a result of introduction of hoist** [describing a lack of confidence in the OT's decision making and disagreement with the assessment process and outcome] "You came here in the morning when they left. We swung, I swung my legs round, it went on the steadi. Then I just… they	"Well actually that has improved immensely… I do have a number I can contact 24 hours a day which I never had before. And you know, the doctors are pretty grim aren't they? And so, there's a leaflet here – I'll show you it. And I had a nurse call yesterday. They always call, I have one call every week. They don't necessarily, they're not coming to give me *care*. They come to see how I am…. can't fault it" **Margaret 7/8 increased contact from nursing team to monitor for change may indicate severe frailty/approaching end of life in light of previous life limiting prognosis** [when asked about the level of support she has at the moment] "Don't see the doctors. I meant that doesn't accumulate a time, nobody comes from there" **Margaret – no increase in contact from primary care, again Margaret perceives community nursing and GP surgery as separate things** "So he came up, I said 'all the lights out? Everything out?'. And she said yeah, they were. And he said to me, of course he said, err, it would be alright if I stayed the night here. So, I said 'do what?'. He said 'well, I could stay the night here, spend my nights here'. I thought yeah, and I'd have to pay. And I said to him 'but, what's the point?'. 'Well, if you wanted anything…'. 'I do very well once I'm in bed. And let me tell you something, I like being in control of myself. I don't want anybody else here, sleeping here or anything. So, and I've got the phone, and I've got the numbers if I need to phone'. 'Well' he said, 'I could look after you…'. 'I don't need looking after!" **Margaret – increase in support offered but declined, Margaret describes feeling in control and able to look after herself when alone overnight, but also describes having nightmares and panic attacks at**

	brought the Steadi machine up here, and so I put my arms on it, and I pulled myself up. I did not get lifted. And that's what all the carers said, but she, she'd been new to the job but she was so poor at it… really really poor. I told her. I mean, she's the sort of, erm, OT, when she was first coming in she come in on a Thursday, once a week, 4 o'clock so she could greet the carers. She was gone by quarter past, quarter of an hour" Margaret 6/7 Difference of opinions about level of ability/need [describing a lack of confidence in the OT's decision making and disagreement with the assessment process and outcome] "I mean now my girl carer erm, [name]… she keeps telling everyone I'm her mentor. And I said to her 'why do you keep doing that?'. So she said 'well you're mentoring me, aren't you?'" Margaret 7 dependence on carers- relationship framed as focussed on mutual alliance or friendship rather than a dependant relationship [when asked about the relationships she has with people who provide care and support] "You know, I immediately retaliate with something and she falls about laughing… I think she'd gone to a clinic about losing weight because yesterday she said to me I've lost a pound. I went 'well where did you lose that from?'. So she's falling about laughing…. She is sweet. She's good at her job" Margaret 7 dependence on carers- relationship framed as focussed on mutual alliance or friendship rather than a dependant relationship [describing her relationship with one of her carers] "Well I didn't have a bloody choice! I really didn't! She just said, someone came in and she just said 'this is Margaret, you know she's mentoring me'. And I just said 'since when?!'… I've got a good relationship with them" Margaret 7 dependence on carers - relationship framed as focussed on mutual alliance or friendship rather than a dependant relationship [when asked how she felt about her carer suggesting she acts as a mentor to her]	night. [when asked to what extent she feels in control of things and what helps with that] "Well it gives me still control of my own independence, and if I want something during the care with the carers well I just ask them, or they might ask me. They always say is there anything you need? I say 'no'. I always have to say 'check the dates of my bloody food'. But apart from that I do welcome my own independence which means my own company." Margaret 6 time alone is perceived as independence, alongside ability to direct carers. Need not framed as complete dependence, more like having help keeping the house [talking about declining live in/overnight care offered by one of the carers, when asked what's important in keeping her in control of her own care or health] "[S]ome as I say are good, some are pretty useless. Some of em I come out black and blue – they will catch my legs on the pole bit. I get very short and sharp, still, some thing is better than nothing." Margaret 7 dependence on carers for transfers at home, poor quality perceived as preferable to not having support at home even if resulting in injuries [talking about limited time of carers and shortcomings in care delivered] "Bless her, I can't remember her name but her face it etched with pain. It's grey white cos she's been waiting for so long for a new hip and she should have had it before Christmas, arranged over Christmas. And it hasn't happened. Bless her. You've only gotta look at her and you think 'God, that woman'" Margaret – noting others around her who also appear to have unmet health needs – sense of stoicism in response as with 'we soldier on' about self [describing visit from the community team the previous day] "I can't see how the carers can take me, cos their timings are very lean. I mean you get half an hour, half an hour. And bed, get you up in the mornings which is three quarters. A bedtime is three quarters" Margaret – 7 limitations of formal carers due to time, 2 x 45 mins, 2 x 30 mins, all double assist care [talking about whether the carers could take her out] "So anyway, they've all got together yesterday, and he said, I've got to change from this very uncomfortable harness which I'm going on now. It really is bad. It

	"Yeah well sometimes they don't, they don't *stay* long enough" Margaret 7 – inadequate time to satisfactorily meet needs [reflecting on the difference between public and privately funded support] "I've got a friend [friend's name], she works at the err [care home], she's a carer. And course, a lot of the things she's introduced to make the carers life easier, they're an absolute godsend. But unfortunately she's not here when the bloody thing breaks down up the top. And she works Saturdays and Sundays lots of times, not so good. But she gets my [up market supermarket] shopping" Margaret 7 carers for personal care [referring to when the hoist stopped working] "[T]he original Occupational Therapist took away my real good thing which was that Sara Steadi. She was useless and I told her to her face she was useless. Ruined my life in a way she did, she did. She, erm, messed up the bed. My bed, which is it, was too low. And she arranged for it to go up… higher, built up And she sent two blokes round here and they went according to her measurements, and the bed she made a complete hash of, was so high I was virtually touching the ceiling. It was ludicrous! The blokes said at the time they couldn't understand it. So course, even the carers, the tall ones couldn't reach it. So I ended up bed… having to stay in bed for at least two months, which is so bad because I've got scoliosis of the spine, which I've had major surgery on. She ruined it good and proper. And it took 6 months for that bed to be brought down!" Margaret 7 dependent on the OT for decisions about the home environment, and on the carers following OT decision to provide a hoist [when asked whether she has health conditions that require her to limit her activities] "You can't get anyone. You can't… who's responsible? There was another OT at [place name] and she said, I could do this straight	cuts in your legs and everything. And the nurses said it's absolutely awful. Well I think they might have stirred it up, I don't know, cos I haven't got a number I could have stirred up. Anyway, he said he's got this new harness and it's, it's amazing. It's like a little padded – you know a baby seat you put in a car. Well, it's a little bit like that. It comes up here [indicates on own body], which is good for the top of my spine, and then it sort of, it's all padded and then, then it just… I don't know it just does up no problem at all. Whereas this one, they have to strap it on and when I can't breathe at all it cuts my breath off all together. But no, this is very very good. So [nurse- ?OT] said [they'll order two] [He said] 'I go back, I put an order through to part of our firm'… And then he said 'then they channel it through another section, then they channel it through another section'…. So she said 'what d'ya reckon, Easter?'. He said 'I wouldn't be a bit surprised'." Margaret – access to expertise to improve quality of care (reduce pain) but dependent on system with long wait times [describing visit from community team and a sling rep the previous day, delayed since before Christmas as the rep did not arrive] "[T]hey said the other week 'is this the only one you've got?'. I said 'it's the only one I've had'. They said 'didn't you have a black one?'. I said 'no, I never had a black one'… I said no I never had one. That's the only one I've had. It's really uncomfortable, it cuts into your flesh. They said you should have had a black one… I think personally, somebody, they did deliver it here probably. And I reckon one of the nurses before I could try it on they thought 'oh well yeah she'll fit that one'. Won't be a nurse I know, but she must have took it for somebody else. I never even tried it on. I'm only surmising… Anyway, it's all in the pipeline now" Margaret 7 dependent on the knowledge and oversight of others to identify gaps in care [describing correcting the community team about which slings had been provided to her] "If I could have done, but I didn't know there was anything like it…" Margaret – lack of information about available resources [when asked whether the recent increase in support was something she would have put in place herself] "[T]he woman that's running these carers, I've been trying since last Wednesday the phone number and it's engaged all the time. And she leaves messages with these carers for me. Are they're really very, they're wrong messages and she

	away, but she's made the mistake and she's got to be responsible for putting it right. Well… as I say, godforsaken chore that was. It was virtually, yeah, six months, over six months" Margaret 7 dependent on others for personal care, care on bed if unable to get up safely, dependent on OT to rectify, exacerbated by non-integrated organisational practice [describing her experience of having OTs from different organisation] "They brought the hoist out, but one hoist they brought was so big we couldn't get it through the doorways. Well my doorways are conforming to proper building regulations. It was a bloody, absolute… mess! And i… she's put oh well you've got no confidence in me. And I said well do you blame me?! You've not done anything right. You've ruined my life really." Margaret 7 dependent on others due to use of hoist. Hoist within home environment creates further restriction to function and satisfaction for Margaret [describing her interaction with one community OT] "[Unintelligible] time… I could list, I've got a list as long as your arm but I give up in the end… yeah… the backup system. I find really, like I say, the things I pay for are good but [local] Council is not good." Margaret – sense of difficulty raising concerns, back-up in place through resources available to fund privately [describing her dissatisfaction with social care OTs and perceptions of paying for support versus publicly funded support] "[I]t was gonna be ok because, err, I was gonna be taken over by the national health… And it was just one appointment, then they said oh no… Well they were doing such a fine job, and [local] Council were getting nothing but complaints about their side of it. And in the end they couldn't face… and the girls at the national health, they said 'we've got it all finely tuned'. I said 'you can tell, everything's going absolutely perfectly'. So as far as	shouldn't be doing it. And I think one of them was, erm, could I let her know the name of my doctor. Well, there's no point, and I didn't get any more. So whether she wanted to know so she could ask questions – well that's not on. You can't give my details to anybody, my health details" Margaret – concerns about information sharing, Margaret not involved in conversation or asked to consent [when talking about who might have raised the concern about the slings 'What my carers? Nah…'] "She's only erm, an office clerk, but her knowledge of things is very very poor, especially for the care industry, it really is. And I, you know, I could literally clobber her really at times. Cos she, you know, sends all these messages to the girls. I just want to say 'please don't do that, you're not allowed to!'. And the girls, or the boys, well time they give em to me, don't make sense anyway!" Margaret 7 dependent on care agency to pass information in an appropriate and accurate way. Concerns about information sharing. "In the overrunning things, if you get people in charge who know what they're doing, they don't have to be iron fisted about it. Gently you go. Now this chap I've got today, I had him the day before yesterday. Erm, he's got a hacking cough. Now I said to my girl carer, her name is [name]… I said to her 'would you please convey to the people, your office, you've got the phone, that I'm not happy with the fact that he's come here on Wednesday with a bad cough'. Well he didn't come here yesterday, I had [another carer] and he was really good, but this bloke's come today. Well, you know they're telling you don't mix with people – well has she tested him? They shouldn't be going out if they've got a cough" Margaret 6 – dependent on care agency leads to have oversight of care quality but able to raise concerns and advocate for self, needs agency help to keep expected standards in her home "Now I've got all this increase… [I clarify whether Margaret means an increase her care package] No… I don't want any more than two. Cos I'll have to pay for the… but care, given like from, erm, I'm trying to show this form to you. You know, where they give you erm, and err, oh that's that other form I've got to fill in. Can't make head nor tail of it – 'Your Chance to help the NHS'." Margaret – increase in contact offered but unclear to Margaret what each form is for [whilst

	I'm concerned, [local] Council… they've never fulfilled their part." **Margaret – negative perception of council therapy service compared to NHS – clear sense of two separate services** [describing her experience of health and social care services] "I still haven't got an Occupational Therapist" **Margaret – perception of a gap resources, absence of a possible route to resolve issues despite referral to ?befriender coming via an OT and recent visits to review sling** "[W]hen they knew that report which said I wasn't really coping with you know, bad heart and all that they cut that bit out with the wheelchair. But, it goes against the grain... The Occupational Therapist says we're supposed to do it. I said 'what Occupational Therapist? They don't come" **Margaret 7 dependent of the decision making of others – sometimes in agreement with each other and at other times not** [describing following a transfer routine that contradicts the OT guidance] "Well, I'm, not really able to do anything. Err, in the mornings they come in early, 7, and then I'm washed in bed and err, I have a good good wash, then, yer, you know talcum powder and creamed. And then we're put into the sling and hoisted, hoisted… you're supposed to, hoisted from the bed to the wheelchair, from the wheelchair down to here, from the wheelchair from there to here. And it's such a waring procedure cos you see all the harness is very tight and it's all cutting." **Margaret 7 dependent on carers for personal care on the bed** [am personal care support, use of hoist] "So I went into bed after, where they prepare me" **Margaret 7** [pm care support] "Friday night we go into the bedroom. I'm on the hoist. We've gone up to the bed to swing me over, put me into the bed, onto the bed to do the nighttime ritual. And the hoist it got stuck up	sorting through her pile of paperwork to show me the details of a support organisation] "I folded it up, one copy so that I can take it to bed with me [looking through carrier bag with medications and essential items in] cos it's got all the numbers on it…Well this has all come out of it. But I mean, and obviously *you* came out of it… ' **Margaret** [explaining the 'single point of access' source of the increase in support – I read aloud from the leaflet- 'nursing or therapists can be contacted by the [phone team] 24 hours 7 days per week.'] "I've got a feeling that came about from an OT person that I didn't ever had… and she referred to him, and they come out from [local town where community team are based]" **Margaret – OT referred on to someone else without assessing the functional needs Margaret raises** [describing having someone visit 'going round to the people if he thought they were on their own and they needed y'know, they were lonely'] "Yeah, no I haven't because a nurse comes every day but if I need one, yeah I've just gotta call em and you know that's it. But, there's this on here but it makes it more reassuring and comforting to think there is someone who can help ya, cos I never did have that. You never get any help from a doctor saying 'oh', you know 'we're here for you' or anything like that…" **Margaret – 7 reassurance of increased accessibility from nurses in addition to carer visits** [when asked whether she had the need to use the 24/7 phone number since being given it] "No, but she was trying to help me because I hadn't got an OT, and my OT disappeared… And she was trying to be me OT. And she was an OT but she was [from another country] or something, and she referred to him and he came round on the off chance." **Margaret – absence of continuity of care, additional support but instead of OT involvement rather than in addition to** [when asked whether she was aware a referral to a befriender was being made on her behalf] "Because we're still waiting to put them all into gear. Y'know, like I still have to be taken up to the bed to have my pad changed, and then they're gonna get this business for the toilet [I asked for more information] Well, that's where I should go to the toilet, on the toilet" **Margaret 7 dependent for personal care and**

	in the top…. So there I was… it is painful cos this squeezes me… And all the legs hurt, so I said 'I can't take much more of this'… 'You've gotta get me down cos this is killing me!'. So, these two… carer ladies, jumped on the bloody bed [laughs] and thought, they'd try to get a little bit of leverage in the strings just so they could lift em off… Well the only other way was, which I thought would be quicker, was to cut the bloody strings… eventually, bouncing up and down in this bed, and they got it free and of course I just went 'BANG' [laughs] on the bed. They couldn't save me! [laughs] Well, it was a relief to get down" Margaret 7 dependent on carers and hoist for bed care routine, and on carers to 'save' her when the hoist stopped mid air "[I] thought well tomorrow morning gotta greet the fact we haven't got us one of 'em [indicates hoist]. And the weekend isn't it… 'oh, bloody hell!'" Margaret 7 dependent on carers, hoist, and availability of services [referring to knowledge of reduced services at the weekend] "Well the thing is, that's not really doing my back a lot of good. That's where an Occupational Therapist would say 'no, you can't have it'. Anyway, that's another obstacle I've got to try and… [trails off]" Margaret 7 dependent on the decision of one OT despite Margaret feeling hoist is contraindicated for scoliosis based on previous medical advice [describing techniques she believes are causing her harm but requiring a healthcare professional to make a change] "[T]hey're no good at cooking things. They don't even, well they mess up the microwave. I have to translate for them. So there's so much stuff that has to be thrown away… You know, there's a motley bunch of food. But they can make the final touch inedible because they don't know how to cook it" Margaret 7 completely dependent for meal prep physically. Although cognitively able to direct a task and monitor skills of others	awaiting OT assessment to change arrangement [when asked whether there have been any changes in what she is able to do for herself day to day since interview 1] "[P]ossibly about 60 years ago… [an NHS nurse] said to me, 'would you mind if I try acupuncture on you?'… So I did get it done. But I made it perfectly clear, you don't stick needles in my spine. I tried it then…. I was private medicine but she wasn't private, she was national health. And I thought to myself ohhhhh. And then I had, I used to have a private clinic at [place]… And she was damn good!… she was private. I don't know, how did I get recommended to her? Probably from, cos a lot of the private medicine I had at [hospital], the doctors were rubbish! They just took your money and were fit for nothing really." Margaret – experience of privately funded complementary care as a positive [when asked how she came to start acupuncture] "[O]ne day [the physio at the private hospital] was there and [the private physio/acupuncturist] obviously came to see her. Cause what they do, they go into private hospitals and treat people. And when he came there… I just passingly I think, just said 'oh, do you do acupuncture?'. And he said 'yeah' and gave me his card. Years ago. It was more than 8 years ago. And he sort of um started to treat me. And he really is good… he's a good egg he is. He's not cheap" Margaret – access to resource through previous use of a private hospital [when asked how she came to be in contact with the private physio/acupuncturist 8 years previously] "One of the nurses kept on and on and on and on and on and on, so I just said I'd get [private physio/acupuncturist] to charge it up. Well it was hilarious when I used to be on it around here. He used to make me go up there, down here, in there, out there. Well it was so bloody sensitive I ended up in the bloody wall every time." Margaret 7, being encouraged by nurse to take action towards 6 [on using her powered wheelchair within the home] "You get new ones and you think 'where have you been, you're ever so late!'. They get, my lunch hour is at, what half past twelve should be the half hour, and then they don't come back til 4." Margaret 7 dependent on carers to arrive when expected [talking about the timings of her carers]

	[describing her frustrations with meal prep support and carers with English as a second language] "The original lot we had were from Pakistan and India… they were brilliant they really were. They were good at caring, they were good at everything. And then the firm, [care agency name], forgot to renew their cover with the Home Office. So they all had to go. That was pretty disgusting. They loved their jobs. They all went out got no jobs. This lot are all from Africa. And err, they really are not, quality. And you'd think you'd be able to *understand* them even. Well… [trails off]" Margaret 7 dependent on care agency, but reduced ability to influence quality of care due to language barriers with new agency [describing her experience of a change in care provider] "[W]hen I was in hospital that time, I went in, I had one carer. But I wondered why I was kept in hospital for over 6 months. It's because, again, the Occupational Therapist said I could only come home if I had two carers. Well you've got to find firms that… I mean, I'm not the only one they go out to, lots of people. But you know, there's [pause] there's always some obstacle." Margaret 7 increase from single to double assist care mandated by OT lead to delay coming home whilst this was sourced. Double assist care indicates greater level of dependence CFS 6 pre-COVID as one carer [when asked how she feels about having people come in and help with lots of day-to-day things now – 'the choice I have to have'] "[T]hey've got a new Physio down, or Occ… he's good… [T]hey got the other one who's not so good, but *he's* good [male PT] will come down and… he sorted that out with that doc… no, he shows a side of him… a *compassion*. That's something nobody's got really, not in doctors or anything. And then they must've mentioned I'm, I mean I'm not gonna [unintelligible] it on, but the notes are there, in reception. But y'know, we soldier on" Margaret 6 involvement of the physio may indicate some degree	"And I said to one of the boys 'what's your name?'. And he said '[name]'. Well I thought 'I can't call you that'.. That's his Christian name. They have some weird names in Africa, they really do. And when he said [name] I thought… they'd accuse me of hassling a coloured chap wouldn't they – giving him a wrong name. Cos if there's one thing people don't like being called, I didn't realise, it's [name]." Margaret – sense of nervousness about protecting relationship with the care agency [when asked about the rapport she has with her carers] "I usually have a slice of toast with marmite if they don't burn it. But overall, I eat what I want – y'know." Margaret- help with keeping house. Choice and control but dependent on perceived competence of others. "And then one of 'em said 'oh, so I can take you out?'. I said 'I doubt it'. I said 'you can't drive my steadi or my hoist, surely you won't drive my wheelchair?'" Margaret 6 help with all outdoor activity but reduced perceived competence of those offering support [on her newly charged wheelchair] "He's my… I pay separate for him. He's my- I've had him for 8 years – he's my… not a physio, he's got a business in [place name]. He does acupuncture. And we did that today. But he, he does hands on. Y'know, I do reap benefits for it… he usually puts… he feeds the birds, waters the plants [laughs]. Well half of them are his plants! Erm, that's his two kids [points to photo frame on unit in front]" Margaret 6 Help with outdoors. Resource available to fund this privately. Expanded role associated with privately funded support. "I do tend to throw away an awful lot of food. Usually fruit. And erm, it's only because my carers don't keep me up to date with what's going out of date. And I say to them 'surely that so and so in there is going out of date?'. 'No'." Margaret 6 Help with keeping house. Reduced choice and control. Increased cognitive load as a result of poor communication with carers "Yeah… I mean I've had the odd day that's not too good I tried to persuade our friends here [indicates carers] not to keep putting me on the bloody wheelchair… To cut it out so I can go straight down to the, the place [gesturing to another room] but she won't [cross tone of voice]… And if I'm her mentor, I'm

	of reversibility, although exact involvement is unclear. Personal qualities stand out to Margaret [describing her experience of health professionals at the GP surgery, and a perception that notes about her prognosis are available but not read] "I was exceedingly fortunate. I worked for [a large organisation] and I had a private health plan because both my parents, we all lived together" Margaret [previous experience of private healthcare] "My GP in [place name] found, at long last, none of the doctors in the hospital where we're going, you're paying but they're not finding anything. Anyway they're putting you, taking their nice little, reap their lump sums out…" Margaret [unmet expectations of privately funded healthcare] "I said to [the doctor] 'I don't know what hospital'… [A]lthough I could have gone to [unit] privately in the [hospital], but he said to me [another hospital]… so I said 'well I've never been in hospital'… So he said 'well as far as we're concerned, I personally, [hospital name] cos it's run on military lines'" Margaret [describing taking advice on where to have surgery at a time when HIV had been prevalent] "I haven't got anywhere, I really haven't got anywhere and um, you know I've just come back on me tracks really. So when they come lunchtime I shall go up there onto the bed… I have to erm, change my pad but they also, if I want to go to proper toilet I have to go up there on my bed. Lots of things that just have not been, loose ends… I mean, I've not just been out of hospital 5 minutes, I came out the week before Christmas!" Margaret 7 dependent on carers for all personal care including toileting via pads on the bed. No progress perceived with accessing decision makers to change this arrangement [talking about the outcome of having requested OT input]	not gonna be her mentor. Cos she's not gonna, I'm not gonna do favours for her…" Margaret 7 dependent on the choices and regulations of others [when asked a point of clarification about whether her life has been fairly steady recently] Researcher notes: The carers arrive outside the property towards the end of the interview, and I ask Margaret whether she needs me to step out to allow the carers to complete personal care. Margaret says this isn't needed. When the carers come in she says 'I don't really want anything, all I want is a cup of tea erm, a piece of… I think it's a little erm [pause] this is what annoys me with these'. I feel uncomfortable as Margaret is talking about her carers in front of them, but respond, 'what's that?'. 'The time they spend on these bloody phones'. I say 'oh, this is where the notes and things are? They write their records on there?' as I recognise that some care agencies use digital systems and as this comment hasn't been made directly to the carers but they are present I feel the need to offer some balance or explanation on their behalf. Margaret says 'I dunno I think they write to their boyfriends personally'. I laugh and says 'I don't think they do', trying to keep the tone light hearted. Carer asks Margaret if she needs the bathroom to which Margaret responds 'no, don't even think about it'. The recording is turned off while carers are interacting with Margaret. During this conversation Margaret asks for a piece of cake, wanting a piece of the new cake, not the one Margaret perceives to be stale/horrible (the open one). Margaret compliments the female carers coffee making skills 'she don't make a bad cup of coffee' and 'she's quite good actually' but indicates can't say much for the other carer and then goes on to indicate she does not actually know the male carer. There is minimal response from the carers during this conversation. I takes the quiet opportunity to look through the interview topic guide and refocus the conversation. Margaret asks if we should carry on, stating something to the effect of 'they don't understand anyway'. Again I feel uncomfortable and aim to close down any conversation that could be offensive to the carers, whilst maintaining rapport with Margaret. I fill some time saying 'what have I missed… what else was I hoping to talk to you about today' etc. We pick up the conversation again taking Margaret's lead once the carers are sitting quietly writing notes on the other side of the room.

	"No!... They just came, like the err, [care agency] this firm. I hadn't heard of them. And course they've messed up with their workers… Really, it's got to the stage where I can't trust anyone" Margaret 7 dependent on services to review the moving and handling plan for personal care. Little evidence of communication with Margaret about this [when asked whether anyone came to assess her when she first came home around Christmas] "So I said to them, before they even got me washed 'give me the number, I'm gonna phone 'em laying in bed'" Margaret 7 passive role in personal care on the bed [indicating dependence on carers for personal care tasks] Summary: CFS7 In describing systems of care around her, Margarets accounts give a consistent picture of dependence on others. In terms of personal care this is a dependence on two carers instead of the one she previously had, and use of equipment she does not feel was warranted. Margaret describes repeated points at which she is dependent on the decisions of others for how her needs are met within the home environment, and difficulty getting her voice heard when not in agreement. Processes in the system are protracted, leading to a long stay in hospital, a long time using a painful sling with no further assessment of home needs. Additionally, Margaret perceives a clear separation between health and council OTs, emphasised by the workers themselves who instead of resolving an observed issue pass this back to the original worker resulting in further delay. Margaret perceives compassion as an unusual quality in the professionals she has dealt with, and believes this is compounded by poor information sharing about her prognosis.	Later in researcher notes: I comment that I've got one more thing I'm hoping to talk about but will pause until carers had completed what they need to do. Margaret comments [again in the presence of the two carers] carers 'like to go early'. It is not clear whether this is intended as criticism as the carers do not respond. Summary: CFS7 Double assist care continues as before, but with additional weekly contact from community nursing to monitor Margaret in addition to providing the 24/7 phone line. Margaret does not indicate any conversation with health professionals about increased care needs or anticipation of any change. Further assessment completed to improve comfort using hoist but no new sling in place yet Dependent on systems with long delays. Proximity of support is significant as Margaret appears pleased that the phone number she has links to a local team who are there all night. However, when live in care or overnight care is offered by a carer but declined despite panic attacks reported. Margaret indicates paying for this would be a downside, however the NHS weekly monitoring calls are readily accepted. A means to raise the alarm and a sense of responsiveness appear more important than immediate proximity at the expense of having home to yourself. Margaret has concerns about inadequate record sharing amongst health professionals, but does not view the carers as an appropriate group to share medical information with. Health and social care OT, and primary care and community nursing are viewed as separate things. Time alone is perceived as having independence, despite descriptions of being dependent on carers.
Psychological Status	"You've not done anything right. You've ruined my life really. I said you've taken away what little pleasure I had. I stood up on	"I'm not full of expectation long as you can keep alright. But I mean a lot of people can't keep alright. You know, you have days don't you that are not good.

• Recognised conditions or symptoms • Motivation & confidence • Emotional wellbeing • Spiritual & cultural fulfilment	that Steadi. 'Well no, you were being lifted'. I was not being lifted!... And that's what all the carers said, but she, she'd been new to the job but she was so poor at it… really really poor. I told her. I mean, she's the sort of, erm, OT, when she was first coming in she come in on a Thursday, once a week, 4 o'clock so she could greet the carers. She was gone by quarter past, quarter of an hour" Margaret 3-6 dependent on the opinion of the OT despite not being in agreement and feeling the carers also not in agreement. Motivated to stand and confident doing so but physically limited by others [describing the emotional impact of the community OT's decision] "I said to them, before they even got me washed 'give me the number, I'm gonna phone 'em laying in bed'" Margaret 5 Motivated to problem solve and complete call herself. Help in higher order IADLs – dependent on someone to pass the phone but able to initiate and make the call [describing her actions to avoid remaining in bed when the hoist stopped working] "That is the choice I have to have" Margaret 7 'have to have' suggests dependence for personal care and not really a choice, acceptance, disguised as choice through word choice [when asked how she feels about having people come in and help with lots of day to day things now] "[T]here's always some obstacle. There really is and you think, 'oh, I'm fed up with *this*'. Y'know, you… you don't wanna get depressed, but you think 'be patient, be patient', but when that one week turns into two, three, four, five, six, seven, eight, and you're into six months…" Margaret 4 Vulnerable to psychological affect due to sustained situation [describing the emotional affect of waiting in hospital until a larger care package could be found] "And the doctor, you'd say 'can you do anything?'" Margaret 5 Dependent on others to resolve the situation but able to	Not good at all" Margaret 3 Managing well due to an adjustment of expectations and an acceptance of some variability [when talking about not having visitors this Christmas] "Because I've got this very *exciting* life, I have a good memory so I do remember [laughs]…" Margaret 3 acknowledgement of reduced activity but using humour and affirmation of strengths when discussing [when talking about the Participant Diary] "Well I don't know, someone must have… you know I got that final, y'know when they said… you do know that? [referencing conversation with medical team at the hospital about limited life expectancy]. And then erm, one of the nurses said to me, 'take no notice' she said 'they all get that'. 'Don't worry'. So I said 'no, it put me down in the dumps at first, two days, and then I thought no, no'" Margaret 4 temporarily vulnerable – low mood due to health news, but returning to managing well/well controlled psychologically (3). Contextualises event with experience of others to regain psychological control. [unsure how the increased nursing checks were initiated, but connecting them to her prognosis] "If I could have done, but I didn't know there was anything like it… The 24-hour care. That was an absolute, well it's amazing you know" Margaret 5 Managing well psychologically with positive perception of having access to 24/7 access to support via phone, but dependent on others to have put this in place [when asked whether the increased support was something she would have put in place herself if she knew how] "I've got a black humour… Cos I could be half dying sometimes. When the doctor's said to me on the rare call 'how are you Margaret?'. 'Well, I'm still alive, but then you wouldn't know that would you?'" Margaret 5 Mildly frail- use of humour again to respond to emotional impact of expectations not being met, but sense of underlying hostility/anger towards doctor [in response to 'what helps keep you going?] "I didn't do it and I told her I'd make a complete hash of it. I make a complete hash of everything else! So she said 'no, don't worry, I'll do it'" Margaret 6

	advocate for self and seek alliances [describing her actions to try and speed up the discharge process] "I didn't want that to have happened, but glad they didn't have to face up to the fact how bad I was gonna be… with my back" Margaret [on the death of her parents within ten months of each other] "I lay flat on my back for six weeks. That was ok, and then the little gap like that [indicates distance] between your bed and the locker. I was so fed up, about the sixth week I tried to turn, and I turned and I got me head stuck down there" Margaret 4 physically dependent but making own decisions about following guidance [on previous outcomes when not following medical advice] "I accept it. I've got my little plants. Got my garden out there for… I don't get a chance to see that because erm, on this hoist you're laid off and you can't have a good look out [indicates reclined position during hoisting rather than upright]" Margaret 6 Loss of motivation due to no longer having access to the thing that gave her pleasure. Acceptance [asked how she feels about not having been out for three years] "I'm very grateful for the support… I've got all that I want in here" Margaret [when asked how she feels about the amount of support she has day to day] "I don't aim for any high hopes, so if I don't… the fact that I don't get any, which has been the usual thing, you don't get any…" Margaret 5 Lowered expectations in response to previous experience. Acceptance of not getting the things she requests [after expressing dissatisfaction with the response when she requested OT assessment]	Apparent reduced confidence in own ability to complete a task, linked to previous experience. First instance of asking others for help due to doubt in own ability, previously asking others due to their professional role, or help provided for physical task not cognitive/advocating. However later expresses confident using 24/7 number independently if needed [describing response to friend suggesting she changes her own utility provider when unhappy with how long this was taking] "Yeah, that is important. Because the other night, erm, one of the nice bloke carers came in and they're going home and I always make a point of them telling me when they're going home. Cos they stay down here [opposite end of the property than bedroom] a long while. So he came up, I said 'all the lights out? Everything out?'. And he said yeah, they were. And he said to me, of course he said, err, it would be alright if I stayed the night here. So, I said 'do what?'. He said 'well, I could stay the night here, spend my nights here'. I thought yeah, and I'd have to pay. And I said to him 'but, what's the point?'. 'Well, if you wanted anything…'. 'I do very well once I'm in bed. And let me tell you something, I like being in control of myself. I don't want anybody else here, sleeping here or anything. So, and I've got the phone, and I've got the numbers if I need to phone'. 'Well' he said, 'I could look after you…'. 'I don't need looking after! You'd drive me bloody mad!'" Margaret 3 managing well/well controlled psychologically. When no physical tasks are required Margaret describes herself as being in control of herself. Clear in making and expressing her decision to decline nighttime support. [when asked about the extent to which she feels in control, and what helps her feel this way] "I said to him 'I'm quite capable of looking after myself! And to be quite honest I find you a bit of a… nuisance'…. I'm used to well alright like 5 o'clock this morning and I couldn't find me water bottle. I think she'd moved the place where I put it. Well apparently it was there but I couldn't find it. But I think I was dreaming about something. And I was erm eyes wide open and I was just thinking" Margaret 3 perception of managing well and able to look after self despite giving an example of not being able to resolve a practical issue independently [on declining an offer of overnight care from one of her carers]

	"I don't want a live in carer… I've got [male carer from agency] – he's so loud!" **Margaret** Summary: CFS 5 Despite being physically dependent on others, Margaret is able to advocate for herself. Prior to admission Margaret indicates a picture of managing well (3), with her perception of her ability in line with her carers perception. There were elements of daily life that were a source of pleasure (seeing garden). During admission Margaret describes an increased vulnerability psychologically due to the prolonged situation, however she continues to seek advocates and influence her situation (4) Upon return home decisions about care level and moving and handling are made by someone else, the decision is not aligned with Margaret's perception of her own needs – reflected in language 'have to have' and account of OT assessment. Description of 'ruined my life' indicates strong emotion and psychological impact (5), focussed on the people making the decisions rather than any health change that underpinned the decision. Language around care is 'have to have' but framed as 'a choice'. Margaret presents herself as self-aware and psychologically independent but her physical dependence on others means she is not in full control of decisions about her care.	"Well it gives me still control of my own independence, and if I want something during the care with the carers well I just ask them, or they might ask me. They always say is there anything you need? I say 'no'. I always have to say 'check the dates of my bloody food'. But apart from that I do welcome my own independence which means my own company." Margaret 4 Emotional wellbeing maintained through getting time alone – perceived as independence. Able to direct others to meet needs, but some suggestion expectations would not be adequately met without Margaret prompting [when asked 'what would you say the important things are in keeping you in control of… your own care, and what's going on with managing your health?'] "Oh yeah they're always watching, and if I said to them… it's like you said you're not, you're breathing or something. Well that's because I stop breathing momentarily, not for any other reason but I'm trying to do two things at once which I shouldn't do. And so the thing that gets forgotten, I forget to breathe. But then I can get on the straight and narrow. I practice deep breathing which is [demonstrates], and I do that most of the night really when I'm awake, or here. So, you know when you feel like… if you're gonna have a panic attack, which I think, was it yesterday morning? Yeah, I could have done, and err I can now say to myself 'don't go down that path, breathe, do your breathing', and you do it." Margaret 4 Describing breathing difficulty – physical and psychological causes to difficulty. Strategies in place to manage symptoms. Confident using strategies to manage panic attacks. Presence of panic attacks suggests deeper discontent psychologically [in response to a follow-up question on health – 'there was fluid, you had fluid around your lungs and inside you…?'] "Early hours of the morning, it's always 5 o'clock… I've got the water bottle and it hangs over the side of my bed resting on a stool [couldn't find this]… erm, I might have had a bad dream, I don't know…I know… yeah it was a bad dream… it was bloody, it was last night I woke up...[describes a story about animal abuse on the news at bedtime] Kept me bloody awake for nights and nights and nights. If I tell [private physio/acupuncturist] anything like that he just goes 'oh you shouldn't worry about things like that'. It's all very well, but [I've had pets and cared for them]" Margaret 5 outside influences causing anxiety attacks. More evident signs of reduced emotional wellbeing and reduced control over

		emotions. [elaborating on a recent panic attack after being asked about the fluid on her lungs since interview 1] "No… the only thing that's come up is all these answers… that was sort of erm, something that came out of the blue really" Margaret 3 more answers than problems – positive [when asked if anything has come up since interview 1 that she's had to problem solve – Margaret indicates the 24-hour phone line/community team leaflet in her response] "Lack of… no body pushed me I suppose… [I clarify that it is a powered chair] Yeah it's got a proper motor at the back… yeah" Margaret 4 vulnerable -absence of someone to motivate and encourage [when asked why she had not used her powered wheelchair for a couple of years] "I suppose the knowing I've got the backup. Y'know, I've got this [indicates community service contact number] I mean it's a 24-hour call. That's put it, it's peace of mind [isn't] it? And yet, I wouldn't take liberties and use it, and yet y'know the nurses saying 'well you know where we are- I tell you you've got to use it. If you don't when you do need to… I mean I, y'know, sometimes when I'm in bed, like the other night I wasn't too good. And I thought, hmmm, no we'll see, but at least now this avoids 111 don't it? Well no body's gonna come, are they?... [pause] She said, 'we're all there at the end of the phone'" Margaret 4 peace of mind, and the reassurance of responsive support, but referring to fluctuation in wellbeing [when asked 'what's helped you to keep things on an even keel? Keep you healthy? Keep going along?'] "Willpower! [laughs] [pause] I don't know really… Dark humour, I was told today. I think, erm… [pause] what keeps me going? I suppose really when you think, erm, all my life I have had to fight my battles. Not bullying or anything like that – health battles. And, so because that determination is sort of instilled in me in also think in my upbringing with my mum and my dad – but my dad was the soft touch – mum was not. So she was of the era during the war she had to look after us and lots of other kids, so you were one of a number." Margaret 3 sense of long-standing identity as someone used to advocating for self. Positive language used to describe own mindset [when asked 'What's keeping you going do you think?']

		"[Y]eah I've always liked to fight, and yet I've had – well I can remember one of them saying, 'she may not be very tall but she's certainly not lacking in a brain'. And those remarks stay with you sometimes, when you've heard them when you're a kid. And erm, you can go through life thinking 'you've gotta live up to the family name'. My mum, you didn't give in, never gave in" Margaret 3 drawing on affirmations of others in the past re: strengths and qualities, expectations of control and self-advocacy [when asked 'What's keeping you going do you think?'] "…it's only the good things in life that I've remembered…" Margaret 3 choosing to draw upon positive experiences to build current belief systems about being able to keep going [when asked 'What's keeping you going do you think?'] "[Y]ou have to take the scholarship. Well you're supposed to take it when you're 11 years old, but because my going into the term was always a lot early than they'd gone in it, so I took the scholarship at [pause] I think just coming up to 10. And you know, you just took it, you didn't know… Well my mum and dad encouraged it cos we could go to the grammar school. Yep, I passed that, so that let me go to the [grammar school]" Margaret 3 framing of self as having exceptional ability, above and beyond others [when asked 'What's keeping you going do you think?'] "Yeah, and also the support I had. Y'know cos… Again, I could always go for a bit of a laugh. Go for a laugh and I did" Margaret [when asked 'What's keeping you going *now* do you think?' – reflecting back on her life despite the prompt 'now'] "And then everybody's laughing which you end up doing! I'm the one in trouble, but you have to laugh because the situation is quite funny! And I know they don't panic… I just said 'cut the bloody things!'. I mean if that's gonna get me down. Oh and when they did they dropped me from a great height! Again, it didn't hurt me it was on me bed, but funny yeah" Margaret 4 describing use of a hoist with carers. Physically dependent but able to direct others and engage in crisis response both emotionally and socially. Emotional response (laugh) lead by others. Humour in a crisis [reflecting on the role of humour in her carer relationships in the context of the previous 'stuck hoist' incident]

		"I'd love to. I can't… if I can't give a dog a way of life it should have, I'm not gonna ruin it's life. All a dog wants is to go out for little walks, go out for rides in the car… Well if you are dependent on carers, it's not fair. I know sometimes if you've got perhaps an old couple and they've got dementia or something and there is a dog already there, that goes down on their routine. But I wouldn't get another one. No, no… it's not fair." Margaret 6 gradual reduction in QOL (going out) is acceptable in an existing home, but not an acceptable compromise in a new home. 'ruin it's life'. Externalizing experience. [on no longer having pets] Summary: CFS 4 There are more examples of statements that reflect psychological status in this second interview. Previous sense of self as a strong self-advocator are central to responses about keeping going now. In day-to-day life Margaret describes strategies to adjust expectations and use humour to mitigate against stronger emotional responses. There is some indication of anger towards professionals who have not met expectations, again mitigated with these strategies. Margaret describes panic attacks which she uses breathing techniques to manage and perceives time alone at home as independence and evidence of being able to look after herself despite examples of not being able to complete tasks alone. Margaret describes using positive experiences to shape her life view. Overall Margarets statements give evidence of managing well psychologically, although there is evidence that some stronger emotional responses are being mitigated against suggesting a higher level of psychological vulnerability which would be typically associated with people approaching end of life.
 Conditions disclosed during interviews: Scoliosis	"Oh yeah most certainly, because erm, I was limited in my going from day to day really by the fact that the original Occupational Therapist took away my real good thing which was that Sara Steadi. She was useless and I told her to her face she was useless. Ruined my life in a way she did, she did" Margaret 7 completely dependent reflected in need to use hoist now. Focus of response is on individual people and their actions, not on any	From researcher notes: Margaret had mentioned during the second call that she was concerned about her life expectancy and the possibility of deterioration, so would prefer to set a second interview date sooner than initially proposed by interviewer. "I've got these glasses on, but it don't make it any easier… You don't know how difficult it is, because I'm having to try and put my head back and use this arm,

Bilateral hip replacements Terminal diagnosis (unspecific) Fluid on the chest Oedema (lower limbs) Knee replacement (?)	contributing change in health [when asked whether she has health problems that require her to limit her activities] "Well, I'm, not really able to do anything… we're put into the sling and hoisted, hoisted… And it's such a waring procedure cos you see all the harness is very tight and it's all cutting" Margaret 7 completely dependent reflected in need to use hoist "[D]on't forget that was in an era when nobody knew… cos don't forget I'm 87" **Margaret** [talking about scoliosis since birth] "Oh I was bloody fine until they hoisted me, which they told me I should never be hoisted. It's not too bad" Margaret 5 to 7 prior to admission had care, indicating CFS5, now using a hoist so dependent CFS7. Again, focus is on decision to use hoist rather than underlying health change [when asked whether her scoliosis affects her now] "[The surgeon] replaced 6 months after that. My right hip, then a few weeks later my left hip" **Margaret** "Then he replaced, I used to wear a splint cos he said knees are not perfected… so he said, 'til they're perfected'. So, I used to go to work, y'know every day, I didn't miss, I used to wear this little knee brace…. And you had Velcro strapping – played havoc with my bloody tights. But err, yeah it was ok. A nightmare in hot weather but I had to go through that for a few years, til he felt the knees were gonna be alright." **Margaret** [reflecting on adhering to medical advice over the years] "[T]hey got a camera in there and Mr [unintelligible] put it on the camera. It's like, err… it's sort of like [pauses to think] … like a thick net curtain really, thick grey, grey thing" **Margaret** [describing investigations into her chest symptoms]	and they've put my shoulder out a while ago" Margaret 5 combination of comorbidities make writing difficult [describing the challenges she finds writing] "Yeah, when I'm concentrating, I forget to breathe… look you see, this is what happens. If I talk to you… I'm not able to, my concentration is pretty lax. [spelling out name out loud whilst writing], how can I turn what I've put there into an [other letter]? [noticing has written the wrong letter]. Oh, I'm gonna scribble. Here yar, it's got progressively worse!... Will you explain to them [the university] how old I am? She has got her… 'her brain's alright'…but she gets a bit fatigued writing now!" Margaret 6 more evident fatigue, reduced concentration and difficulty writing [when I comment she sounds a little short of breath] "I have got my diaries. I mean I forgot to use my new diary to put the appointments in [laughs], like who was coming and who wasn't. And I've had several visits this week" Margaret 6 more evident slowing reflected in forgetfulness. Reduced ability to track and coordinate visitors/appointments "No, not really" **Margaret** [when asked whether she is able to do anything more for herself day to day than at the previous interview] "And now I've got me err, [private physio/acupuncturist] charged up me wheelchair I am supposed to be whizzing around on that… Get out of my way, I shall be dangerous – it's so sensitive!" Margaret 6 continued involvement of private acupuncturist, need for powered wheelchair if aiming to get around indoors [when asked if there have been any changes in what she can do day to day since interview 1] "The other little chair that I use for my transfers here. That's the other little chair and that's one that I could self-propel but I've never been able to self-propel it. I don't think my arms are bloody long enough! So, what they do, they lift me off here onto the wheelchair – oh it's a rigmarole, wasting time all the time, but there you are…" Margaret 7 dependent on others to get around indoors for personal care tasks [on using a wheelchair with her carers]

	"I was going in every 6 months… I used to go down to the hospital… but then when the fluid couldn't be drained, that's why this leg is so fat [indicates swollen legs elevated on recliner chair]. There was no way they could suck it out – that's why it went up here [indicates chest]" Margaret 7 dependent on medical team to manage fluid and prevent spread to lungs [when I referred back to a pre-interview comment she made about previously having her chest drained regularly, up until COVID hit and drainage could not be offered at home] "I can easily just go asleep" Margaret 5 more evident slowing/fatigue [when I suggest drawing the interview to a close so as not to tire her] "I wanted an Occupational Therapist – I haven't got one. That one I did have, she was useless… it's little things like [my carers] … they have to have guidance, and their office is no good, but… for instance if I, like when they come in for lunch, I'll go up, they'll take me up on the hoist to the bedroom. Well, an Occupational Therapist would have *shown* them what to do, instead of having to go all the way up there every time [indicates bedroom along corridor] and change my pad. But we don't do it, we have to do it up there [bedroom]. And we've got the combined thing in there [toilet opposite] but no body's shown them what to do" Margaret 7 pad changes indicate incontinence, high impact of daily routines to manage needs using hoist [when asked how she came to be in contact with the community team that identified her as a potential study participant] Summary: CFS 7 Margaret discloses multiple health conditions and symptoms during the interview. Conversation focusses on impact on daily life and the decisions of others in responding to symptoms, less on the conditions themselves or any medical intervention.	"This is me, especially at the end of the day, all the names go out." Margaret 6 more evident slowing, forgetfulness when fatigued [when unable to recall a carer's name] "I don't watch. I mean, what's been happening, I fall asleep of a night. [I've] been watching a bloody murder, and I don't even find out who did it!... I never used to do that!" Margaret 6 more evident fatigue "I err, dawdle along. I will say the girls, you know, they cream my body the girls religiously… I'm still going up to the bedroom and she'll obviously change your pad and then cream all your legs again… I can't question neglect in any way or form… not really, not with this little band I've got at the moment." Margaret 7 dependent on carers for personal care and pad changes [when asked 'how are things from a health perspective since I last saw you?'] "Oh yeah, they're always watching, and if I said to them… it's like you said you're not, you're breathing or something. Well that; because I stop breathing momentarily, not for any other reason but I'm trying to do two things at once which I shouldn't do. And so the thing that gets forgotten, I forget to breathe. But then I can get on the straight and narrow. I practice deep breathing which is [demonstrates], and I do that most of the night really when I'm awake, or here. So, you know when you feel like… if you're gonna have a panic attack, which I think, was it yesterday morning? Yeah, I could have done and err I can now say to myself 'don't go down that path, breathe, do your breathing', and you do it." Margaret 7 pronounced breathing difficulty, using strategies to prevent panic attacks [in response to a follow-up question on health – 'there was fluid, you had fluid around your lungs and inside you…?'] "Oh, a pain shot under my arm… I get those. We all get pains, don't we? Arthritis or something" Margaret 5 arthritic pain "I mean I've had the odd day that's not too good I tried to persuade our friends here [indicates carers] not to keep putting me on the bloody wheelchair" Margaret 7 dependent on carers, acknowledging fluctuation in day to day health Researcher notes:

	History of adherence to medical advice and regularly attending appointments. Fluid no longer drained due to COVID restrictions, leading to fluid spreading to lungs.	Whilst the recording is switched off during the carers visit, Margaret comments about having gone off very sweet things, and recently having digestive issues with other richer foods. Later she comments "I've really gone off sweet things. A lot of the cakes and things are so sweet. I didn't realise how sweet most cakes and things are, but your tastes change. You don't realise…" Summary: CFS 7 Margaret remains dependent on carers for personal care including management of incontinence, using a hoist and wheelchair. She describes more pronounced fatigue and breathing difficulty including panic attacks which she manages using breathing exercises. A combination of poor eyesight and limited upper limb strength make writing difficult, and Margaret has pain during the interview. Margarets legs remain swollen and elevated.
	Margaret describes use of incontinence pads which her carers change on the bed. These are used for both urinary and faecal continence. It is not clear whether continence issues are environmental or biological. Margaret it not independently mobile, and reports having changes from a Steadi to a hoist approximately 6 months prior. No planned or emergency acute care. Summary: CFS 7	No changes to Margaret's frailty syndromes are raised. Margaret describes having panic attacks and has a new plan in place to contact the NHS community team rather than 111 if assistance is needed. Community teams have increased their presence, making wellbeing telephone calls to Margaret to monitor her. Summary: CFS 7
CFS calculated by researcher	CFS 7 Living with severe frailty Completely dependent for personal care. Even so Margaret seems stable at not at high risk of dying (within approx. 6 months). Margaret is dependent on two carers for all personal care tasks and meals. She uses a hoist and attendant propelled wheelchair to move around indoors and has not left the house for approximately 2 years (prior to COVID). Margaret has some signs	CFS 8 Living with very severe frailty Completely dependent, approaching end of life. Typically, could not recover even from a minor illness. Margaret remains dependent on two carers for all personal care tasks and meals. She uses a hoist and attendant propelled wheelchair to move around indoors and has not left the house for more than 2 years (prior to COVID). Margaret has some signs of reduced concentration and memory when tired and describes falling asleep whilst watching programmes more now. Margaret is

	of reduced concentration when tired and describes easily falling asleep in her chair during the day. Margaret states she has a life limiting diagnosis but does not provide details to suggest she is at high risk of dying within 6 months.	receiving regular contact from community nurses 'just to see how I am' – an increased level of monitoring which may indicate progression in Margarets life limiting condition. Margaret asks for this second interview to be earlier than planned, to accommodate her anticipated short life expectancy.

Appendix 32: Researcher diary entry 21/11/23 – Reflection after first interview with Margaret (6 pages)

CPDme
Development for Life

CPD Reflective Entry

Title
ProfD - Reflection after first interview - transcribed from dictaphone

Date of event being reflected upon
Tuesday 21 November 2023

Reflection
Hi, it is Tuesday 21st November 2023. Just reflecting out loud on my way from an interview. Elements that are playing on my mind around capacity, consent, vulnerability, and my role and behaviours as a researcher, possibly in comparison to as a clinician, maybe. Erm, I don't think I've done particularly well in terms of the timing. So, it's the first interview I've been at, erm, sort of started, not quite with the second I walked in the door. It wasn't quite like that, but it started... as I came in and said hello and introduced myself... I think it was because, because I phoned in advance, as discussed. Said that I would ring on the day make sure everything was alright still, still happy to go ahead, all those things. And this lady had said to me this morning, I'm expecting a district nurse in because I need to have some bloods done today. They're fasting bloods, so I haven't had my breakfast yet, as I usually would. I don't know exactly what time the nurse is coming, so it might be, y'know I'm still happy for you to come, but it might be that I have to sit and have my toast part way through the conversation, if the nurse has only just been by the time you get here. So I said, that's absolutely fine. It doesn't make any difference at all. Thank you for still letting me come. So following on from that, as I arrived at the property and said, Hello, I said has your nurse been, how are things looking, have you managed to have your breakfast, and we sort of then picked up where we left off in conversation about the practicalities of the morning and what was going on with the nurse and why that might be, and a little bit of the background about that. And the lady started to tell me about having erm, she didn't specifically say what the blood test was for, but she talked about a gradual shift in her wellbeing, more investigations and things like that, since, since covid, since not being able to regularly have something in her chest drained, had meant that fluid had migrated to elsewhere in her body and it'd affected her lower limbs and it'd kind of thrown her off a little bit essentially. And she sort of started in this conversation, started to talk about, essentially, a lot of the things that I want to talk about in the interview, and I said a few minutes into all of this, 10 minutes or so, just to hold that thought for one second, I'm really conscious we haven't done consent paperwork, things like that. I haven't started by recording, if you're happy for me to record things like that. We hadn't done the paperwork and things like that so I'm just really conscious not to not to go too far into things. I said anything you tell me about your health, things you're more than welcome to tell me anything, but just so that you know, introductions again I'm Kate work from, I do similar things to the people that put you in touch with me kind of thing, but different team, and I don't have access to any of the medical records. She apologized for telling me the medical stuff. So I said, well no, please don't be sorry. You're more than

welcome to tell me anything that you want to as part of this. I just want to make you aware, really, that I am not coming in with any prior knowledge of what sort of medical records or anything. And she said, oh no, you can't have preconceived ideas of people, I suppose. So good insight, really sensible and rational, no particular concerns or alarm bells. Recalled having spoken to me last week when I rang this morning and when I arrived again today, prior conversation about the study the pack hadn't come through yet, frustratingly, since last week, and that's my reflection about leaving enough of the cooling off period to make sure that that pack has definitely arrived and being digested. I suppose we'll get there, but we went through the pack together.
We talked about frailty. And I said, I was looking toi interview people who, err, who had had maybe a series of things go on or change for them, with typically older people who9 had had thingsgo wrogn and not got back fully to where they were before, and looking to understand the role of support around that person, what's helpful in keeping things nice and stable in life and what helps people to manage themselves when things go wrong, and what's useful to have available when people don't feel they can manage things themselves. What that needs to look like to be right for people. And she said, Oh yeah, you know, sounds like valuable stuff. It's important to have the right support around people. I said, it's what it's not always a very popular term. I know that people feel a bit uncomfortable with it sometimes, but it's what the doctors often refer to as frailty. And she said, Oh yeah, just be honest about how things are. That is just the reality of things. She said, Don't be worried about saying anything in front of me, about how you say something, something like that, cos I was consciously picking over my words, being quite cautious about the term frailty, I think. She said I'm quite open about things, there isn't really anything that I wouldn't be happy to talk about. So we went through the consent stuff, related back in your own words of what we were talking about in terms of the purpose of the study. At that point, we haven't talked about repeated interviews if I'm honest because I didn't want it to be a deal breaker, because if any participant doesn't consent to a follow-up interview it has a big restriction on my ability to look longitudinally about what's going on with people, but I would rather have the opportunity to have a conversation with somebody, get their perspective as a one off, than lose that opportunity because they didn't feel able to commit to more than one interview. So at that stage, I didn't talk about it, I came back to it at the end, which almost feels a little bit better. I think more appropriate, because at that point, person kind of knows first hand what is they're consenting to do again, but if they've had that experience of an interview, and what sorts of questions, how long it will be those kind of things and continue to obviously ring on the day as well, to have that double checking of making sure they're happy to do the interview. So to me, it's a slight adjustment that I feel comfortable with.
So things didn't start off. They started off in a... guess I didn't have, and this is a terrible word to use, but I didn't have control of the conversation. I didn't go in and start with, you know, let's set the scene. Let's talk about the community stuff. Let's now bring the focus back into the home environment. How things are managing. Because of this ladies... I

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don't know if it's cognition. Don't know if it's personality… It was really challenging to keep the conversation focused where I had originally thought it was going to focus. Initially, for quite a long time, I didn't try to force it back in the direction that I wanted it to be in. I allowed the conversation to flow, where the lady, to what the lady wanted to talk to me about. At times, it did feel, felt that the subject had gone off tangent and was going there were points where I did then have to make efforts to try and refocus it back on, support in the hear and here and now, trying to acknowledge the historic friendships and connections that were being discussed were giving me insight into this person's connectedness, a kind of history of connectedness, how they value long standing relationships, the nature of those relationships as people that provided care and support. That was all described as receipt of care and support from a couple that were otherwise quite self-sufficient. I didn't really get an impression of what was flowing back in the other direction, I suppose. But that could easily be because I was asking about the receipt of care and support, not the giving up doesn't necessarily mean it was one directional. Erm,yeah so there were points where the conversation kind of strayed off-topic, and points where I was then questioning, questioning capacity, cognition… am i questioning capacity?... No, I suppose I'm not. I think this is what I want to reflect on, actually, at the start of this, at the start of this conversation, I think there's two points; So I did do the various checks around capacity to consent, not in a structured, formal question by question kind of way, but in kind of gaging responses as I outlined what the study was about and talked about things, at the start of things at that stage. What I think I started to pick up on as we went on was probably cognition, varying, focus and attention waning, a little bit, straying into another subject, a little bit, probably as part and parcel of fatigue, because it was really quite a long visit. And there was a point at which I said, I'm really mindful that I've kept you talking for a long time, and then I still said, can I just ask you one more question that actually probably wasn't the right thing to do that was serving my own interests, really, as wanting to just claw back some of the lost questions that I hoped to ask, but haven't been able to, because this lady had gone down a very different line, at length. Suppose I'm feeling a level of guilt that I asked that additional question. I think I was worried as well. She picked up on it. She was talking about, how do you feel about your level of support? She said, I'm very grateful for it. And she started to talk about how she could get ahead of dividing out her assets and things that were of monetary value before she passes away, rather than wait until she goes because they're things she's not able to enjoy now. And actually, that's not an unreasonable thought process to have. It was in relation to a question about, how do you feel about the support? And the support that she went to, in her mind was those long-standing relationships, rather than paid carers. The emphasis she places was on those other relationships, which is really important. Maybe I just I own agenda… because I was, I was worried that she was going off on a tangent (for want of a more professional term), we're not talking about what's important to you, and keeping stability in the here and now. We're talking about where and what friends old flat used to look like, where they moved to, and details that didn't

feel as though they were particularly answering what they had hoped to go there to answer. In hindsight, I do see the relevance. I need to look back at the recording and the transcript and look objectively, really, at why I I felt the way I did at that point, I guess in terms of capacity and consent and things. I think it's partly the fact that there's a power of attorney in place for finances does raise question marks in my head about this person's capacity. However, those power attorneys only come into effect when you're not able to make the decision yourself. Just because you've appointed somebody doesn't necessarily mean that right now that person needs to make the decisions on behalf of this lady. And also capacity is decision specific. It's one thing to make complex decisions about financial assets and payments for care, you know, whatever. And it's a different, a totally different thing to ask somebody whether they consent to talking about their own experiences and beliefs about support and living with frailty. They are different things to consent to. I've also got a little bit of a question mark that I'm going to need to deal with around some of the care practices that were disclosed during the interview. She described an incident at the end of last week where the hoist had got stuck in an elevated position. There's lots of things around that, hoisting… The sling's uncomfortable. The lady says, due to her scoliosis, she was advised she should never be hoisted, and she feels that she was alright until she began to be hoisted. I'm mindful that that's also been in an unpopular decision, because she preferred the Sara Steadi (equipment) and the OT advised a piece on a piece of equipment that wasn't what to say he would prefer to keep using, which is contentious for her. So I'm mindful of that context to it, but she's saying that she shouldn't be hoisted, and she is being hoisted, and it's uncomfortable, and the routine of how it's being used doesn't make a lot of sense. The OT is telling them how to do it, but is kind of having the final say, but isn't actually there. Yeah, so last Friday, she was hoisted up to go onto the bed, and then the hoist stopped, and they couldn't actually lower it, and nobody in the room at that point seemed to be aware of the stop button, big red button that the emergency stop could be easily pressed in by accident, and you need to check it and pull it out. I didn't mention that I was aware of this, cos I didn't want to change the dynamic or disclose that I was an OT by background, because a lot of what she was talking about was specifically about Ots. So they weren't aware. She had suggested that they cut the straps on the on the sling. They didn't want to do that, so what they ended up doing was managing to unhook part of the sling manually while she was mid-air, which must have been a hugely risky thing for their fingers. Moving and handling, all the rest of it. And she described them sort of crashing down onto the bed, released out of the sling that way. But again I don't know how they'd have done that, bringing her whole body, body down… you'd have had to do one, one hook at a time. So she'd have come down at an angle, and then bits and twisted, and really quite a dangerous… they panicked, I think. There was a suggestion that somebody else would be called. The person who was present said, Oh no, they don't know what to do either. They're not going to know any more than we know and low and behold actually that person did know about the stop button probably could have given that advice in the

moment. They also did know about the emergency phone number on the base of the device, which they were then able to ring. And it was the equipment provider who told them about the button. So there were… a training issue, something about crisis management, when something unexpected happens, and the fact that they allowed her to crash down, and I don't know whether she was injured in the process at all. But it's poor practice, all round on the care agencies part, really which should be highlighted.

Yeah, as I said at the start of this ramble, I'm just reflecting out loud really, feeling a bit unsure and uncertain about that. I think because the carers came in at the end of the visit, and clearly were a little bit unsure about who I was, they came in which would be their I company policy. Erm, this lady was able to tell me her key save number. When I came to knock on the door, she knew who it was that was coming, I'd spoken to her an hour before. She knew who I was and why I was there, and she was able to give me the key safe number to come in and direct me on whether to put it back in the box, she's directing her own that's self-care, safety… knowing that she still needs to have a breakfast, those kind of things. Insightful I guess, able to oversee those parts of her own needs.

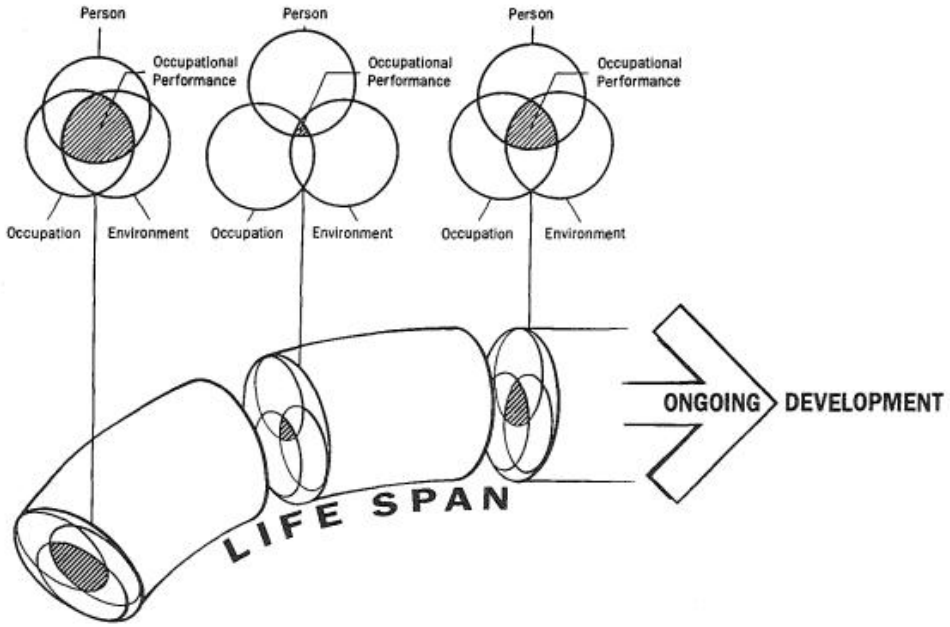
The carers came in the end, had PPE on. She didn't ask me to put any PPE on, but equally, was able to direct me about the key safe and how she wanted that managed. So I believe she could have asked if she wanted. Equally, could have disclosed if there was an illness that she was carrying but there was no coughing or anything like that during the visit, no indication that she was (acutely) unwell particularly. I guess I kind of felt that moment of, should I disclose to these people who I am, in order to give them some assurance that I am a stranger that's come into the house, but I'm not a haven't come in uninvited or with any mal intent or anything like that. Obviously, CRB checked and, you know, all those types of things I need to be, I'm there in a very above board kind of a way. I don't know. I didn't disclose who I was.

All in all, I think maybe the biggest issue, really, you have two issues. One was the amount of cooling off time and the opportunity to make sure that that intervention pack had arrived, and she had an opportunity to talk it through with somebody, although, having said that, she didn't say there was anybody that comes in regularly and checks post for her or.... And anybody that comes in. There was no indication that she was uncertain that she would have liked to have someone there. Y'/know, people sometimes drop a comment, like when they're talking about their POA, there could have been a throwaway comment at that point - we could ask her that actually, so and so deals with all that, I'll give you a phone number. You can ask her, if you want. Often there's that type of comment thrown in, but there wasn't anything that always lines at all, there was no hint of wanting to bring somebody else into the conversation. I probably could have left it a bit longer, and it's probably because I was ringing at the same time as I was ringing my other participant who had cancelled her date in the diary as when I rang on that day, she wasn't feeling well. She still wants to do it. Can I do it another time? So we booked it rescheduled for this week in the hope that she'd be feeling better. I was going to ring up

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the day, which I have done today, and she's still not feeling better, so it's cancelled again. But that's probably that situation probably influenced me to think I'll just try and book something in there and then, and then I'll send out the information, and then ring on the day, and then there's still an opportunity for them to say no. So it does seem to help with engagement. But I worry with this one. I wonder if I've done it too quickly, gone too far the other way, not given enough time, I don't think I've done I don't think it's kind of an ethical conflict as such, because capacity should be assumed, unless proven otherwise, and there's no, there's no, no indication that this lady lacks capacity, just that she has some vulnerabilities around her. And I think if I were to go back to see her again, I think I would ring in advance to book the day and say, does she want to have anyone with her, or is she happy to talk again by ourselves, and I think I will set some clearer parameters around the length of the conversation. Maybe that could be part of the parcel of asking whether she wants anybody there. I think, if I'm gonna, I think the best approach is probably open and transparent with her and say I noticed last time, last time we talked, quite a while in the end, and I did wonder whether that left you feeling quite tired? As we hadn't met
before, maybe I didn't spot the telltale signs as early as somebody that knew you could have done. If you want to have somebody there with you, you're more than welcome to have somebody else come and sit with us as well to keep an eye out for if you're getting worn out. But I'm also going to try and do the same in this conversation, because I don't want you worn out for the rest of the day. Something to that effect.
Yeah, also got a conflict with work life because inevitably, I had to go into my working computer to find the contact details for the second lady who I was going to go and see, but it's getting the content details to ring and see whether we would go ahead or not. And I see all the work stuff, and the temptation is to dip into those bits. Really becomes very, very difficult to separate work, uni and downtime, because they all just there. Really isn't such a thing as downtime. Really, as soon as I try and do uni stuff, I'll see the work stuff, because they're on the same device in the same place, and can't separate to two. It's a battle. Anyway... Debriefed, reflected… Bye.

Appendix 33: Depiction of the Person-Environment-Occupation Model of Occupational Performance across the lifespan illustrating hypothetical changes in occupational performance at three different points in time (Law et al. 1996)



Appendix 34: Example of data recording sheet for concept analysis

Data recording sheet									
Heath H and Phair L (2009) *The concept of frailty and its significance in the consequences of care or neglect for older people: an analysis* International Journal of Older People Nursing									
Discipline/population group	Attributes	References	Identification	Antecedents	Consequences	Management	Related concepts	Model case	Philosophical view
	Att1: Has Frailty been operationalised, defined or conceptualised? **Att2:** Presents key characteristics, qualities or features inherent to Frailty? **Att3:** Is Frailty a useful concept?	**Ref1:** Identifies situations, incidents or phenomena in which Frailty can be considered. **Ref2:** Seeks to clarify the perception of perspective of a specific professional or population group	**Ide1:** A specific means to identify or assess frailty is recommended and commented on?	**Ant1:** Events or phenomena preceding Frailty	**Con1:** Occurrences that follow Frailty defined	**Man1:** A specific management approach or intervention is recommended for frailty?	**Rel1:** Identifies and/or discusses other concepts related to Frailty **Rel2:** Presents the important aspects of the relationship	**Mod1:** Provides a clear example of Frailty	**Phi1:** Entity, dispositional or evolutionary view of Frailty concept?
• Academics (A) • Researchers (R) • Geriatricians (G)	**Att1:** (A)"implications of frailty as a consequence of care or neglect for older people" p121 **Att2:** (G) "at high risk of complications" p123 (A)"a state of vulnerability" p123 (A)"synonyms for frailty included: biological old age, failure to thrive, wasting syndrome, chronically dependent, functional vulnerability,	**Ref1:** **Ref2:** (R) "much of the research has focussed on identifying the determinants, components and consequences of frailty" p123 (A)"affected by individual subjective perceptions" p125	**Ide1:** (A)"Various tools have been developed… most are impractical for bedside screening by frontline providers because they require the multidimensional clinical data that constitute (CGA)" p124 (A)"Edmonton Frail Scale… a brief, valid and reliable tool that can be completed by	**Ant1:** (A)"can originate from factors within an individual or from factors in the persons context or environment" p125 (A)"before frailty occurs… deterioration is not sufficiently severe to interfere with the person's (ADLs) or the person is able	**Con1:**	**Man1:** (A)"proactive, individualised, multi-disciplinary interventions, targeted at the individual or the environment" p125 (A)"affected by individual subjective perceptions, interventions offering psychological, emotional or social support can help to reduce the degree of frailty" p125	**Rel1:** "neglect" p122 "vulnerable, vulnerability, fragile, fragility, co-morbidity, dependency" p122 "medically vulnerable" p123 "reserve capacity" p125	**Mod1:**	**Phi1:** **Entity**

Appendix 3

Concept analysis – Thematic analysis by stakeholder category							
Discipline/population group	Attributes	Identification	Antecedents	Consequences	Management	Model case/ References	Philosophical view
	Att1: Has Frailty been operationalised, defined or conceptualised? **Att2:** Presents key characteristics, qualities or features inherent to Frailty? **Att3:** Is Frailty a useful concept?	**Ide1:** A specific means to identify or assess frailty is recommended and commented on?	**Ant1:** Events or phenomena preceding Frailty	**Con1:** Occurrences that follow Frailty defined	**Man1:** A specific management approach or intervention is recommended for frailty?	**Mod1:** Provides a clear example of Frailty **Ref1**: Identifies situations, incidents or phenomena in which Frailty can be considered.	**Phi1:** Entity, dispositional or evolutionary view of Frailty concept?
The people being described as frail	**Att1:** END OF LIFE "older people and their carers associated the term with end-of-life, cancer syndromes and high degrees of functional dependency" LACKING - WELLBEING "requiring the mobilisation of resources to create wellbeing" **Att2:** SENSE OF SELF • UNSUCCESSFUL • VALUE • FAILURE • AUTONOMY	**Ide1:** FUNCTIONAL THRESHOLD • TRIGGER POINT VISIBILITY • PHYSICALLY SMALL • OBJECTIVE • GESTALT	**Ant1:** POTENTIAL FOR CHANGE • VULNERABILITY • CHANGE • RISK • UNCERTAINTY PATTERNS • TRAJECTORY – GRADUAL • SPECTRUM • TRAJECTORY – CYCLE PSYCHOLOGICAL CONTRIBUTORS • STATE OF MIND KNOWLEDGE • REDUCED AWARENESS OF RISK	**Con1:** PHYSICAL CONSEQUENCES • MORTALITY • SLOWING • DEPENDENCY • HOSPITAL ADMISSION • DISABILITY PSYCHOLOGICAL CONSEQUENCE • SICK ROLE • NEGATIVE EMOTIONAL • LACK OF DIGNITY SOCIAL CONSEQUENCES • WITHDRAWN • DEPENDENCY • EXCLUSION LOSS • LOSS OF CONTROL • LOSS OF AUTONOMY • LOSS OF IDENTITY	**Man1:** MODIFIABLE FACTORS • BEHAVIOURAL CONTRIBUTORS • PREVENTATIVE • LIFESTYLE MODIFICATION • OVERCOMING ATTIUDINAL BARRIERS • HEALTH PROMOTION PERMANENCE • PERMANENCE • INEVITABILITY MAINTAINING IDENTITY • CHOICE • ROUTINE • AUTONOMY • CONTROL • AGENCY	**Mod1:** "nothing wrong with my health but I have fallen five times and… I've broken everything" "for some a gradual decline and for others a sudden and shocking rupture which they related to a specific event, for	**Phi1:** Dispositional: 8 Entity: 1 Evolutionary: 1

	• MAINTENANCE OF IDENTITY • THREAT • DIMINISHED VERSION • ACCEPTANCE • IDENTITY • LOSS OF AGENCY DEFICIT • LACKING LIVED EXPERIENCE • EMOTIONAL EXPERIENCE • INDIVIDUAL EXPERIENCE • CONTEXTUAL • BALANCE • DEPENDENCE • MEANINGFUL ACTIVITY • HOME • PERSONAL BIOLOGICAL • MORTALITY • PHYSICAL CONSEQUENCES • PHYSICALLY DIMINISHED • SLOWING • GENDER PSYCHOLOGICAL • PSYCHOLOGCIAL CONDITION • PSYCHOLOGICAL CONTRIBUTORS • EMOTIONAL RESILIENCE • SICK ROLE • NEGATIVE EMOTIONAL • WILLPOWER SOCIAL		PHYSICAL SYMPTOMS • PAIN • FATIGUE	• LOSS OF INDEPENDENCE • LOSS OF CONNECTIONS • LOSS OF MEANINGFUL ACTIVITY	• INDIVIDUAL EXPERIENCE • PERSONAL TRAJECTORY • ANCHORAGE • DOING TO V DOING WITH COPING STRATEGIES • RESISTANCE • LEVELS OF INTER-DEPENDENCE • PLANNING BELIEFS • REWARD/MOTIVATION • PERCEPTION ADAPTATION • ACCEPTANCE • ADJUSTMENT • DELEGATION • COMPENSATION • MANAGING CHANGE • ENVIRONMENTAL POSITIVITY • FOCUS ON ABILITY • FOCUS ON INDEPENDENCE PSYCHOLOGICAL CONTRIBUTORS • KEEPING GOING • INTERNAL DRIVE • EMOTIONAL EXPERIENCE • PERSONAL SENSE OF VALUE • INNER STRENGTH • KNOWLEDGE • RESILIENCE • RESPECT • ENGAGEMENT • MOTIVATION	example a fall” “a person that’s sitting in the armchair all the time” “losing independence, dignity and control” “isn’t strong… doesn’t have a lot of emotional resources… needs to be taken care of… they don’ have the resources themselves, they haven’t found the resources themselves… dependent… at risk… deteriorating. . more and more isolated”	

	• SOCIAL CONSEQUENCES • WITHDRAWAL • DIVIDING • SOCIAL CONSTRUCTION **Att3:** NEGATIVE • LINGUISTIC • LABELLING • DEFICIT FOCUS • IDENTITY • NON-MEDICAL • CONNOTATIONS • RESISTANCE • OBJECTIFICATION SKEPTICAL • WHOSE INTERESTS • RESONANCE • UNCLEAR BENEFITS • VARIOUS UNDERSTANDINGS				QUALITIES OF PROFESSIONAL • RESPECTFUL • RELATIONSHIP CENTRED • AGE • NON-SPECIALIST • COMMUNICATION SERVICE PROVISION • SPECIALIST INPUT • CONSIDERATION OF LINGUISTICS • TIMELY SUPPORT • INTENSITY OF SUPPORT • COMMUNITY BASED • NON-MEDICALISED PREFERRED • ACCESS • KNOWLEDGE • HOLISTIC • PERSONALISED • PRACTICAL • DURATION • CONTINUITY • FLEXIBLE • INFORMATION PROVISION SOCIAL SUPPORT • MAINTAIN CONNECTIONS PHYSICAL • MAINTAINING MOBILITY • EXERCISE		

Discipline/population group	Attributes	Identification	Antecedents	Consequences	Management	Model case/ References	Philosophical view
Clinical Experts	**Att1:** **Att2:** MULTIFACTORIAL COGNITIVE SYMPTOMS PHYSICAL SYMPTOMS PSYCHOLOGICAL SYMPTOMS	**Ide1:** PHYSICAL SYMPTOMS • WEAKNESS • POOR ENDURANCE • LOW ACTIVITY • UNSTEADY • MALNOURISHED PSYCHOLOGICAL SYMPTOMS • FEAR OF FALLS	**Ant1:** SOCIOECONOMIC DEPRIVATION		**Man1:** MODIFIABLE FACTORS: • HEALTH BEHAVIOURS ETHICAL CONCERNS • RESPONSIBILITY		**Entity: 1** **Dispositional: 0** **Evolutionary: 0**

	• FEAR OF FALLS RISK • POLYPHARMACY • MEDICAL COMPLICATIONS **Att3:** AFFIRMATIVE • RISK ECONOMIC • BURDEN – SERVICES • CLINICAL CONCEPT • CLINICAL TOOL • CARE PLANNING • THREAT – ECONOMIC SUSTAINABILITY OF SERVICES SKEPTICAL • CONCEPTUAL • LINGUISTICS AMBIGUITIES						
Discipline/population group	Attributes	Identification	Antecedents	Consequences	Management	Model case/ References	Philosophical view
Professional and national governing bodies	**Att1:** (WHO) "defines frailty… as "Extreme	**Ide1:** ASSESSMENT TOOLS • STANDARDISED • EFS	**Ant1:** PHYSICAL SYMPTOMS • REDUCED MOBILITY		**Man1:** PREVENTATIVE • PROACTIVE • EARLY INTERVENTION		**Entity x1**

	vulnerability to endogenous and exogenous stressors that expose an individual to a higher risk of negative health related outcomes" WHO glossary of terms "defines a frail older person as "an older person in need of a substantial level of care and support" p1173 **Att2:** VULNERABILITY TRAJECTORY – PROGRESSIVE/ GRADUAL **Att3:** AFFIRMATIVE • PUBLIC HEALTH PRIORITY • HOLISTIC APPROACH • LEGITIMISING CLINICIANS • INCREASE UNDERSTANDING • PUBLIC HEALTH BENEFIT	• OBJECTIFIABLE • FOCUS ON DEFICITS PHYSICAL SYMPTOMS • REDUCED MOBILITY • URINARY INCONTINENCE • SIDE EFFECTS OF MEDICATION COGNITIVE SYMPTOMS SIDE EFFECTS OF MEDICAL INTERVENTIONS PROACTIVE SCREENING • AGE 65+ • EFS	• NEW URINARY INCONTINENCE MEDICAL INTERVENTIONS • SIDE EFFECTS OF MEDICATIONS FALLS		• EARLY IDENTIFICATION SERVICE DESIGN • MISALIGNMENT OF SERVICE CRITERIA • LONG TERM CONDITION • MONITORING • EFI THEN CLINICAL ASSESSMENT PERSONALISED • PATIENT LEAD • INDIVIDUALISED GOAL SETTING • INDIVIDUALISED CARE PLANS INTERVENTIONS • EDUCATION • ANNUAL MEDICATION REVIEW • FALLS ASSESSMENT • ADVANCED CARE PLANNING • SOCIAL ENGAGEMENT • RESISTANCE EXERCISE • DIETARY CHANGE (LESSER) COORDINATED • GP COORDINATION • INFORMATION SHARING AIMS • HEALTH • QOL • PRODUCTIVITY • WELLBEING		

	• PROVIDE SUPPORT • ADMISSION PREVENTION • REDUCE SERVICE USE • IMPROVE PATIENT OUTCOMES • REDUCE SERVICE COSTS SKEPTICAL • LINGUISTIC / INTERPRETATIONS • DEMONSTRATING OUTCOMES • LINGUISTIC INTERPRETATIONS • MISALIGNMENT BETWEEN SERVICE CRITERIAS NEGATIVE • ANTIPATHY				• COMMUNITY LIVING • REDUCE ADMISSION • REDUCE BURDEN ON SERVICES LOCATION • SUPPORT AT HOME PSYCHOLOGICAL • HEALTH BEHAVIOURS (ETHICAL CONCERNS)		

Discipline/population group	Attributes	Identification	Antecedents	Consequences	Management	Model case/ References	Philosophical view
Non specialist qualified or senior staff delivering interventions	**Att1:** **Att2:** SUBJECTIVE • COMPONENTS SUBJECTIVE OBJECTIVE • VISIBLE PRESENTATIONS • THIN • PHYSICALLY SMALL COMPLEXITY • COMPLEX SYSTEM FAILURE • CUMULATIVE - PSYCHOSOCIAL ENVIRONMENTAL / DISEASE • COMORBIDITY • POLYPHARMACY • NO SINGLE OVERRIDING DIAGNOSIS • UNCERTAINTY • CHANGE	**Ide1:** INTUITIVE • PERCEPTION • DESCRIPTIVE TERM • GESTALT • INTUITIVE • INSTINCTIVE • FEELING • JUDGEMENT • 'JUST KNOW' • UNCERTAINTY • VARYING PRESENTATIONS CLINICIAN FACTORS • CONFIDENT IDENTIFYING AND PREDICTING RISK • LACK OF KNOWLEDGE • ADVANCED INTERPERSONAL SKILLS • ADVANCED ASSESSMENT SKILLS	**Ant1:** PHYSICAL FACTORS • GRADUAL WEAKENING • AGEING PROCESS • INCREASING COMORBIDITIES • DEMENTIA • FALLS RISK SOCIAL FACTORS • OVER PROTECTIVE FAMILY FUNCTIONAL • DEPENDENCE • PHYSICAL ENVIRONMENT CHANGE ACUTE EPISODE • MENTAL OR PHYSICAL HEALTH	**Con1:** PHYSICAL • FALLS • POOR HEALTH OUTCOMES • FALLS • ILLNESS • INJURY • DEATH • INFECTION • PRESSURE SORES • REDUCED MOBILITY USE OF SERVICES • HOSPITALISATION • USE OF SERVICES • ADMISSION DEPENDENCE • INSTITUTIONALISATION • DISABILITY CONSEQUECES PERCEIVED DIFFERENTLY BY PROFESSIONS	**Man1:** TRAINING • CLINICIAN - UNCLEAR MANAGEMENT PATHWAYS • TRAINING – UNDERGRADUATE RESILIENCE • ACCEPTANCE NOT SEEN AS RESILIENT • ?DEFINITION OF RESILIENCE • PSYCHOLOGICAL RESILIANCE • SOCIOECONOMIC RESILIENCE PSYCHOLOGICAL • INDEPENDENCE MOTIVATES • PERSONALITY • HEALTH PERCEPTION • PSYCHOLOGICAL – RESILIANCE • COPING STRATEGIES • PSYCHOLOGICAL SUPPORT	"people of advancing age, unable to carry out independent activities of daily living and considered to be vulnerable to physical decline" "elderly people who are becoming more vulnerable and susceptible to falls and poor health" "he can present as	**Move from dispositional to entity view X1** **Entity X4** **Dispositional X2**

	• VULNERABLE • DYNAMIC STATE GENDER • FEMALE IDENTITY • LACKING PURPOSE • NEGATIVE IDENTITY • WEAKNESS OF PERSONALITY TRAJECTORY • SCALE FUNCTIONAL • FUNCTIONAL DEFICIT • FUNCTIONAL LIMITATION • DISABILITY • REDUCED COPING • REDUCED INDEPENDNCE • DEPENDENCY PHYSICAL • DISABILITY • PHYSICAL DECLINE • MALNOURISHMENT • END OF LIFE • FRAGILE • THIN • POOR MOBILITY • WEAKNESS • PHYSICAL • PHYSICALLY SMALL • RESUSCITATION ORDER	• TOOLS USED DEPEND ON PROFESSIONAL BACKGROUND OBSERVABLE INITIAL INDICATORS • SCALE: EASIER WHEN MORE ADVANCED • VISIBLE • ENVIRONMENTAL CLUES • CONTEXTUAL INFO PRACTICAL CONSIDERATIONS • TIME CONSTRAINTS • LACK OF ACCESSIBLE MEASURE • ACCESSIBILITY OF ASSESSMENT TOOL – BARRIER • SUCCINCT INFORMATION • SHORTHAND • INFORMATION SHARING TRAINING • TRAINING NEEDS – HOW TO ADMINISTER TOOLS UNDERSTANDING VALUE INTERPRETATION OF SCORE	PSYCHOLOGICAL FACOTRS • BEREAVEMENT • REDUCED ENGAGEMENT • PSCHOLOGICAL IMPACTS PHYSICAL	PSYCHOLOGICAL • LOW MOOD • SUICIDE	PATIENT EMPOWERMENT • PATIENT EDUCATION • DEPENDENT ON LEVEL OF FRAILTY • PATIENT PRIORITIES • PATIENT LEAD • PERSONALISED • CONSIDER POWER DYNAMICS • NEUTRAL LINGUISTICS • PATIENT KNOWLEDGE OF SERVICES • PATIENT ACCESS TO SERVICES • PATIENT AUTONOMY PROFESSIONAL RELATIONSHIPS/SKILLS • MANAGING EXPECTATIONS • STRONG PROFESSIONAL RELATIONSHIP WITH PATIENT • ABILITY TO ANTICIPATE NEED • ACCEPTABLE LEVELS OF RISK INTERVENTIONS • MUSCLE STRENGTHENING • FALL RECOVERY TECHNIQUES • ENVIRONMENTAL MODS • LOCAL SERVICES • COMPENSATION	frail but not all the time, when he's physically unwell he's quite vulnerable but not all the time" "unsteady on their feet… appears vulnerable, requires assistance to complete normal day-to-day things" "leaving the oven on and almost setting fire to the place… tripping the electric and not knowing that it's gone and they're sitting there in the cold" "she's not a frail person in herself but	

	SOCIAL • POOR SUPPORT SYSTEM • FINANCIAL CONCERNS **PSYCHOLOGICAL** • ANXIETY • LOW MOOD • NEGATIVE EMOTIONAL • PERSONALITY • HEALTH PERCEPTION • LOW SELF-ESTEEM **COGNITIVE** • COGNITIVE DECLINE **PERMANENCE** • IRREVERSIBLE • PERMANENT STATE • CUT OFF POINT FOR IMPROVEMENT • NOT UNIVERSALLY PERCEIVED AS PREVENTABLE • PREVENTABLE **Att3:** **AFFIRMATIVE** • ANTICIPATE NEEDS • TAILORED CARE • IMPROVE OUTCOMES • UNIFYING	**ASSESSMENT TOOLS** • ROCKWOOD CFS ✓SIMPLE • ROCKWOOD CFS ×SUBJECTIVE ×CONTEXT AFFECTS USE × ACCURACY • TIMED UP AND GO ×IMPRACTICAL ×UNCLEAR PURPOSE • RECOGNISED ASSESSMENT TOOLS VALUED • SIMPLE SCORE VALUED **ASSESSMENT APPROACH** • EVIDENCE BASED PRACTICE • MULTIFACTORIAL ASSESSMENT TOOL • BIOPSYCHOSOCIAL • HOLISTIC ASSESSMENT • GRADUAL PROCESS • ROUTINE SCREENING – NEGATIVE • EARLY IDENTIFICATION			• MULTIDIMENSIONAL • COPING STRATEGIES • HEALTH PROMOTION- EXERCISE / SOCIALISING / FINANCE SKILLS / ENVIRONMENTAL ADAPTATION / NUTRITION / MEDICATIONS / PERSONAL HYGIENE / CARER EDUCATION / COMPUTING SKILLS / MOOD / MEMORY • PRACTICAL SUPPORT • SIGNPOSTING • MEDICATION MANAGEMENT • INTERLINKED COMPONENTS • NUTRITION • MOBILISATION **FOCUS** • TARGET LOW OR MODERATE FRAILTY • PRIORITISING – SAFETY / FINANCES / BEING AT HOME **LOCATION** • HOME • ADMISSION – RISK TO PATIENT • ADMISSION – NEGATIVE FOR PATIENT BUT GETS ON RADAR **BARRIERS** • PROFESSIONAL TIME • PROGNOSIS UNCLEAR	she does have a lot of weakness" "he's sitting on the loo with his wife trying to help him and he's struggling to get up off the toilet and back, walk anywhere. I mean that is total frailty in my mind. He no longer can cope with everyday living without support" "a hoarder… she's at high risk of falls… her frailty then becomes worse because she's not mobilising so she gets weaker"	

	• HOLISTIC • AIDS DECISIONS • IDENTIFY RISK • PREVENTATIVE • INDIVIDUALISED INTERVENTIONS • INCREASE UNDERSTANDING • INCLUDE IN GRADUATE TRAINING • RESEARCH IMPLICATIONS • UNDERSTANDING ALIGNS WITH PATIENTS • ALIGNMENT WITH PERCEPTION OF ROLE SKEPTICAL • LINGUISTIC INTERPRETATION • SHARED MEANING • NON PRAGMATIC NEGATIVE • NON-SPECIFIC • LACKING DIGNITY • NOT INDIVIDUAL • ASSOCIATIONS • ANTIPATHY • LABELLING • DESCRIPTIVE • HARMFUL TO IDENTITY • PHYSICALLY DIMINISHED • LINGUISTIC CONNOTATION • UNCLEAR MANAGEMENT PATHWAYS				SERVICE DESIGN • SERVICE AVAILABILITY • CONTINUITY • PERSONALISED FREQUENCY • EASE OF ACCESS – REFERRALS • ACCESS TO OT – CLINICIAN • PROLONGED • IN DEPTH • ABILITY TO MEET PATIENT WISHES • PROACTIVE AND REACTIVE • PREVENTION • REHAB PROGRAMMES • PLANNING AHEAD • SCREENING • MULTIDISCIPLINARY • INFORMATION SHARING • SHARED FRAILTY PROFILE • REVIEWS		

	• PSYCHOLOGICAL IMPACT OF LABEL						

Discipline/population group	Attributes	Identification	Antecedents	Consequences	Management	Model case/ References	Philosophical view
Informal carers of frail individuals	**Att1:** **Att2:** IDENTITY • LACK OF PURPOSE • NEGATIVE • EMOTIVE CHANGE • TRAJECTORY • TRANSITION VISIBLE • VISIBLE APPEARANCE GENDER • FEMALE PHYSICAL • END OF LIFE INDEPENDENCE • FUNCTIONAL DEPENDENCY **Att3:** AFFIRMATIVE • SERIOUS	**Ide1:**	**Ant1:**	**Con1:** PSYCHOLOGICAL DISABILITY END OF LIFE	**Man1:** PRIORITIES • SUPPORT AT HOME • FINANCES (PERSONAL) • SAFETY USE OF LANGUAGE • POSITIVE LINGUISTICS PATIENT CENTRED • INCLUSIVE • KNOWLEDGE • ACCESS • PATIENT SHAPING SERVICE SERVICE DESIGN • HOLISTIC • JOINED UP • FREQUENCY • DURATION • CONTINUITY INTERVENTIONS • HEALTH PROMOTION • PSYCHOLOGICAL • PRACTICAL SKILLS • KNOWLEDGE • SOCIAL • MEDICATIONS REVIEW • HEALTH BEHAVIOUR		**Entity x1**

					QUALITIES OF CLINICIAN • COMMUNICATION • QUALIFICATIONS		
Discipline/population group	Attributes	Identification	Antecedents	Consequences	Management	Model case/ References	Philosophical view
Non-healthcare public	**Att1:** **Att2:** GEOGRAPHY • CARE HOMES PERMANENCE • PERMANENT VISIBILE SIGNIFIERS • MOBILITY AID • WALKING STICK • OBJECTIFIED CHARACTER • PASSIVE • VULNERABLE • LOST • QUALITATIVE PHYSICAL • WEAKNESS • FRAGILITY	**Ide1:**	**Ant1:** INACTIVITY	**Con1:** SOCIAL POSITION • DEPENDENCY PHYSICAL • DECREPITUDE • DEATH INDEPENDENCE • DISABILITY	**Man1:** TRAJECTORY • CONTROL PROGRESSION SOCIAL • SOCIAL CONNECTIONS AIM • MAINTAIN INDEPENDENCE TECHNOLOGY • MONITORING • SMART TECHNOLOGIES – ETHICAL CONSIDERATIONS • NEW TECHNOLOGIES PHYSICAL • ACTIVITY • EXERCISE	**Ref1:** “from a laypersons perspective, frailty…often referred to as weakness, delicacy, and being fragile”	**Entity x1** **Evolutionary x1**

	AGEING PROCESS • DEATH • DECREPITUDE • ELDERLY • DECLINE • OLD AGE • AGEING • SUCCESSFUL AGEING • MENTAL DETERIORATION • PHYSICAL DETERIORATION **FUNCTIONAL** • DEPENDENCY **IMPERSONAL** • HOMOGENISED **PSYCHOLOGICAL** • WORRY • FEAR • HUMILIATION • HELPLESSNESS **ABILITY TO ADAPT** • FOCUS ON PAST • ACTIVE PARTICIPANTS • REDUCED COMPETENCE • REDUCED SELF-MANAGEMENT **CHANGE** • AT RISK **SOCIETAL ROLE** • UNPRODUCTIVE • RETIREMENT				**ADAPTATION - ENVIRONMENTAL** • SUBTLE ENVIRONMENTAL ADAPTATION • TACTILE PLEASURE IN ADAPTATIONS • ENVIRONMENTAL INFLUENCERS • ENVIRONMENT DESIGNED FOR INDEPENDENCE **ADAPTATION - PERSONAL** • ADAPTATION • COPING **PSYCHOLOGICAL** • ENVIRONMENTAL 'OWNERSHIP' • PSYCHOLOGICAL STRATEGIES • MENTAL ACTIVITY		

	• CONSUMER CULTURE • REJECT WANING OF VIGOUR • STIGMA • NEGATIVE SOCIAL IMAGERY • PROBLEMATIZED • NEGATIVE • DEPENDENCY **Att3:**						