Ageing in Place: An Exploration of What Works Well in a Northern City

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Abstract

Population ageing is a significant global challenge for the 21st century with advanced age closely associated with poorer health outcomes, particularly amongst those in deprived areas. Population ageing poses significant challenges for formalised health and social care services who are finding it difficult to meet current demand. Increasingly older adults are seeking to age in place and manage health conditions at home rather than in institutional settings. This is also indicative in current policy and research which frames ageing in place as a means of relieving pressure on services whilst maintaining the independence and wellbeing of older adults. This study explores what older adults feel is positively helping them to age in place, and what they feel is important to them in this endeavour. Due to coronavirus, the research was conducted virtually via telephone or videocall. Eight qualitative semi-structured interviews, informed by appreciative inquiry were conducted. Through thematic analysis, supportive factors for ageing in place were identified. Older adults' long-term views on ageing in place were complex and variable. They posed new understandings that ageing in place could be seen as a part of the ageing journey rather than the destination or sole objective. The success of the older adults' transition from health to illness and long-term coping strategies were dependant on a range of social, environmental, and personal conditions, but maintaining a positive or motivated mindset was important to achieving better outcomes. Services and communities were generally supportive of older adults and worked to enable ageing in place, however, it was the people more than the services that are valued by older people. The comparison showed, however, that policy makers both locally and nationally had mismatched priorities with the older adults in this study. Although ageing looks different to everybody, the misalignment of priorities suggests that more opportunities to engage older adults in meaningful opportunities to voice their needs and opinions are necessary to create a purposeful and sustainable ageing policy.

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Chapter One: Background and Research Context

1.1 Overview of Chapter

Population ageing is a globally accepted trend that is anticipated to continue over the coming decades (WHO, 2022). Ageing well at home is considered to be part of the solution to supporting ageing populations both in the UK and globally (PHE, 2019). Consequently, the importance of maintaining health and wellbeing whilst continuing to live in our own homes and communities as we age is increasingly recognised and advocated by policy makers and practitioners at a local, national, and global level (GMCA, 2018a; PHE, 2019; WHO, 2020).

Research to date indicates that older adults prefer to age in place (Pani-Harreman et al., 2021), and that welfare states, such as the United Kingdom, support this as a means of deflecting or reducing health and social care costs (Pani-Harreman et al., 2021; Singh et al., 2022).

In this chapter, I provide an overview of my study and include a brief introduction of myself and my motivations for this research. I then discuss Greater Manchester, United Kingdom as the location for this research and review the relevant policy. I consider the appropriate literature for this study including the policy context and outline the theoretical framework and methodological approach.

My interest in research with older adults is primarily associated with a close relationship with my ageing grandparents, and my professional work over the last six years in a variety of social care and healthcare assistant roles. I have been fortunate enough to work across the health and social care sector within the UK, and yet I remain intrigued by the differences across the two services especially within the context of integration and devolution in Greater Manchester (Walshe et al., 2016). Having witnessed the impact of the austerity agenda in the UK first-hand as a health care worker, it is clear that services for older adults have been disproportionately affected (Glasby et al., 2020). I have also observed the ambition of older adults to have more ‘say’ and ‘control’ in their care choices such as wanting more options available to them in the community. Under the Greater Manchester Devolution programme, (see next section) (Walshe et al., 2016) there are opportunities for this to come to fruition through collaborative research and intervention programs thanks to a renewed emphasis on inclusivity, on which this PhD intends to build. As this study progressed, the COVID-19 pandemic emerged irrevocably changing research and everyday life. The impact of COVID-19 will therefore be woven throughout this thesis as ‘no writing can fail to reflect the time in which it was written’ (Freidson, 1970: xii).

The overall aim of my doctoral study is to explore the physical and emotional experiences of well-being in community-dwelling, older adults with long-term health conditions as they are seeking to remain living at home as they grow older. Through undertaking this study, I intend to contribute to local policy, and health and social care practice to support ageing in place. Additionally, this research hopes to contribute towards a methodological understanding of appreciative methods and research with older adults during a global pandemic.

1.2 Research Aims and Objectives

The overall aim of this study is: to explore the physical and emotional experiences of well-being in community-dwelling, older adults with long-term health conditions as they are seeking to remain living at home as they grow older.

In line with this aim, the following research objectives (RO) have been used.

- **RO1**: To examine the provision of health and social care for older adults with long-term conditions in Manchester within the context of devolved health and social care budgets and integrated services.
- **RO2**: To develop knowledge of what is working well for the older adults in Manchester and how can continue to deliver this.
- **RO3**: To establish a participatory approach accessible to chronically ill older adults.

- **RO4**: To explore how older adults could contribute to the ageing in place agenda.
- **RO5**: To inform future direction and provision of health and social care for chronically ill older adults in Manchester.

1.3 Positionality

Early in my research journey, I wrote in my reflective journal:

> "I do not feel like an insider or an outsider on this topic. I am young and healthy therefore not part of this community. However, I have spent my entire life both personal and professional with people who are both older and with long-term health conditions. Does this constitute intrinsic knowledge? I don't know"

I struggled for several months with how to define my positionality and as a novice researcher, I needed to situate my position within this study before I began to research with others. At a surface level, I have no lived experience to relate to the participants. I am not an insider researcher in the traditional sense of being a member of the community (Kirpitchenko and Voloder, 2014). However, neither can I approach this research with the blank slate impartiality considered of outsider researchers (Dwyer and Buckle, 2009). This internal conflict is reflected in the work of Merton (1972) who proposed that traditional insider/outsider labels were often characterised too rigidly. Both Merton (1972) and Hellawell (2006), consider an insider to be a person with intimate prior knowledge of a community as opposed to necessarily having to be a member, something I reflected resonated with me and my position in entering this research.

The choice to declare research interests is personal to the individual whether consciously or not (Finlay, 2003). As a researcher, I am inspired and informed by my professional experiences as a health and social care worker, and my personal experiences of close relationships with my grandparents. In line with the reflexive nature of constructionist research and influenced by Hellawell (2006), I will weave personal reflections throughout this research to scrutinise my motivations and any underlying bias (Noble and McIlveen, 2012). Drawing on my social constructionism lens and thoughts (that I consider in Chapter Three) and in agreement with Burr (2015), I as the researcher, will be part of the data. Thurairajah (2019) suggests that I should, therefore, continually examine my writing and role in the research to challenge my assumptions where they might skew the data towards a certain direction.

Professionally, I have spent seven years working between health and social care services in the North of England between 2014 and 2021. For two years, I was a care worker in a nursing home caring for both adults and older adults with a variety of health conditions and specialised in caring for those at the end of their lives. Following that experience I spent five years working in the NHS as a general healthcare assistant, and then as a specialist palliative and end-of-life healthcare assistant. Although I have not worked in a social care setting since 2016, I find myself reflecting often on my experiences there and the people I cared for. The sector continues to face extreme pressure on many fronts (Glasby, 2020), and it was not an easy job to work with given the insufficient staffing and low wages. However, as a result, I remain to this day a passionate advocate for improvement and support for social care. Additionally, my undergraduate dissertation was inspired by my work in social care and evaluated the impact of emotional labour on care workers. Framed against the austerity agenda (Hoddinott et al., 2022) and the low-skilled status of care workers in UK society (Bottery, 2020), in retrospect I realise my undergraduate study contributed to the deficit-oriented narrative prominent in health and care research. Although working thirteen-hour days without breaks and being short on staff meant that we were more often firefighting than caring, I remain fondly attached to the people I cared for and with and treasure the genuine moments that happened along the way. I struggled to find accounts of working or being in care that were positively framed and was driven to change this.

As I moved to work in the NHS, I remember the shock of how different the work culture was. Although as busy as social care, the role prioritised health and independence over the small caring roles I had come to know. However, between both health and social care roles the prevalent narrative has been one of illness, dependency, and reliance on services. Reflecting on this, I realise that aside from seeing my grandparents, all my interactions with older adults have been within the constraints of formalised health and social care services. I enter this research aware that my perspectives of ageing with long-term health conditions are likely framed by an acute exacerbation of symptoms as witnessed in health and care settings, rather than everyday reality. I wrote in what would become my reflective journal:

> ‘I am thinking, reading, writing much about services. I expect that this will be a prominent theme. But do I? would I be surprised if this is not the case?’

I have significant personal experience of ageing and health from close relationships with my grandparents. In exploring my motivations for this research, I turn towards how I have constructed my views of older adults and recognise how contact with grandparents is significant in this respect (Flamion et al., 2019). Academically there has been much debate surrounding the quality of contact with grandparents as opposed to length of contact in terms of shaping a young person’s views of older adults (Flamion et al., 2019). I spent a considerable amount of time with my grandparents both as a child and an adult and was fortunate to have two great-grandparents until adulthood. The close relationships I have enjoyed with my grandparents have shaped my views on both older people and living with long-term conditions. All my grandparents have experienced significant health concerns but approached health and ageing in different ways. My paternal grandparents are twenty years older than my maternal grandparents yet remained independent with a positive outlook. Grandma (paternal grandmother) had lifelong physical complications from having a hereditary neuropathic condition in addition to complications from polio as a child. She had one ankle fused at a 90-degree angle, needed specialist orthopaedic shoes to stand, and was unable to stand for prolonged periods. My Pa (paternal grandfather), had glaucoma, hypertension, requires blood thinners, had chronic kidney failure, and needed surgery on both knees and his spine due to degeneration and wear on the joints. Despite this, they lived very independently in their own home without any care. Their outlook was broadly positive, and they made the most of every opportunity, continuing to seek new experiences, enjoy lifelong hobbies, live active social lives, and remain in their own home until the end.

My maternal grandparents had different experiences. At the start of this study in 2017, they were both in their late sixties and therefore significantly younger than my paternal side. My granny, diagnosed blind approximately ten years ago, had type 2 diabetes, chronic kidney failure and glaucoma. Her conditions were due to her lifestyle and could have been prevented or reversed at the point of diagnosis. At the beginning of this research journey, Granny experienced several falls exacerbated by her health conditions from which she did not recover physically or mentally. She spent the last two years of her life in a nursing home.

Starting on this research project I believed that my motivation to engage with this topic came from my professional experiences. However, as I began my reflective journaling process, and started exploring my positionality I realised the weight of my personal experiences within my own family. I have been raised between three sets of grandparents, all very different, yet all an important part of my life. Equally, the disparity between how they have approached ageing and health intrigued me and this research is as much inspired by them, as any of my other experiences.

Ageing has always been a prevalent theme of my ‘academic life’, and I have moved between viewing ageing as a stigma and understanding its asset-based potential. Firstly, that of ageing as a stigmatised condition, of burden and need, influences my assumptions of ageing as being a negative experience for older adults (Corner et al., 2007; Schroyen et al., 2022). Secondly, asset-based practice and community empowerment for changing the lives of older people (Daly and Westwood, 2018; Russell, 2011). The literature I engage with, although endeavouring to facilitate change for good is frequently underpinned by stigma, ageism, and power issues (see for example, Cookson et al., 2016; Eriksson et al., 2019; Porter et al., 2020). I would be left feeling frustrated by the conclusion surmising of long lists of improvements the writers felt were needed (Carrier and Newbury, 2016; Eriksson et al., 2019) and yet were rarely actioned in practice due to a systemic lack of funding, support, and staff. I set out in this study to change this, wanting a conclusion that would reflect the good aspects and not just the inevitable need for change. However, I also wanted to do justice to my grandparents, who have shown me that ageing in place can be done and that it can be done well. Continually monitoring my assumptions as I undertake this research is important to me. To improve research rigour, provide context for decisions and explore pre-existing thoughts I will utilise a reflective diary (Snowden, 2015). By weaving my reflective process throughout this final thesis, I hope to allow the reader to understand my frame of mind when making observations and drawing conclusions, this is discussed further in my methodology chapter.

I have always known that I wanted to study and work with older adults, however, defining who I would consider an older adult was problematic. Using the national retirement age would be problematic as the age is different for different age groups in the UK but also differs hugely globally. The NHS defines an older person as being 65 or over (NHS England, no date). However, throughout this study, I will refer to and consider an older person to be over 60, which is consistent with the World Health Organisation (WHO: 2002).

I now turn to the setting where the study took place.

1.4 Greater Manchester as the Setting

Greater Manchester (GM) is a region in the north-west of England, comprising ten local authority areas. It has one of the UK's most diverse populations (Bullen, 2016), and is the only English city outside of London with all ninety ethnic groups as citizens (Bullen, 2016). It is well-established that the UK population is ageing at unprecedented rates, with huge increases in the number of older adults expected by 2050 (ONS, 2019b).

Greater Manchester, however, represents an anomaly amongst UK ageing data, anticipating only marginal rises in its older population (Bullen, 2016; Wall, 2021). This has largely been attributed to the fact that Greater Manchester has the largest student population in the UK and is centralised around a large youth culture (HESA, 2019). Health data reveals that Greater Manchester's older adults are in significantly poorer health than the remainder of the UK (Bullen, 2016; Wall, 2021), suggesting that even though they represent a relatively minor percentage of the population there are still significant health and social care needs to be addressed for this age group; evidenced by significant numbers of long-term health conditions and by deprivation indices (Manchester City Council, 2019).

Contemporary data estimates that 50,000 Greater Manchester (GM) older adults live in poverty with inequalities continuing to grow (GMCA, 2018a) contributing to poorer health and wellbeing outcomes (Centre for Ageing Better, 2017). At the time of writing Manchester City is currently ranked as the fourth most deprived local authority with over a third of people aged over sixty living in poverty (Wall, 2021). Significant evidence suggests that this is due to a combination of factors from the Government's austerity agenda (from 2010) under David Cameron, the North/South divide, and growing social, economic and health disparity during the covid pandemic (Beard et al., 2017; Centre for Ageing Better, 2017; Dorling, 2018: Wall, 2021). Greater Manchester also ranks in the lowest five areas nationally for life expectancy and healthy life expectancy (Bullen, 2016; Wall, 2021). Older adults in GM are more likely to require support from health and social care services based on deprivation and health outcomes. However, half of all older adults in the area are renting their homes (of which 90% are renting social housing) (Bullen, 2016). Therefore, older adults in GM are likely to have fewer assets to self-fund care as they enter older age and rely increasingly on local authority support.

In 2015, Greater Manchester was granted devolved status from the central UK government in an experiment to tackle the widening inequalities and to bring the budgets together (Walshe et al., 2016). Subsequently, control of public responsibilities including transport, health, social care, planning, and housing was handed over to the newly formed governance of Greater Manchester Combined Authority (GMCA) (Walshe et al., 2016). GMCA identified 10 key areas of improvement [Figure 1.], with ageing and health outcomes taking precedence. Resultantly, the GM ageing hub was established to improve the lives of older adults in GM and in 2018 the area was awarded the title of the UK's first age-friendly region (GMCA, 2018b).

Figure 1. The GMCA 10 Priorities (GMCA, no date: Online)

The 2021 White Paper ‘Integration and Innovation’ (DHSC, 2021) explicitly stated that the current government expected local areas to develop their own models to meet local challenges. In Greater Manchester, this has come as part of the GM Integrated Care System (2022) which aims to bring together different organisations across the borough to improve access and patient outcomes. However, this partnership has gone live after the data collection for my study and therefore, is not reflected in the findings or discussion. This study will, however, focus solely on Greater Manchester to create tailored local proposals for change that will sit within the existing umbrella of ageing challenges identified by GM Ageing Hub and GM Integrated Care Systems.

1.5 Ageing Populations

The global population is ageing, and current estimates predict the number of older adults worldwide will double to 1.5 billion by 2050 (UN, 2019). In the U.K., the current number of older adults is also expected to double in the next 25 years to 22.4 million (ONS, 2018) [see Figure 2]. Contemporary data suggests that while life expectancy has broadly plateaued (ONS, 2021), the number of centenarians is continuing to rise at unprecedented rates (Robine and Cubaynes, 2017). Furthermore, the number of people living over the age of 85 has doubled in the last 50 years, with predictions suggesting that this number could double again by 2041 (ONS, 2018). The rising number of older adults in the UK is associated with increased pressures on health and social care services, the economy and housing (Robinson et al., 2020), creating significant interest from policymakers, service providers and communities. The predicted uprises in population ageing were, however, questioned in the wake of COVID-19. Evidence emerged rapidly that older adults were adversely affected by COVID-19 in comparison with the rest of the population (Verity et al., 2020), with higher rates of severe symptoms, mortality and long COVID (Levin et al., 2020). Additionally, research indicates that there were approximately 85,400 excess deaths in 2020, indicating significant population changes in all age groups. At the time of writing, there is no published evidence to suggest that the impact of the pandemic will lead to changes to pre-pandemic population ageing projections.

1.6 Delivery of Health and Social Care for Older Adults

Decentralised models of social care are dominant across Europe (Sheard et al., 2017), and emerging in the UK with both health and social care funding and decision-making being handed over to devolved local governments (Chapman, 2018). As detailed in section 2.0 devolution has spread to a regional basis in some areas, following a growing consensus that those who live in the community in question, know what that community needs best (Pemberton et al., 2015; Pierson, 2008). This aligns with current political trends moving towards community care (Glasby 2017) and personalisation

(Needham, 2011; Tetley et al., 2018) and was explicitly mentioned in the 2021 White Paper Innovation and Integration (DoHSC, 2021b). The resulting legislation from this, the Health and Care Act (Department for Health and Social Care, 2022) has built on these themes to establish legislation around integration and focuses on place and localising support. Consequently, co-productive approaches to building social capital and localised change have dominated contemporary thought on service delivery (Vanleene and Verschuere, 2018). However, in England, social care is modelled on a quasi-market (Baxter et al., 2019) dominated by for-profit providers (Glasby et al., 2020; Williams et al., 2014) with the need for profit eclipsing the wider needs of the community (Blakely and Quilter-Pinner, 2019). However, the White Paper Innovation and Integration (DoHSC, 2021b) has set out the repeal of the internal market within the NHS though it remains unclear whether social care will follow suit.

1.7 Political Background

As a major 21st-century challenge, successive UK Governments have attempted to respond to the rapidly ageing populations and their associated challenges (Binstock and George, 2006; Walker, 2018). However, a contemporary definitive policy on ageing is yet to emerge (Walker, 2018). Instead, policies concerning older adults are frequently combined with a wider health and social care agenda, given this group is well established as being the primary consumers of health and social care services (Lloyd and Heller 2012; Timonen, 2008; Yarnell et al., 2017). Unsurprisingly, the UK tends to value ‘successful’ ageing in terms of health rather than in combination with wider socio-political factors (Walker, 2018).

Social care is also a significant challenge across the political divide and when I began this study in 2018, social care was widely considered to be in ‘crisis’ (Glasby et al., 2020; Green, 2017). Social care has been struggling under a near decade of austerity since 2010 (Levitas, 2012) and is lacking a clear policy on how to improve and sustain the sector. In the last 20 years, various Labour, coalition and Conservative Governments have published three core White Papers aimed at reforming health and social care for older people. These are the National Service Framework for Older People (DoH, 2001), Caring for our Future (DoH, 2012), and Innovation and Integration (2021). Caring for our Future (DoH, 2012) set out an ambitious reform strategy including, promoting independence, putting the service user in charge of their care, providing better housing, and valuing informal carers (DoH, 2012). However, the paper came under heavy criticism for failing to acknowledge social care and address how the reforms would be funded, particularly against the background of harsh austerity measures (Glasper, 2012; Hughes, 2012b).

In the intervening years, the problems with funding support for older adults have become increasingly apparent and led to the announcement of a social care Green Paper for older adults in 2017 (Cabinet Office, 2017), followed by a White Paper in 2021. Whilst the green paper announcement was generally well-received (Age UK, 2019a; Dean, 2019), it remains subject to repeated delays and subsequently is thought to have been abandoned in favour of the 2021 proposed White Paper (Jarret, 2019).

In 2019 the Johnson-led Conservative government won significant support with a manifesto claiming that they were going to ‘fix social care’ with a plan that they had already prepared (Campbell, 2019). The crux of the 2019 promises was a cap on care costs to prevent the selling of homes to pay for care, and in 2021 it was announced that a care cap would go ahead (UK Government, 2022a). The care cap was proposed alongside an amended means test requiring everyone to pay £86,000 (UK Government, 2022a). A flat means test would mean those with less money, but less need would be paying much more for care over a longer period before they could access support. Additionally, houses and assets would still need to be sold as a smaller percentage of the population would have access to £86,000 unless in property or other assets (Warren, 2022). Rather than reducing inequalities, this policy seemingly is contributing to them and has led to delays in the introduction of a cap. A second attempt by the Johnson government to fix social care came in the form of a National Insurance Levy. It was introduced in April 2022; however, the majority of funds were redirected to the NHS (Murray, 2021). The levy was cancelled only a few months later by the successive

Truss government (UK Government, 2022b) which continued the contemporary trend of policy makers failing to commit to a stable and sustainable policy.

Most recently in 2023, an open consultation on a workforce pathway for adult social care has been announced which included reduced or unmentioned figures previously promised to help the sector (DoHSC, 2023; Cooney, 2023). At the same time, public satisfaction with both social care and the NHS is at an all-time low and workforce vacancy is at an all-time high (The Kings Fund, 2023). The UK Government has in April 2023 published a reform plan for UK social care (UK Government, 2023b). However, within 12 months two local authorities had declared bankruptcy (Institute for Government, 2023) and there remains at the time of writing a paucity of evidence demonstrating ground-level change. This all draws together the conclusion that the current government in England is lacking a clear and comprehensive policy on ageing and health and social care.

1.8 Implications of Policy and Practice for Population Ageing in the UK

My study is based in England, and here I will focus on the implications of policy and practice within England and the UK. Population ageing in the UK has multiple implications for society and represents previously unseen pressures (Colombier, 2018). For example, a primary concern is the economic impact of ageing populations (Naegele and Walker, 2007). The ratio of older adults to working-age adults is set to increase over the coming years representing a decreasing workforce (Foster, 2017), with a lower proportion of people available to pay taxes, work, and care for those who need it (ONS, 2019a). Current Conservative-led policy has focussed on increasing the retirement age as a means of controlling the proportion of adults in the workforce (Naegele and Walker, 2007). However, extensive research has shown employers have a negative bias towards hiring and retaining older workers as well as accommodating any additional health needs associated with older age (Centre for Ageing Better, 2021a).

Population ageing is also closely associated with poorer health outcomes (Clarke and Bennett, 2013), older adults are considerably more likely to have long-term physical health needs and disability (Porter et al., 2020). Contemporary research indicates that the need for services is rising, with approximately 1.9m requests for care in 2020 (NHS Digital, 2021), but that health and social care spending is not rising in line with the need (BMA, 2023a). Research outcomes suggest that growth in unmet needs is reflected in the rising numbers of informal carers, predominantly spouses who are themselves older adults (Binstock and George, 2006; Bottery, 2019; Glasby et al., 2020), and has identified that being an older informal carer comes with significant mental and physical implications (Dury, 2014; Greenwood et al., 2019). Additionally, the link between older age and declining health has profound implications for housing (Abramsson and Andersson, 2016). Research indicates that older adults are disproportionately likely to be living in unfit or non-decent housing (Centre for Ageing Better, 2020). Whilst alternative living options are becoming more varied, in the UK older adults predominantly choose from three options; making do, residential care, or sheltered and/or specialist accommodation (Robinson et al., 2020). Literature on ageing in place is continuing to expand, and therefore, this research seeks to address gaps in what older adults themselves feel is positive about ageing in place and what is helpful to them in this endeavour.

1.9 Chapter Summary

In this chapter, I have explored my personal motivations for undertaking this research and have explored the political and social background of my study while situating it within Greater Manchester. I have given an understanding of how ageing is a multifaceted challenge and considered the current UK political background to this. I have also outlined the challenges that the intersection of ageing and long-term health conditions has on multiple aspects of society. In completing this study, I aim to contribute to understanding what works well to support ageing in place with long-term health conditions. In the next chapter, I will explore existing literature on the research background of ageing in a UK context and long-term health conditions. My study will explore what older adults want and what they find helpful and supportive. It also contributes knowledge to whether what matters most is situated in structural and formalised services, or community and informal support. The next chapter will consider the relevant literature that has underpinned this study and highlight were deficits in knowledge currently occur.

Chapter Two: Literature Review

2.1 Chapter Overview

Since the 1990s there has been a significant growth in ageing research globally, and the number of gerontological journals has expanded rapidly (Warnes and Phillips, 2007). Whilst this body of research is diverse and interdisciplinary, it is widely accepted that the number of older adults is set to grow substantially (WHO, 2022), and with older age comes poorer health outcomes resulting in greater demand on health and social care services (Carrier, 2016; Porter et al., 2020). It is also accepted that the majority of older adults seek to age in their existing homes or communities (Chapman, 2019; Corneliusson et al., 2019). In this literature review, I consider the underlying evidence for the above points and the increased demand ageing populations place on society and resources. In addition to examining evidence and research about ageing, health and ageing in place, this chapter will also consider relevant literature on the COVID-19 pandemic and its impact on ageing populations. The breadth of literature on ageing and LTCs is extensive, creating difficulties for systematic searches. I addressed this by developing an iterative approach and applying alternative literature search strategies including reviewing reference lists, citation searching, hand searching and including grey literature. The literature in this chapter is almost exclusively from the global north. This focus is intentional as it is closely related to my study location in Greater Manchester in the UK. However, I appreciate that there are other definitions of ageing in place and ageing in the community with LTCs across the global south that could also offer value to this study (see for example, Brosius and Mandoki, 2020; Villena-Sanchez and Boschmann, 2022).

My study will contribute to knowledge by exploring what works well for older adults. There are currently limited studies using appreciatively informed methods to understand what is working well, however, they are often concerning specific concepts or areas outside of the scope of this research. For instance, appreciative methods are well integrated across the field of nursing (see for example Curtis et al., 2017; Jack et al., 2019b) but not necessarily about older people and managing health in the community. Additionally, there is extensive literature on asset-based community development (ABCD), however, the nature of this research was about how people could contribute to the wider community rather than their construction of what is working well (See: Klee et al., 2014). This literature review provides an overview of current relevant literature to the over-arching themes of ageing and long-term conditions and where possible interweaves existing findings on what is working well.

2.2 Ageing in a UK context

In chapter one, I located ageing as a challenge for policy makers, services, and communities. The literature review and political context have supported my belief that ageing in place has become a core policy focus as a means of supporting older adults whilst reducing systemic pressures on the health and social care system. However, ageing in place is not a straightforward solution and there is a lack of coherence on what it looks like, as I will explain. Additionally, as previously mentioned, the enormity of literature published on ageing in homes and communities is daunting and impossible to completely evaluate. Therefore, in this chapter I will critically examine the literature on ageing in a UK context, exploring what ageing in place means in the UK, and how the current political agenda reflects this.

2.2.1 Ageing in Place

Increasing research narratives have focussed on ageing in settings, places, and spaces (Andrews and Philips, 2005; Abramsson and Andersson, 2016; Brim et al., 2021). From this has grown the development of the concept of ‘Ageing in Place’ (AIP), which explores the experiences of older people who seek to age in their own homes or communities (Sixsmith et al., 2017). However, the underlying motivation to pursue ageing in place is varied and contested. Research both globally and in the UK, has concluded that older adults would prefer to remain living in their own homes or communities as opposed to residential care (Corneliusson et al., 2019; Lewis and

Buffel, 2020; Sixsmith and Sixsmith, 2008). Additionally, it is indicated that preferences for AIP stem from a fear of residential services compounded by systemic and long-standing issues within the social care sector (Chapman, 2019), which is explored later. However, there is evidence to suggest that older people, particularly those with health conditions, are open to moving but are restricted by a lack of knowledge, affordability, and availability (Brim et al., 2021; Robinson et al., 2020).

A common presumption of contemporary research on AIP is that it assumes AIP to be a long-term goal, rather than a reflection of a person's current living arrangement or a short-term goal (See: Brim et al., 2021; Sixsmith et al., 2017; Vanleerberghe et al., 2017). This is problematic as extensive evidence suggests that a significant barrier to AIP is the suitability of a home in the context of poor health, disability, and accessibility (Sixsmith and Sixsmith, 2008; Ouden et al., 2021). In conjunction with this, Pani-Harreman et al., (2021) identified that there is a non-consensus on where exactly we mean by place in ageing in place. Though not universal, there is a tendency in research to assume AIP refers to an individual's current place of residence (See Brim et al., 2021; Lewis and Buffel, 2020; Means, 2007). Therefore, research that works on these assumptions does not account for whether the long-term goal of an individual is to AIP or whether it is an ideal or only a smaller part of what older adults want. Additionally, it overlooks the agency and self-introspection older adults possess about their health and abilities. There is extensive literature exploring why older people may resist various aspects of ageing, but little on how they might plan their living arrangements for future ageing challenges. Evidence does exist to support that housing options for older people wanting to make these choices are at best limited and subject to regional disparity (Abramsson and Andersson, 2016; Robinson et al., 2020). The Social Care White Paper (2021) sought to address this gap by announcing £300m to build supportive housing for older or disabled people. However, a 2023 call for feedback on the paper lacked any mention of it and draws in to question the reliability of whether the money or housing will materialise (Cooney, 2023).

Politics is a significant driver of the AIP agenda, informed by an urgent need to meet the challenge of population ageing and its associated implications for services and wellbeing (Brim et al., 2021; Sixsmith and Sixsmith, 2008). In the UK this includes neo-liberal political motivations to improve population health and reframing the home as a long-term space of care for economic benefit (Aspinal et al., 2016; Lewis and Buffel, 2020). This is underpinned in the main, by rising concern over the cost and availability of care (Lewis and Buffel, 2020), which has driven a demand for new and extended community services and housing options. The move away from high-cost and reactive institutional care (Robinson et al., 2020) is a trend that is replicated globally (Dobner et al., 2014; Stones and Gullifer, 2016) drawing on the dominant social research narrative of communities, most notably experienced in Scandinavian countries (Aidukaite, Hort and Ainsaar, 2022). This neo-liberal, laissez-faire agenda is favoured by contemporary UK governments including the current Conservative government which has been in power since 2010. Consequently, ageing in place is frequently framed in the UK as a strategy for diverting older adults from reliance on the state and reducing government expenditure (Graybill et al., 2014; Pierson, 2008). However, it is reliant on a strong health and social care system which the evidence reviewed here suggests the UK is lacking. The associated problems within health and social care services are explored later in this chapter. Here it should be noted that widespread inequality and a lack of systemic ground-level change are impeding the success of ageing in the community, leading to increasing demand for informal carers (Glasby et al., 2020).

Despite questionable and variable motivations for ageing well in place, it remains a consensus amongst academics and policy makers that everyone benefits from being and feeling healthy, choice is imperative in the wellbeing of older adults, and support should be available and accessible if the preferred place of care is a service user’s own home (Baxter, et al., 2019; Board and McCormack, 2018; Sixsmith et al., 2017. There are a plethora of research outcomes supporting this, indicating that AIP contributes to improved wellbeing, greater advocacy, control, and individuality (see for example, Aspinal et al., 2016; Corneliusson et al., 2019; Vanleerberghe et al., 2017). However, research has also indicated that ageing in place can be a negative experience leading to isolation, and poor health and wellbeing outcomes (Sixsmith and Sixsmith, 2008). This is particularly apparent when policies, services and environments fail to meet the needs of older people. The link between advancing age and increasing rates of chronic illness is well-established both in the U.K. and globally (Chapman et al., 2018; Radley, 1994; Yarnall et al., 2017). This means there is concern over the suitability and safety of ageing at home with long-term physical health conditions (Means, 2007; Stewart et al., 2014). Furthermore, some studies expect older people to be able to predict future needs (see for example, Aspinal et al., 2016 Robinson et al., 2020), thus failing to account for the unpredictability of long-term conditions, which can onset without warning and deteriorate quickly, questioning the long-term viability of AIP This has limited the growth of required services, as the cost-benefit ratio is unclear and contested (Sixsmith and Sixsmith, 2008).

Research on AIP is wide-ranging, intersecting with a plethora of social research trends such as care responsibilities (Chou and Kröger, 2020; Vreugdenhil, 2014), fear of institutional services (Chapman, 2019; Pierson, 2008; Timonen, 2008) and technology as an enabler to independent living (Carnemolla, 2018; Kim et al., 2017; Tsertsidis et al., 2019; Wang et al., 2019). The dominant narratives from these research topics were barriers to AIP including health and access to appropriate care (Sixsmith and Sixsmith, 2008; Ouden et al., 2021) and health outcomes (Corneliusson et al., 2019; Michael and Yen, 2014). This was also evidenced in the World Health Organisation's (2022) statement on ageing and health and more locally in the GMCA Age-friendly strategy (2018). However, many of the papers and policies fail to encapsulate the limited agency older adults have over the choice of living arrangements, particularly in the wake of poor health. Additionally, whilst AIP is well documented in terms of preferences and barriers, there is a paucity of evidence to suggest what the older people themselves feel they need. In particular, there is little written and researched on what older adults feel is the most supportive and important to enable ageing in place, and why. Therefore, the overall aim of my study is to address this gap and explore the positive experiences that are frequently absent from established literature.

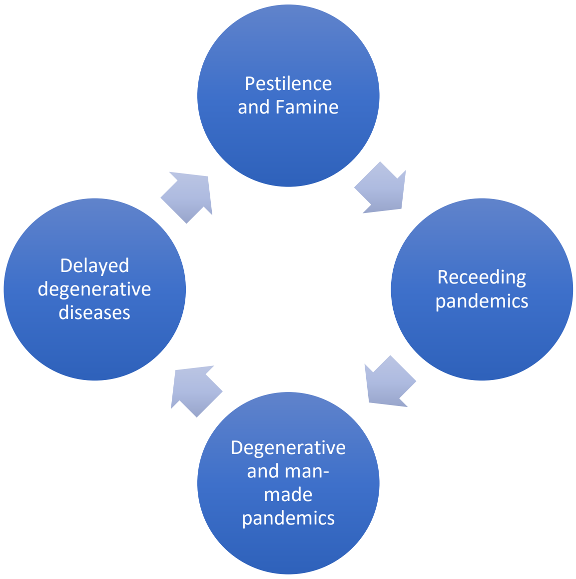
2.3 Older Adults' Health and Wellbeing

Long-term health conditions are closely associated with older age and present a difficult addition to the challenge of ageing populations (Clarke and Bennett, 2012; Porter et al., 2020). The previous section has established that health is a primary barrier to ageing in place and therefore, maintaining good or stable health for as long as possible is key to promoting ageing in the current environment. However, the previous chapter also asserts that health is fickle and prone to change particularly in older age, therefore, having a significant bearing on where and how we age. The literature surrounding health and long-term conditions amongst older adults is again insurmountable for this study. Therefore, this section will explore select areas with relevance to the study and the aim of exploring what works well in the context of Greater Manchester. I will start by considering what good health is by exploring how we measure life expectancy and the differences that are apparent just within a UK context. This section will then explore the context of living with long-term health conditions before accounting for literature on health inequalities, relating this to policy and Greater Manchester as the site of this research.

2.3.1 Measures of Life Expectancy

Demographic changes are used as evidence for extensive research projects, for this research it is necessary to consider the long-term and short-term shifts in population mortality (Katzmarzyk et al., 2020). A profound reduction in mortality has occurred over the last century and created a dramatic increase in population numbers. The causation of this is well explored in literature and is attributed to widespread public health improvements and the development of preventative health measures, notably vaccines (Lunenfeld and Stratton, 2013). The epidemiological shift or transition is a model used to define the changing population mortality trends (Figure 3.). However, despite it being a four-stage model, society has failed to effectively plan for its circular form (see Figure 3. Below) and its predicted likelihood of a global pandemic as seen with the Covid-19 outbreak.

Figure 3. (Adapted from: Katzmarzyk et al., 2020)



At the commencement of this study, the UK and global north had effectively eradicated infectious diseases and instead developed a strong focus on non-communicable diseases in both research and policy (Barry and Yuill, 2016). Consequently, total life expectancy (TLE) has established itself as the primary tool for indicating a society's health and longevity (Modig et al., 2020). Increased life expectancy (TLE) on the scale seen over the last century is considered a defining achievement of humankind, however, with it has emerged the rise of ageing populations and age-related diseases (Lunenfeld and Stratton, 2013). In the 20th century, long life and health showed a significant correlation, this is no longer the case in the 21st century society. Contemporary evidence suggests that the older we get, the more likely we are to experience chronic conditions (Carrier, 2016). Therefore, long life no longer automatically equates to a healthy life (Kuh et al., 2014; ONS, 2019a). Current UK TLE is 79 years for men and 82.9 years for women (ONS, 2021) representing for the first time in decades a slight decrease.

With the outbreak of the COVID-19 pandemic in 2020, existing thoughts on demographic changes, epidemiological trends and TLE need to be re-examined. The health and care system in the UK had evolved from treating single infectious diseases to managing long-term conditions and now needed to revert to a programme of managing infectious diseases (Katzmarzyk et al., 2020). However, unlike in previous generations, contemporary health and science were able to rapidly develop and implement public health measures including vaccines to mitigate the impact. There remain several considerations for future research. Firstly, whether the theory of epidemiological transition remains relevant. The 20th-century terminology is problematic and implies that famine and pestilence are invariably interlinked. Additionally, it fails to account for intervention and socio-economic influences, implying that all areas of global populations are at equal risk and will follow the same cycle length. COVID-19 was the first large-scale pandemic in the UK for 100 years, and evidence indicates that whilst not a disease of the poor, there is a significant link with poverty (Whitehead et al., 2021). Secondly, early evidence suggests that covid has had a significant impact on TLE, and contributed to an overall reduction in life expectancy (Lacobucci, 2021). This initial data indicates a variability in life expectancy across the UK suggesting regional inequalities may be a factor. However, exploring TLE on its own fails to account for how and why these inequalities exist or why a pandemic may impact one area more than another.

Healthy life expectancy (HLE) is a measure used to estimate the number of years a person can expect to live in good health (Wood et al., 2006). TLE and HLE measures come under criticism for isolated use, but as a combined tool they provide statistically significant indicators of inequalities in health (Steel et al., 2018; Storeng et al., 2017), deprivation (White and Edgar, 2010; Wood et al., 2006), and ethnicity (Levine et al., 2001; Wohland et al., 2015). In the Office for National Statistics (ONS) 2018 data set, life expectancy in the UK was 79.2 for males and 82.9 for females, however, the healthy life expectancy was 63.1 for males and 63.6 for females. Research estimates that we can currently expect to spend 20% of our lives in poor health (PHE, 2017). HLE has been a driver of health policy for many years however, the latest data release reveals that there has been no significant change to overall health during this time (ONS, 2022a). ONS has also started collecting data on disability-free life-expectancy (DFLE), which since inception has only shown a downward trend. Using the three tools in collaboration it is evident that people are living longer but in poorer health, and significant inequalities exist across the country (Table 1).

Table 1: Differences in LE/HLE/DFLE measures

	Male LE 2018-2020 (Change in years since 2015-2017)	Female LE 2018-2020 (Change in years since 2015-2017)	Male HLE 2018-2020 (Change in years since 2015-2017)	Female HLE 2018-2020 (Change in years since 2015-2017)	Male DFLE 2018-2020 (Change in years since 2015-2017)	Female DFLE 2018-2020 (Change in years since 2015-2017)
UK	79 (-0.2)	82.9 (0)	62.8 (-0.3)	63.6 (0)	62.0 (-0.8)	60.7 (-1.2)
North West	77.9 (-0.3)	81.7 (-0.2)	61.5 (0.3)	62.4 (0.2)	60.2 (-0.2)	59.1 (-1.1)
South East	80.6 (0.2)	84.1 (0.1)	65.5 (-0.6)	65.0 (-0.2)	64.3 (-1.0)	63 (-1.0)

(ONS, 2021; ONS, 2022a)

Comparing the North-West of England with national figures and the South-East, as the most affluent region of the UK (ONS, 2022b), demonstrates significant inequality. However, the data is unable to account for the significant lifestyle, and individual and environmental factors that can determine each expectancy measure. The remainder of this chapter will explore the incidence and prevalence of LTCs and the literature surrounding health inequalities to consider the impact this has on an individual.

2.3.2 Long-Term Physical Health Conditions

The terminology ‘disease’ and ‘illness’ are often used interchangeably, however, the seminal work of Friedson (1978) contested that there is a tangible difference between the two. Disease is a pathological process and is often considered objective, with a presence we may be able to see, touch or measure (Boyd, 2000). Alternatively, illness is more often the experience of being unwell, and despite frequently co-existing with a disease, it also exists independently of it. This distinction allows us to recognise that whilst several individuals may have the same disease or symptoms, their experience of illness can vary (Porter et al., 2020). A growing body of research has dedicated itself to understanding the experience of being unwell, however, this is often framed by a specific condition rather than exploring the experience of wider society (See: Cheraghi-Sohi et al., 2019; Tan et al., 2023). It is accepted that where and how we live has ramifications for our health and wellbeing, particularly as we age (Lewis and Buffel, 2020). Expanding existing research to account for locality on how illness is experienced amongst particular communities is essential to developing area-specific strategies. This would coexist with the growing devolution movement across the UK to understand how commissioning and services could improve wellbeing (Wright and Simpson, 2020).

How we understand and experience illness is also shaped by the nature of the illness itself, acute illness often presents suddenly and lasts for a comparatively short time. A chronic or long-term condition, however, can onset abruptly or over a period of time and it can have constant symptoms, periods of remission or fluctuate (Cheng et al., 2020; Porter et al., 2020). Globally, there is some inconsistency amongst what constitutes a long-term condition (Schone, 2019). However, in the UK both the NHS and policy makers have adopted a wider description, defining chronic or long-term conditions as health conditions to be managed but not cured. Consequently, it is widely accepted that chronic conditions become part of an individual's identity and shape their wider life experiences (Clarke and Bennett, 2012; White et al., 2016).

Accepting or adjusting to a lifelong condition can be difficult given the implications it may have for every aspect of a person's life. Firstly, the language used to refer to a condition that is chronic or long-term is contested and variable (Green, 2009). In response to the epidemiological shift (see section 2.2), the term 'chronic patient' was popularised in the UK in the 1990s (Radley, 1994). There isn't a set consensus on how to refer to non-acute illnesses and those who experience them. Various groups indicate a preference between long-term or chronic, and condition or illness. More recently, the terms morbidity and multi-morbidities have taken precedence, particularly in healthcare research (Banerjee, 2015; Bramley and Moody, 2016). However, I have chosen to use the phrase 'long-term conditions' (LTC) in line with current NHS and social care discourse (Khunti et al., 2023). Part of this decision concerns avoiding the term 'illness' which excludes those with disabilities (Radley, 1994). The contested nature of disability mirrors the ongoing debate around long-term conditions (Green, 2009; Schone, 2019). In some instances, acute health concerns such as a broken bone can leave a person temporarily disabled, however, the UK Equality Act (2010) contends that a disability must be substantial and long-term. Although each person with a disability or LTC will have unique experiences, they will also have a shared experience of manging the incurable. Despite this, a substantial portion of literature exploring what it means to experience LTCs excludes disability and erases their viewpoint of what is important from their recommendations.

In the UK, 15 million people live with a long-term condition (Chapman et al., 2018) and they currently represent the leading causes of death both in the UK and worldwide (ONS, 2018b). Contemporary research has indicated that the number of people experiencing an LTC is rising every year, and so too is the number of people who are living with multiple LTCs (Owen et al., 2022). 25% of adults are estimated to have two or more chronic conditions (Reeves et al., 2018), but this figure rises significantly to 50 % for people aged over 65 (Kingston et al., 2018). Extensive research has indicated that

LTCs are linked with adverse individual outcomes, including increased mortality rates (Owen et al., 2022), poorer quality of life (Cheng et al., 2020), a higher prevalence of mental health needs (Karakus and Patton, 2011), and increased housing and personal care needs (Lloyd and Heller, 2012). Additionally, LTCs have a significant socioeconomic impact, accounting for 70% of health and social care spending, 70% of inpatient bed days, and 78% of GP appointments, (Eaton et al., 2015:181). With higher hospital admissions and poorer health outcomes, older adults with long-term conditions are the primary users of health and social care services in the UK (Lloyd and Heller, 2012; Timonen, 2008; Yarnall et al., 2017), consequently NIHR, NICE and WHO (2020) have all made this group a research and policy priority (Yarnall et al., 2017).

To overcome the personal and socioeconomic impact of LTCs, understanding the lived experience has become essential. A growing body of literature has sought to explore people's challenges and needs, and the growing notion of self-management (Clarke and Bennett, 2012; Francis et al., 2018; Porter et al., 2020). Self-management has grown from a socio-political environment transferring responsibility from the state to the individual (Clarke and Bennett, 2012). It is regarded as a partial solution to the overburdened UK health system, with the NHS Long Term Plan (2019) prioritising it as a key driver of personalised care. However, Cheraghi-Sohi et al., (2013) have argued that the ability to self-manage is complex and fluctuates due to patient perceived barriers including gender, age and socio-economic status. In addition, it is recognised that the nature of some conditions, particularly among older adults, is impeded in self-management by insufficient energy and agency (Francis et al., 2018). Consequently, there is a significant critique of self-management theories for only partially examining the lived experience of LTCs, framing them with a higher-level of personal responsibility for poor health than can reasonably be ascribed. Resultantly, those who become unwell as they age are increasingly stigmatised and may withdraw rather than adapt to the physical, mental and emotion challenges associated with an LTC (Clarke and Bennett, 2012). Additionally, evidence suggests that rather than improving individual outcomes, self-management strategies push care needs from established services onto informal carers and increase unmet needs. Porter et al., (2020) argue for a greater recognition of embodied knowledge to instead frame the meaning of illness and recognise that people need support to explore the interrelationship between health and its management. The links between embodied knowledge and appreciative or asset-based research have been implied but little data exists to suggest whether this is sufficient to challenge the dominance of problem-oriented research and deliver tangible outcomes.

2.3.3 Health Inequalities

The national disparity in healthy life expectancy (HLE) is explained in part by health inequalities (Garthwaite and Bambra, 2017). Health inequalities are systemic but avoidable barriers causing differences in life expectancy, prevalence of conditions, access to care, quality of care, and wider determinants like housing (The Kings Fund, 2020). Certain groups are adversely affected by inequalities including older adults (Centre for Ageing Better, 2017; Lippert-Rasmussen, 2019; UN, 2018), people of black or minority ethnic backgrounds (Public Health England, 2018; Rao et al., 2010), and those in deprived areas (Davidson et al., 2008; Ellis and Fry, 2010; Garthwaite and Bambra, 2017). This is reflected across the GM population and conclusive with the findings from section 2.0 which identifies the area as experiencing significant deprivation (MHCLG, 2019), poor health outcomes (Bullen, 2016), and is among the lowest life expectancy in the country (Bullen, 2016; ONS, 2018a). Regional divides in health are apparent across the country, but particularly so in the divide between the north and south of the country (see section 2.0 GM as the setting) (Ellis and Fry, 2010; Townsend et al., 2023). This is partly attributable to wealth divides, with wealthier classes experiencing better health outcomes and requiring less health and social care intervention, despite having more and better-quality services available to them (Binstock and George, 2006; Radley, 1994; Townsend et al., 2023).

The impact and reach of health inequalities have been exacerbated by the austerity agenda, which disproportionately impacted the groups already most at risk from it (Bambra, 2019). Health inequalities are closely linked with poor health and wellbeing outcomes (The Kings Fund, 2020), and increased need for health and social care services (Cookson et al., 2016). Therefore, as local authority and national funding for public services decreased, need has seen a sharp upturn (Hoddinott et al., 2022). Consequently, austerity in conjunction with the COVID-19 pandemic has increased NHS face wait times to the largest on record (BMA, 2023b).

2.4 Health and Social Care Services for Older Adults Since 2010

Despite the provision of health and social care services in the UK significantly evolving over the last century (Glasby, 2017; Pierson, 2008), they remain centred on the treatment of singular disease (Kingston et al., 2018). It is generally acknowledged that health services are largely overwhelmed with the management of long-term conditions (Chapman et al., 2018; Eaton et al., 2015), with one in three attendees to Accident and Emergency departments having five or more long terms conditions (DHSC, 2021). Social care has faced its own changes having developed from institutional care (in the form of infirmaries and elderly care wards) to home-based care (Woolham et al., 2017), despite ever-shrinking budgets under the austerity agenda (Glasby, 2020). Significant research demonstrates that older adults with long-term conditions are frequently overlooked and are caught between health and social care services, resulting in fragmented care (Yarnell et al., 2017) and being passed between the two services without experiencing a quality of service (Glasby, 2017). This section will focus predominantly on social care services, which provide a significant portion of the home-based support available for ageing in place. It will then explore health services before critically exploring how both health and social care services are delivered in the UK.

2.4.1 Social Care

This section will explore the dominant narrative on social care in the context of the UK. Evidence suggests that most older people in the UK live independently in their own homes (Pani-Harreman et al., 2021). Yet it is established that older adults are the primary consumers of social care (Glasby, 2017), and as this study focuses on long-term physical health conditions it is likely that some of the participants may be accessing social care. Additionally, as social care has been deinstitutionalised over the last half a century it has become increasingly community-oriented and reflects care at home as the potential site of this research (Vanleerberghe et al., 2017).

Literature has tended to subject social care to a narrow discourse which has often homogenised the sector towards older adults and care homes (Walker, 2018). However, there is growing contemporary recognition that there is an increasing need for social care amongst working-age adults (Bottery and Mallorie, 2023). In undertaking this review, I am aware that the discussion that follows could unintentionally reiterate this stereotype. The breadth of literature on social care is extensive and I am unable to review it all in the confines of this study. Therefore, as the overall aim of this research is to explore what is working well for older adults with long-term conditions the literature reviewed in this section is concentrated on older adults. However, it is necessary to unpack this social construction of older people as the only users of social care. Walker (2018) contends that this is problematic on a number of levels in that it contributes to an ageist narrative of social care, creates barriers to older people seeking help, and others people of working age from using social care. Despite recognition since the 1990s (Friedan, 1993), there is a continued reiteration of ageist stereotypes across political and public sectors (Harper, 2020; Walker, 2018). This is reflected and written about in a wealth of publications, particularly considering the use of ageist images (Thayer and Skufca, 2020), and attitudes to older workers (Centre for Ageing Better, 2021a; Harris et al., 2018). Eastman (2019) considers that this underlying bias is the result of 'compassionate ageism' which socially constructs the idea that older people are passive needers rather than active users or choosers of social care.

Choice is a difficult concept to unpack in relation to social care in theory, there are numerous opportunities to make a choice, including; whether to use social care, which service you may need, which company to use, how much money to spend, how far you would like to travel. However, evidence suggests that older adults, in particular, are disempowered to make these choices through a series of social and structural barriers (Brim et al., 2021; Baxter et al., 2019). Firstly, socio-economic status restricts access to care as individuals from these groups are less likely to have the time, ability, or finances to organise and use social care (Garthwaite and Bambra, 2017) contributing to significant health inequalities. Secondly, structural barriers include a documented lack of information and support, particularly for older adults in making decisions on care. The austerity agenda has meant that funding for social care services has been decimated in the last ten years. Consequently, to access care at home you must have a significant level of need (The Kings Fund, 2023). Literature often focusses on unmet need in social care (See: Brimblecombe et al., 2017; Dunatchick et al., 2019; Vlachantoni, 2019), however, evidence has emerged that older adults may be choosing to live with unmet needs either due to financial constraints or from a fear of social care services (Chapman, 2019; Woolham et al., 2017).

Social care has been negatively perceived amongst the UK population for many years, due to a mix of poor service provision, decreasing availability and widespread media coverage of scandals in the sector (Morris et al., 2023). Current research has stated that 57% of respondents are dissatisfied with the sector (Morris et al., 2023) and 56% believe standards have deteriorated over the last twelve months (Buzelli et al., 2022) Consequently, UK social care has been constructed as something to avoid rather than a means of providing support and promoting independence (Chapman, 2019). The challenges in social care are underpinned by a ‘triple knot’ of delivery, financing, and staffing (Binstock and George, 2006; Glasby et al., 2020), and without significant change, it will become unsustainable (Glasby et al., 2020). These challenges are thought to have been exacerbated by Brexit, with an expected downtrend in EU workers migrating to work in the social care sector due to changes in immigration policies (Read and Fenge, 2018). There is little academic literature on the subject at present however, initial grey literature seems to be supportive of this (Nuffield Trust, 2022).

The literature suggests that there is an evidential lack of planning on the UK policy front for meeting the extended care needs associated with population ageing (Walker, 2018, Bottery, 2020). The issues within social care are well documented and yet across both academia and grey literature it is still widely considered to be in crisis with little productive and sustainable policy on the agenda (Binstock and George, 2006; Glasby et al., 2020; Green, 2017; Walshe et al., 2016). Without a sustainable care system, pressure will increase across society and the implications are profound (Blakely and Quilter-Pinner, 2019). Older adults seeking to live in their own homes with long-term physical health conditions are one of the groups for whom this unsustainability will significantly impact. Without social care support at home, health services will also become unsustainable and older adults could face increasing in-patient admissions and preventable delays to discharges (Glasby et al., 2020). Additionally, there is extensive literature linking social care shortages with increased reliance on informal care and support (ONS, 2019a).

Exact data and figures on the social care system are more difficult to locate than it is for healthcare. This is likely due to the disjointed nature of social made up of private, local authority and third-sector providers as opposed to the centralised NHS system. Current estimations are that 818,000 adults receive publicly funded social care in England (NHS Digital, 2022: Online) and a significant portion of adults also pay for their care. However, finding exact figures is difficult and it is unclear how these numbers breakdown between working-age and older adults. This lack of robust data on numbers is also reflected in its failure to recognise those who do not qualify for formalised social care services but instead rely on informal care.

2.4.2 Healthcare

In chapter one I considered older adults with long-term conditions (LTCs) as being the primary users of healthcare in the UK. Building on this, this section explores the underpinning political landscape and literature on healthcare. Social care is widely considered the poorer sibling of healthcare on a background of less funding and increased vacancies (Glasby et al., 2020; Lloyd and Heller, 2012). However, recent years have seen the NHS face increasing pressures, mirroring social care with an escalating crisis in staffing, funding, and conditions (Jeffries, 2022). The challenges faced by the NHS are widely associated with a myriad of underlying social issues including, rising ageing populations, the austerity agenda, an inability to discharge patients quickly and safely to the social care sector, and rising workforce vacancies (Glasby, 2017; Jeffries, 2022). Meeting the challenges faced by the NHS was a priority of the NHS Long Term Plan (2019), four years since its inception there is a dearth of academic evidence exploring its progress. However, a search of grey literature confirms that as, yet its impact is minimal and has been significantly disrupted by the Covid pandemic (Thorlby et al., 2021). The Covid impact on health and social care is explored in the following section.

Evidence suggests that across different age groups, but particularly among older adults, having quality relationships with healthcare staff is important to building trust and improving wellbeing outcomes (Francis et al., 2020; Mitsi et al., 2018). However, recruiting and retaining the workforce is one of the key challenges faced by the NHS and a core facet of The Long-Term Plan (NHS Digital, 2019). Despite implementing recruitment and retention strategies, contemporary evidence suggests that both public and staff satisfaction with the NHS is falling year on year (Baird and Murray, 2022; Bimpong et al., 2020; Morris et al., 2023). The literature presents a varied and multifaceted picture as to why these workforce issues remain prescient. Firstly, The Long-Term Plan (NHS Digital, 2019) was developed in a post-Brexit landscape but published before the impact of Brexit and specific exit strategies were negotiated (Alderwick and Dixon, 2019). Consequently, aspects of the plan have been unable to account for unforeseen challenges posed by the UK leaving the European Union (Alderwick and Dixon, 2019). The NHS is reliant on international recruitment to fill its roles, however, Spiliopoulos and Timmons (2023) suggest that there is a growing xenophobic environment in Britain that is restricting both recruitment and retention. Secondly, at the end of 2022 and the beginning of 2023 there has been extensive media coverage of unprecedented strike action across different factions of the NHS reflecting that current political strategies for enhancing retention are falling short of their targets (see for example, Badshah and Thomas, 2023; BBC, 2023; Unison, 2023).

I have established that healthcare and in particular the NHS is facing significant contemporary challenges to its sustainability. Evidence suggests that the underlying political narrative to combat this appears to be of a neoliberal approach (Peacock et al., 2014). Consecutive Conservative governments have failed to meet the needs of current challenges and evidence suggests they instead promote narratives of health prevention and self-management (Carrier and Newbury, 2016). The preventative approach is underpinned by a large body of literature (DoHSC, 2021a; Matricardi et al., 2020; Seedsman, 2020; Wolfenden et al., 2012) and Seedsman (2020) contends that challenging health behaviours early can combat increasing rates of mortality and disability. Prevention is evidenced to have already been successful in areas such as reducing lung pathologies due to smoking cessation (Strassmann et al., 2023). However, this model consistently fails to account for illnesses that are not lifestyle-contingent, conditions that are not easily preventable, and underlying socioeconomic inequalities (Seedsman, 2020). Similarly, self-management strategies for living with LTCs in the community are favoured by politicians as a means of diverting people from secondary care services (Carrier and Newbury, 2016). They are also favoured by a body of literature that connects them with increased control and independence (Clarke and Bennett, 2012). However, Francis et al.’s, (2020), work described self-management as being used by people with a higher level of need than for which it was initially intended. Additionally, self-management is only appropriate to a certain level and is not a long-term care strategy given the degenerative nature of many LTCs (Francis et al., 2020).

Cheraghi-Sohi et al., (2013) reflect in their study a disjoint between the priorities of patients and practitioners. Additionally, there is a significant body of literature that reflects my own experiences of individuals wanting more choice and control over their health to address this disjoint (Carrier and Newbury, 2016; Owen et al., 2022; Seedsman, 2020). This is long established in literature yet opportunities to engage with the development of health services and policy remain hidden, inaccessible, or tokenistic (Chapman, 2019; Hunter et al., 2016). Owen et al., (2022) have suggested that to redress this disparity research should champion a means of working collaboratively with patients, exploring what matters to them. This research aims to fill this gap and seeks to use asset-based approaches to recognise older people as experts by experience (Owen et al., 2022). This contrasts with significant health research which is dominated by problem-based learning (Compton et al., 2020).

2.5 COVID-19 and Ageing

The emergence of the COVID-19 pandemic in early 2020 signalled significant health challenges but also profound implications for research and everyday life (Philip et al., 2020; Troutman-Jordan and Kazemi, 2020). Publications on COVID-19 have been generated at a rapid pace particularly concerning the specific impact of the virus on older adults (Harper, 2021). Significant data has emerged identifying older adults with long-term conditions as disproportionately suffering the impact of the virus (Angel and Mudrazija, 2020; Gomez-Belda et al., 2020; Harper, 2021).

The COVID-19 pandemic has exposed a multitude of societal flaws both in the UK and globally (Angel and Mudrazija, 2020; Bottery, 2020; Harper, 2021), and in doing so we have witnessed both negative and positive implications for older adults with long-term health conditions. Prominent rhetoric's throughout contemporary COVID research and wider public and media discourse have been ageism and how it has framed our response to the pandemic (Harper, 2021; Monahan et al., 2020; Reynolds, 2020). It is possible that the implications of ageism in the pandemic may have significantly impacted how participants feel about home and illness, and in turn how they respond to this research. Firstly, older adults were asked and at times pressured into shielding by a conjoined effort from central government, formalised health and social care services and loved ones alike (Reynolds, 2020). Surface intentions appear admirable for the safety of the individual in question; however, it is considered that asking older people to shield reinforces the derogatory construction of all older people being a homogenous vulnerable group (Harper, 2021). Additionally, several studies have argued that given older adults' existing propensity for loneliness prolonged shielding for physical health benefits may have come at the expense of mental wellbeing (Monahan et al., 2020; Moore and Hancock, 2020; Whatley et al., 2020). Furthermore, ageism and homogenisation of older people have led to widely criticised policies on healthcare and treatment rationing based solely on age (BSG, 2020; Harper, 2020); again, emphasising the social construction of adults as vulnerable and less worthy than other age groups (Monahan et al., 2020). Conversely, these policies and ideologies may have inadvertently had the opposite effect. Given the widespread media and public criticism, it could be that COVID-19 has acted as a catalyst for positively reframing how older adults are perceived in society given the exposure of poor treatment and regard in a pre-COVID-19 world (Bottery, 2020).

Following this line is the impact of COVID-19 on health and social care services and how it has exposed fundamental flaws in both systems (Baxter, 2020; Bottery, 2020). The impact has been widely discussed for both services but with social care arguably coming out worse off. The sector experienced a high volume of excess deaths of older people due to a combination of; discharge from hospital without COVID testing, poor or limited access to adequate PPE, and higher numbers of agency workers (cross-site contamination) (Baxter, 2020; Bottery, 2020). This handling, particularly at the start of the pandemic, has contributed to growing mistrust in the safety and efficiency of the sector which in turn means lower care home occupancy rates (this is in addition to excess deaths), fewer requests for support, and a dramatic increase in informal carers (Bottery, 2020). Whilst this has contributed to the existing market fragility, the pandemic has, however, effectively combatted vacancy rates in the social care sector (Bottery, 2020). With high redundancies and furloughs in other sectors, many people have turned to social care employment, partially solving long-established workforce issues (Bottery, 2020). However, by late 2021 this trend had already begun reversing (Skills for Care, 2021).

An additional consideration is the medium to long-term impact of the virus on services, individual health, and the mental and emotional toll on both health and care workers and older adults (Bottery, 2020; Gomez-Belda et al., 2020; Whatley et al., 2020). Initial research publications suggested that a mental health crisis may follow the COVID-19 health crisis as a result of isolation and grief amongst other stressors (Palmer et al., 2020; Whatley et al., 2020). However, more contemporary publications have concluded that the mental health impact has been less than anticipated (Sun et al., 2023). Amongst the older population, poor mental health has associated repercussions for physical well-being, personal identity, and self-worth (Troutman-Jordan and Kazemi, 2020; Whatley et al., 2020). Therefore, as we rebuild post-pandemic the voices of older adults must not be lost amongst other groups of society.

An additional concern is the trend in applications for health and social care support. It was initially considered that support applications may decrease with the excess mortality seen from COVID-19. However, research suggests that older adults who survived the virus are more likely to experience significant physical complications or report having long covid (Bottery, 2020; Daitch et al, 2022; Palmer et al., 2020). Therefore, individuals may need social care support sooner than initially anticipated as a result of contracting COVID-19. Initial data on this either supportive or contradictory is unclear. Generally, the number of support applications has declined, however, the overall number of people receiving help has increased; although this is attributed to an increase in support for working-age adults, rather than older adults (The Kings Fund, 2022). Whilst there is some evidence to suggest that older adults chose not to access support during the pandemic it is unclear at this stage whether there are any other reasons for the drop in support and how this may change over the next few years.

2.6 Chapter Summary

In this chapter, I have reviewed the literature on themes intersecting with my study and set these into 4 main themes: ageing in a UK context; older adults’ health and well-being; health and social care for older adults and Covid and ageing. I have interwoven the socio-political debates underpinning each theme throughout the sections and introduced the concept of ageing in place. The literature has demonstrated the challenges associated with current health and social care provision, particularly in meeting the needs of ageing populations and has supported the narrative that ageing in place can lead to increased independence and well-being. The literature reviewed in this section has reiterated how well-documented the problems associated with ageing and health and social care are and has reaffirmed my desire to investigate what works well for older adults. In undertaking this literature review I have also tried to take an appreciative stance while reviewing papers. The majority of papers I have reviewed had a deficit-oriented stance, however, within that narrative there were examples of positives. To summarise, the main positives that have been identified in this review are: living in the community offers more independence and control for older people, staff at health and social care services make a considerable difference to how older adults feel about their condition and their services, having opportunities to contribute to policy and practice is important. My study aims to build on these current understandings about what older adults want and how this compares with current policy directives on a national and local scale. In the next chapter, I explore the theoretical underpinnings that have shaped my study and align my chosen methodology with the aims and objectives that I have developed.

Chapter 3: Framing and Undertaking the Study

3.1 Chapter Overview

In chapter two I considered the literature about the wider personal and societal implications of ageing and long-term illness, resulting in the emergence of two main assertions: (i) in the future, society and resources will be placed under unsustainable strain caused by rising demand for health and social care services; (ii) community-centred approaches are key. The COVID-19 pandemic is a further pressure on these areas and is likely to represent a significant current and future challenge, particularly among older adults with existing physical health conditions (Harper, 2021).

In this chapter, I will explore the conceptualisation of this study, clearly stating the objectives and outlining its design and the rationalisation for the research framework and discuss it alongside the underlying philosophical debate. I will explore the methodological approach and justification of methods for recruitment, data collection and analysis. A clear discussion of the strengths and limitations of this study is acknowledged and interwoven throughout. Also included is a clear ethical discussion due to the inclusion of human participants, particularly given that they will be over 65 with LTCs who are on occasion considered to be ‘vulnerable’. The methodology and design of this study were conceived before COVID-19 but were adapted following the widespread social-distancing and public health measures imposed in 2020. Therefore, additional ethical concerns raised by the COVID-19 pandemic will be discussed and practical solutions presented.

3.2 Theoretical Underpinnings

The evaluation of ageing is heavily influenced by the perspective through which it is seen. Whether biomedical, sociological, psychological or a combination of the three (Carver and Buchanan, 2016). Despite substantial research and publications, my literature review found that gaps remain. There is a lack of clarity and consensus on what older adults find supportive. Contemporary researchers have, therefore, sought to innovate with non-traditional approaches to work beyond existing thinking (Bossio et al., 2023; Miller and Brockie, 2015; Monson et al., 2021). Consequently, a significant shift has occurred amongst organisations and researchers towards participatory, community-oriented methods as a means of elevating participant voice and knowledge to create effective, tailored, and caring services (Owen et al., 2022). This has shaped my desire to explore the thoughts and opinions of older adults. Informing the aim of my study to explore what is supportive for them and create deeper, personalised understandings of what it means to age well, in place.

Having worked for many years in the health and social care sector, predominantly with older adults and in a palliative specialism, I noticed that many of the patients told me that they lacked control over their care and conditions. This is important, particularly for those with LTCs, as it creates a barrier to living independently, and hinders opportunities for work, socialisation, and housing (Carrier, 2016). This lack of control was reflected in the literature review in Chapter Two concerning the research approach, with many studies choosing to ask closed questions as part of research with limited aims. Studies such as Chapman's (2019) highlighted that older research participants felt they were limited in what they could say and often felt the focus was misaligned with the needs of the participants. Additionally, a large body of long-term condition research focuses on a singular specific condition, despite extensive evidence demonstrating that the older population generally have multiple long-term conditions requiring complex interwoven support (Carrier, 2016; Lloyd and Heller, 2012).

Co-produced or participatory research remains seminal in health and social care, however, there is growing dissent amongst contemporary researchers such as Chapman (2018), Hunter et al., (2016) and Sandman et al., (2020). This contemporary critique centres on opportunities to contribute to research or health and social care change not being made visible or accessible, a lack of post-activity feedback opportunities, and having outcomes overshadowed by budget limitations (Chapman, 2018). As emphasised in the literature review, it was conceived that in designing this research and in line with previous studies by Carter (2006) and Dewar and Kennedy (2016), the methodology should be participatory and focus on placing the participants centrally.

3.3 Study Aim and Objectives

The overall aim of this study is: to explore the physical and emotional experiences of well-being in community-dwelling, older adults with long-term health conditions as they seek to remain living at home as they grow older.

In line with this aim, the following research objectives (RO) will be used.

- **RO1**: To examine the provision of health and social care for older adults with long-term conditions in Manchester within the context of devolved health and social care budgets and integrated services.
- **RO2**: To develop knowledge of what is working well for the older adults in Manchester and how we can continue to deliver this.
- **RO3**: To establish a participatory approach accessible to chronically ill older adults.
- **RO4**: To explore how older adults could contribute to the ageing in place agenda.
- **RO5**: To inform future direction and provision of health and social care for chronically ill older adults in Manchester.

3.4 Paradigm

The selection of a research paradigm is universally acknowledged to be influenced by the researcher’s own beliefs, values, and experiences of the world – often intrinsic to culture and society (Denzin and Lincoln 2018). Crotty (1998:3) affirms that in social research the four core elements of a paradigm (methods, methodology, theoretical perspective, and epistemology) are ‘thrown together’ and incomparable. It is, therefore, essential that the researcher clarifies the ontology and epistemology to justify the methodological approach thus ensuring a sound paradigm for research. This research is underpinned by social constructionism and reflexivity. This section explores the ontological and epistemological assumptions that informed the development of my study and analysis.

The epistemology for this study is founded on tacit knowledge produced through practice, interaction and lived experience (Burr, 2015). The literature review highlighted the compelling epistemological belief that those who experience illness, know best what they need to ease and support themselves through it yet there is a scarcity of studies exploring this. Social constructionism is inherently linked to participatory approaches and strengths-based approaches, recognising that knowledge is created through the context of its application (Gergen, 2001; Whitney and Trosten-Bloom, 2010). Traditional positivist research is framed by its endeavour to find a universal ‘truth’ and spends considerable time playing theories against each other in this pursuit (Law, 2004). Social constructionism in contrast is revered by contemporary researchers for its multiplicity; it believes inherently that there are multiple realities, with no individual view considered superior to others (Burr, 2015). As Gergen (2001), explains singular accounts and truths can marginalise people and voices, something this study sought to move away from. For Burr (1998) this generates the possibility for people to reconstruct themselves and their ideas. In doing so we can reconsider that socially constructed categories such as gender, age, disability and illness are heterogeneous and should be considered in conjunction with biological determinants and lived experiences.

The constructionist paradigm advocates that individual thought is social interaction and structure, which in turn creates knowledge. As knowing is considered to take place through social interaction, it is considered that communities are sites of unlimited relational capacity (Burr, 2015; Gergen, 2001). Hence a community was selected as the site of this research, the context of the community of Greater Manchester is considered in section 1.4. Knowledge is filtered through culture and interaction and is in essence, capricious (Burr, 2015). The literature review in chapter two emphasised that social connections contribute to feeling valued and supported and are key to the desire to age in place. Therefore, my theoretical position influenced my decision to explore personal constructions of what is important and what works well through this study.

Contemporary research has dedicated considerable time to understanding the biomedical model of older age – characterised by a decline in ability (physical and mental) and increased prevalence of illness (Barry and Yuill, 2016). With old age and illness comes considerable change to all aspects of a person’s life, social constructionism offers researchers the ability to understand how a person makes sense of this transition (Nettleton, 2013; Pakenham, 2008; Radley, 2012). A key message from the literature review was that with increasing illness and declining mobility, ageing has a significant impact on social networks, therefore the way that these adults make sense of a long-term illness will be considerably impacted (Binstock and George, 2006).

Social constructionism also underpins a significant body of literature on how we understand and construct illness and disease. Freidson’s (1970:223) work on the social construction of illness has influenced my research in his argument that through the process of diagnosing illness, we assign the meaning of illness to disease. Subsequent work by Conrad and Barker (2010) has posited that the act of gaining a diagnosis or failing to gain a diagnosis has a significant bearing on how a person sees themselves and understands the world around them. Although this paradigm comes under criticism for its classifications of ‘disease’ and ‘illness’ and its separation of the two terms (Timmermans and Haas, 2008), it remains a widely utilised framework for exploring how meaning and illness are shaped by cultural and social systems (Conrad and Barker, 2010). In the literature review, I identified that often long-term illness and ageing are both constructed and framed negatively. By acknowledging that people have agency for change it is considered by Reed (2007) that certain methods of inquiry could lead to positive reframing. In this sense, this research assumes an aspect of salutogenesis – relocating research as a means of strengthening research based on what is perceived to be good (Antonovsky, 1997). The paradigm of social construction of illness, is therefore, interwoven into wider frameworks including, critical disability studies, appreciative inquiry (AI) and collaborative inquiries (Reed, 2007).

On an ontological level, I consider myself to be a realist believing that things can be in existence without us perceiving them (O'Reilly, 2009). Bhaskar (2013) has championed the cohesion between social constructionism and realism, contending that there are two distinct layers of agency and structure which are interconnecting and can transform each other. This has informed my study on the basis that these two layers are considered to be boundless and interwoven, each able to change and influence the other (Davies, 2008). This means that for this research we can frame older adults as reflexive beings who have an iterative relationship to social structures and conditions (Davies, 2008). Recognising these different layers means that as a researcher I can explore the older adults' experiences of ageing in place with LTCs whilst also investigating the structures they feel are supportive to them. Reflexivity occupies an integral role in critical realism as it recognises how the researcher constructs and frames their knowledge as part of their research (Bhaskar, 2013). I explore this further in the following section.

3.5 Reflexivity

In chapter one I positioned myself as a reflexive researcher and have woven my narrative throughout this thesis. However, in this section, I address the concept of reflexivity and how it aligns with my ontological stance and methodological choices.

Reflexivity is well established as a key component of qualitative research and is defined by Berger (2013: online) as being the process of critically self-evaluating your position as a researcher and acknowledging the impact this has on the research. Reflexivity is concurrent with the social constructionist ideal in that it contends that research is not a neutral or passive activity (Madden, 2017). The time and space in which something is written are interwoven into the framing of the subject (Coffey, 1999). This thesis has been crafted over five years of seismic social change, from multiple policy changes, a global pandemic, a UK recession and significant personal changes for myself as the researcher. From a reflexive stance, all of which have implications for this research. As such I have interwoven reflective accounts throughout this thesis to acknowledge my emotions, alongside the time and space in which this is written.

As discussed in Chapter One, my role in this research has been one of insider/outsider, and therefore, there has been a clear intersection with social constructionism's belief that there is an unavoidable co-construction of data between myself and the participants. By utilising reflexivity to focus on challenging assumptions and scrutinising that which we take for granted, as a researcher I intend to create fresh social action. Additionally, by including my reflective narrative alongside the research it is possible to capture a sense of how any bias may have been constructed and where it is being challenged.

Etherington (2004), however, urges that restraint must be considered by researchers taking a reflexive stance. It is possible that as a researcher my voice could overpower or conceal the narratives and beliefs of the participants. As the literature in chapter two contended that the voices of older adults are often overshadowed, I must exercise caution to not contribute to this trend. Despite this, Pillow (2003) writes that we can only reflect on or be mindful of that of which we are conscious of, therefore, this research is likely to be imperfect. To minimise this, my findings chapter will be interwoven with thoughts from my reflexive journal to highlight my thought patterns and acknowledge how I have constructed the data.

In these sections, I consider the methodology that I used in the study. The methodology evolved over a period of time, originally, I planned to complete a two-phased appreciative inquiry (AI) however, due to the COVID-19 pandemic this was reworked. The following sections set out why I was drawn to AI as a method and how I drew on this to instead complete an appreciatively informed qualitative study.

3.6.1 Exploring Appreciative Inquiry

A review of the literature in Chapter Two identified that the overwhelming majority focused on problems rather than examining what was working well and why. Mills et al., (2006) consider that by negatively framing research, social hierarchies are reinforced, and it fosters a culture of negativity and deficit-oriented language. Glasby (2017) echoes this belief and exposes sociological health research as being held captive by stigma theory – emphasising that the negative language surrounding ageing and long-term illness directly impacts how an individual makes sense of these experiences. My personal experience of working in health and social care was also framed by negative reactions to my work, as society seemingly located work with older adults as being of little status and low importance. Therefore, I felt compelled to take an alternative approach with this research that would focus on a positive approach to developing knowledge, supporting older adults to feel able to speak up for what they need and emphasising the meaningful work done by those who support older adults.

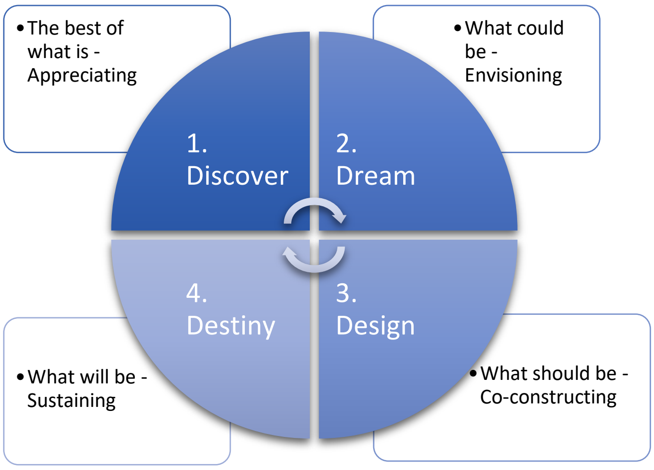
In searching for a methodology, I was quickly drawn to AI, a constructive form of action research (Cooperrider and Srivastva; 1987; Reed, 2007). It is considered by Cooperrider and Srivastva (1987) as a tool for engaging communities in self-determined change by acknowledging that models of the future are socially created. AI's focus on working with and for communities to develop ownership and challenge traditionally constructed beliefs resonated with me and my desire to promote the voice of older adults in research. Black et al., (2015) reflected this desire and encouraged the use of AI as a tool to encourage older people to contribute towards action and acknowledge that they are the experts of their own needs.

Originally developed as a tool for organisational psychology, AI offers an alternative to traditional deficit-oriented models of change (Cooperrider and Srivastva, 1987).

Although well-established in corporate research and business, over time AI has made its way into health and social science research due to its strengths-based orientation. In my literature review, I emphasised that such approaches were needed to combat the traditional problem-focus in health and social care research. However, I also asserted that current methods of doing so were looking at what older adults can contribute to wider systems rather than seeking to explore their beliefs on what works well for them. Through my reading, I was particularly drawn to the emphasis that researchers placed on the transformational possibilities of AI (Carter, 2006; Dewar and Macbride, 2017; Jack et al., 2019b). This was particularly evident in the growing use of AI in healthcare research (See: Carter, 2006; Hung et al., 2018; Watkins et al., 2019). However, during my extensive reading, I realised that AI is rarely used in social care, which favours less prescriptive community-based participatory methods (CBPR). Similarly to AI, CBPR places the participants centrally in the decision-making process, however, it does not have a set of methods prescribed to it and it is not underpinned by the appreciative discourse of AI. Initially, one of the reasons I sought to use AI was because its prescriptive nature felt reassuring to me as a novice researcher. However, the nature of the AI process favours organisations and requires a degree of control over putting the findings of the research into effect, which I would not have.

The AI process has four principal stages discover, dream, design, and destiny. The process begins with an exploration of the ‘best of what is’ (discovery stage), then collaborative inquiry of ‘what might be’ (dream stage), a discussion of ‘what could be’ (design stage), and finally implementation ‘what can be’ (destiny stage) (Whitney and Trosten-Bloom, 2010).

[Figure 4.] The process of AI



(Developed from: Reed, 2007)

This model establishes AI as a four-stage cyclical process that is intended to be a continuous form of inquiry (Hammond, 2013). However, AI is also underpinned by an overarching philosophy constructed of five principles:

1. **The constructionist principle**. Reality and knowledge are created through the social constructionist stance. What we believe to be real we create through social discourse – we create what we can imagine.
2. **The principle of simultaneity**. Inquiry is intervention. The questions we ask create stories that influence how we construct the future.
3. **The anticipatory principle**. Understanding our actions is based on what we learn from our environment and what we imagine will happen in the future. The most important resource for constructive change is collective imagination about the future.
4. **The poetic principle**. Understanding storytelling as a valuable way of collecting facts, feelings and experiences. An organisation's story is constantly being co-authored – change can happen.

5. **The positive principle**. Positive approaches to learning are just as valid as negative approaches. The momentum for change requires positive affect and social bonding.

Adapted from (Watkins et al., 2011).

From an early standpoint in this research, the four stages and five principles did not seem to fit with the requirements of the research. The following section will address these critiques of AI and discuss how they have informed my research method.

3.6.2 Critiques of Appreciative Inquiry

From early on in my research process I was aware of the wider critique surrounding AI. In this section, I will address the critiques that led to me using an appreciatively informed methodology rather than the prescribed AI model.

When searching for studies utilising AI, I acknowledged that it had not been embraced widely in academia. Instead, AI has mostly been used in organisational development where the emphasis may not be on systematic evaluation. I noted that AI had come under scrutiny for not being critical (Bushe and Kassam, 2005; Clouder and King, 2015). However, criticality can be defined in different ways with Grant and Humphries (2006) advocating that critique is an integral aspect of AI. On a personal level, I felt that AI could be considered critical as it challenged the traditionally dominant negative discourse.

Carter (2006), suggests that the conflationary language of AI (such as: dreaming, destiny etc) has received criticism and led to its rigour being questioned. In health research particularly, AI has come under scrutiny for glossing over genuine problems, arguing that researchers may be wearing rose-tinted glasses; if you look hard enough for some good, it will be found (Carter, 2006). This emphasis on positivity created criticism that any resultant findings may be partisan and distorted. However, heading into this research I felt that the negative aspects of illness and ageing had been well explored and by reframing this from a positive aspect this research would develop new understandings. Additionally, on an ontological level, it has been argued that AI's aim of overshadowing the negative is in opposition to relational constructionism and its multiple realities. However, it is considered by Van de Haar and Hosking (2004) that AI is sympathetic to exploring the negative by hearing differing accounts of experience, but that the focus is on possibility rather than problems. Similarly, Carter (2006), argues that AI is not to be interpreted as a panacea, but it could provide a way forward for producing meaningful change.

The extent to which AI achieves transformational change is debated amongst academics. A 2005 study by Bushe and Kassam indicated that only 35% of cases achieved this as an outcome. There is a paucity of contemporary evidence examining AI's effectiveness at achieving transformational change, however, its growing popularity amongst researchers leaves an opportunity for future reflection on effectiveness. Research to date suggests that AI is most effective amongst practitioners, whether in health and social care or beyond. This is likely because the effectiveness of AI hinges on stage 4 destiny and requires those involved with the project to have the power to implement change. For participants, particularly in health and social care, this role is limited and emphasises that power imbalances still exist within this participatory method. However, Heron (1996) contends that the outcomes of research do not need to be necessarily structurally transformational. Personal development or informative outcomes are equally as transformational (Mitchell-Williams et al., 2004). Additionally, Egan and Lancaster suggest that the destiny stage can evolve from a set of activities towards an open process of empowerment and ongoing change and development (Egan and Lancaster, 2005).

3.6.3 An Appreciatively Informed Study

In my research, I set out to address the gap in the literature concerning what works well for older people ageing in place. Initially, this seems to overlay perfectly with the concept of AI, however, as I explored the critiques further, I became aware that an exclusively AI approach would not feel rigorous or compatible with the aims and site of this research. This section explores the rationale for pursuing an appreciatively informed study rather than traditional AI.

I will return to the AI principles noted in section 3.6.1. The positive principle was the main draw for me in exploring AI. Both the review and my experiences noted a lack of narrative about what older adults believe works well. However, Johnson (2011), contends that negative experiences can arise from positive inquiry. It has never been the intention of this research to erase negative narratives and experiences from the narrative. The literature review found that older people and health and social care systems face many issues. These issues will affect how older people can age in place. Therefore, this research will employ the principle of positivity to explore what works well but recognises that there are polarities of experience that allow for multiple perspectives (Johnson, 2011).

The constructionist principle is also, at the core of this study, focussing on the co-created knowledge with the participants. As a means of informing knowledge about the future, this study explored participants' past and current experiences. Cooperrider and Whitney (2003) emphasised that the constructionist principle enhances the communal base of knowledge, in turn increasing the generative capacity of knowledge. For this study, the core aim was to generate knowledge and theory to support ageing in place, whilst challenging assumptions of ageing and long-term illness. However, AI is intended to be collaborative (Carter, 2006; Cooperrider and Srivastva, 1987) and the stages should be conducted in a group format however, the recruitment process during a global pandemic was difficult and fragmented preventing such an approach. Despite this, Reed (2007), asserts that there are collaborative possibilities between researcher and participant that can be explored. It is necessary in this sense to be mindful of power relations that could disrupt this research narrative. Therefore, I have introduced reflexivity into this research to challenge power balances and explore existing biases.

Finally, as I envisioned how the four-stage model of AI would materialise in this study, I was drawn repeatedly back to the fixed nature of the model. The requirement to adhere to a fixed four-step process is in contrast to the intended reflexive nature of this research. Looking reflexively over AI as a methodology meant that I felt the rigid stages of the model could change reality for the participants rather than allowing for an open-ended inquiry to generate discussion and explore their pre-existing framing. In addition, the model needed to be reflexive given the COVID-19 pandemic that emerged during the data collection and methodologies had to be altered to suit data collection during social isolation.

In conclusion, AI has informed my study with its generative and positive principles however, as an entire methodology it felt restrictive and at times incompatible with the research. The following chapter will explore the methods employed in this research and how they are influenced by positive inquiry and collaboration.

3.7 Sampling

Sampling in AI takes place in a variety of ways, often at the discretion of the researcher. However, a significant number of studies involve a sample of convenience whereby the researcher is also an 'insider' (Dewar, 2011). For my study, Individuals were chosen to participate based on the disclosure that they were aged over 65 years old and had been diagnosed with a long-term physical health condition. It was decided that anyone with a long-term mental health condition would be excluded, as the core focus of this research is physical health, and it was felt from initial literature searches that those with mental health conditions need and access different types of support - constituting different research entirely. The wording of 'long-term physical health condition' was also specifically chosen for its ability to include those with disabilities in addition to those with illnesses.

I began searching for participants in the spring of 2020, just as the UK entered an initial 3-month lockdown. Consequently, connecting with older people in the community became more complicated and recruitment needed to be via COVID-19 safe means. With the support of a local community news group for older adults, I put out a Twitter call for research participants. However, I realised this may restrict access based on the digital divide between older adults and younger people (Centre for Ageing Better, 2021b). Therefore, I started to undertake desk-based internet searches of local community organisations for could act as gatekeepers to connecting me with older adults. Many community organisations were running in a restricted manner at this time, due to the national lockdown and restrictions on resources. Therefore, I was only able to access organisations that had an online presence and they in turn were only able to access members who themselves were keeping in contact online or over the phone. Although many people were isolating at home and would have, in theory, more time for participation, many were scared, vulnerable to the virus and unwilling to take on extra commitment at this time. Recruiting 8 people took 12 months. Through several gatekeeping organisations, I was able to contact participants either over the phone or online based on their preferences. The participants were asked to sign a consent form and answer a series of screening questions such as age, condition, and whether they lived alone – to provide context to their narrative. Each participant was allocated a pseudonym to protect anonymity, with a final sample size of 8.

Traditionally, sample sizes under 20 are considered ‘small’ (Crouch and McKenzie, 2006), and are often criticised for their lack of rigour, generalisability and validity (Vasileiou et al., 2018). Small sample sizes are particularly common in qualitative research where its generative nature often leads to longer, more in depth data collection requiring extensive analysis. In this way, Vasileiou et al. (2018), contends that small sample sizes have capacity to generate rich data based on increased researcher capacity to explore and analyse the data. Additionally, Hennink and Kaiser (2022) propose that large sample sizes in qualitative research can saturate the data. They argue that smaller sample sizes often fielded more homogenous sample groups and narrowly defined objectives and recommendations. The implications of conducting this research with a ‘small’ sample size is discussed further in section 6.4 Limitations.

3.8 Methods

Neither traditional strengths-based studies nor AI have a specific set of methods prescribed to them. However, the research I explored in my literature review highlighted a tendency to use interviews and collaborative workshops. Reed (2007), emphasised that creative methodologies also intersect well with qualitative methods and could be employed to encourage participation amongst marginalised groups. I considered several creative methods including diaries, and walking interviews however, I ended up using traditional interviews. For one this was a comfortable space, that as a novice researcher, I felt confident inhabiting. Secondly, the nature of the pandemic excluded the use of face-to-face methodologies. Thirdly, COVID-19 and recurrent lockdowns meant that I needed a method that could be utilised from a distanced approach whilst remaining accessible if some participants did not have internet access. To include an element of participant choice I was able to offer the participants the option of telephone or video-call interviews.

Carter (2006:58) says ‘the most precious resource is participants time’, and there is conflicting evidence on how much time a researcher should expect a participant to give up in aid of the research (Dennis, 2014). Often the time needed to participate is not necessarily seen as a cost to participation, but instead a necessary condition, however, it is well recognised that time remains a barrier to participation (Dennis, 2014). I initially planned a two-phase approach; first individual interviews then focus groups. However, given that one of my aims was around participatory methods, I decided to speak to the participants at the end of the interviews and gauge their willingness to participate in a second phase. This put the power and the direction of the research in the participant's hands, in line with collaborative research. Three expressed willingness to engage in a second phase, however, the majority felt this was unappealing. The reasons for this were varied, however, each mentioned that as the lockdown was coming to an end, they wanted to spend their time reconnecting with people and hobbies, rather than commit more time to a study. Although this could have been facilitated with the few participants that were interested, as a novice researcher I felt overwhelmed by the amount of data already generated and was acutely aware of time pressure, given how covid had delayed the initial data collection. On the balance of this, it was decided to proceed with a one-phase approach.

3.8.1 Interviews

One of the aims of this research was to understand what older adults believed was working well for them and how this could be supported. I considered early on in this research that what works well might involve formalised services, however, in conducting the literature review it was emphasised that socialising with others is equally important. Therefore, I made a choice to use semi-structured interviews so as not to restrict what the older adults could discuss. I began my interviews by asking the participants to talk about themselves and their conditions. I decided to start with this so I could gain an initial familiarisation with the participants and so they could take the conversation forward in the way they wanted.

Initially, I intended to use unstructured interviews, however I recognised this can be a difficult method for novice researchers (Bryman, 2012). Therefore, Carter (2006), recommends preparing and using provocative propositions within the interviews as a trigger for storytelling or a prompt to elicit more information. I designed a list of these prompts (appendix 1) which could act as a guide for myself to elicit a narrative without guiding the participant too much. By choosing to use provocative propositions I moved away from unstructured interviewing and instead decided to embrace semi-structured interviews. However, Carter (2006) equally maintains that prescriptive agendas should be avoided to follow participants' individual experiences, therefore, I employed the prompts in a way that was intuitive to each interview. The prompts were not necessarily used sequentially and not all the prompts were used in each interview. In this was I attempted to be led by the participants agenda rather than enforcing a fixed list of questions. Face-to-face interviews are the preferred method of study, due to the rich non-verbal data that can be collected (Bryman, 2012). However, due to the COVID-19 crisis, many of the participants were identified as being in the shielding[1] category. Therefore, to protect their best interests' interviews were offered over the phone (n=4) or via Microsoft Teams (n=4). To mitigate the digital divide (Centre for Ageing Better, 2021b) I designed instructions that could be emailed or posted to participants on how to use Teams (appendix 2) and made myself available to assist with any technology queries in advance of the interview. The use of mixed technology for interviews was important to me in ensuring the accessibility of the study where possible. It meant that I was able to give people options as to what suited them best or felt most comfortable for them. However, the phone interviews lacked the connection of the video calls, and I was unable to observe body language.

3.8.2 Reflective Journaling

Reflexivity is widely encouraged in qualitative research, particularly in collaborative methodologies. Instead of attempting to erase the researcher's values and preconceptions, reflexivity situates them within the research and allows the reader insight into the construction and analysis of the data (Ortlipp, 2008). The use of a research journal is common in reflective practice and appealed to me as a means of capturing and conveying reflexivity. However, there is limited literature and guidance on the use of a reflective journal for research rather than in practice (Ortlipp, 2008).

Meyer and Willis (2018) recommend reflective journaling for novice researchers for problem-solving and as part of a developmental process. As a novice researcher, I was apprehensive about managing my pre-assumptions and not allowing this to influence the participants. Although a journal does not necessarily equate to reflexive practice, it

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[1] Shielding was defined by UK government as being 'clinically extremely vulnerable' (UK Government, 2019:online) full list of those considered to be in the shielding category could be found at https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19 Those shielding were advised to stay at home and only contact one person from outside of the household (advice as of June 2020).

provides me with a tool to develop and explore reflexivity (Meyer and Willis, 2018). I was initially nervous to begin the process, as journaling is a deeply personal experience. The prospect of sharing excerpts of my journal within this research was daunting as was the fear of criticism that I would not be reflexive enough. The reflections gave me a means of processing my thoughts and constructing my findings. Throughout the findings chapter my reflections are interwoven so as possible to see why and how I drew certain conclusions.

3.9 Data Analysis

The data collected from this study was almost entirely qualitative. Holloway and Wheeler (2010) describe qualitative data analysis as systematic but complex and non-linear. Analysing data from AI can be similarly complex with differing analytics required after each stage. Therefore, PhD research undertaken by Kilbride (2007) and Dewar (2011) advocates the use of a more intuitive approach led by the data. As AI has no ‘prescribed’ methods, there is similarly no set guidance on analysis. Previous AI studies employ a range of analytic techniques for example, Jack et al., (2019b) – framework analysis, Dewar (2011) – immersion/crystallisation, Gray et al., (2019) – constant comparative method, Curtis et al., (2017) – thematic analysis.

Holloway and Wheeler (2010) describe how a phased approach is common in qualitative research, therefore analysing using multiple methods requires a reflexive approach. Additionally, within the paradigm of the research, it was important to recognise the researcher’s role in being immersed and engaged with the data, and equally its analysis. Consequently, thematic analysis (Clarke and Braun, 2013) was chosen as the method of data analysis for its ability to represent participants' narratives with a degree of validity, whilst maintaining a critical awareness of the researcher's own influence and bias (Curtis et al., 2017).

Curtis et al., (2017:157) describe thematic analysis as:

a rigorous inductive method of analysis involving the systematic generation and refinement of categories to themes and sub-themes.

Thematic analysis was popularised by Braun and Clarke in 2006, and despite widespread use, it has only recently gathered ground as a recognised and rigorous form of analysis (Clarke and Braun, 2013). Although thematic analysis has been criticised by authors for being essentialist and method rather than a form of analysis (Guest et al., 2012), Clarke and Braun (2013) continue to emphasise its theoretical flexibility given; thematic analysis is not subscribed to any particular language or framework, it works with a wide range of research questions, it can be utilised on differing data types, and it works with small data sets.

Carter (2006) and Jack et al., (2019b) have both advocated the use of thematic analysis in appreciative studies. In traditional AI methodology, thematic analysis can be used to develop provocative propositions out of interviews in the dream phase. Additionally, thematic analysis allows the researcher to respect individual narratives along with allowing the researcher to identify the core research themes (Clarke and Braun, 2013). The thematic analysis also broadly underpins the research paradigm by avoiding a hierarchy of ‘truths’, focussing instead on comparing experiences without asserting a singular one as ‘truth’.

Thematic analysis is broadly considered recursive rather than linear, however, Braun and Clarke (2006) have developed a broad 6-phase guide to successful thematic analysis:

1. **Familiarisation with the data**: The researcher reads and re-reads the data to familiarise themselves with it. The researcher uses this stage to identify initial observations and themes.
2. **Coding**: Creating a list of emergent themes and generating them into broad labels. Every data item should be coded. At this stage, the labels will be broad and will go on to be refined.

3. **Searching for themes**: Themes should be identified based on relevance to the research questions and coherence throughout the data set. Searching is to be an active process that results in all of the coded data being allocated a theme.
4. **Reviewing the theme**: The process of ensuring all the themes and codes are harmonious. The researcher should reflect on each of the themes and the relationship between them. Often some themes are split or combined at this stage.
5. **Defining and naming themes**: The researcher should analyse the themes and identify a relevant, concise and distinct name for each.
6. **Writing up**: Weaving the themes together into an analytical narrative. This should allow the reader a coherent story that is contextualised in the relevant literature.

The interviews I conducted were audio recorded and later transcribed. Given the nature of thematic analysis, the audio recordings were integral in familiarising me with the data. Once transcribed verbatim the data was coded and placed in themes in line with stages 2 and 3 of thematic analysis. Being a novice researcher, I explored several methods of data coding, using this opportunity to identify which methods worked best for me and the data. I started with NVivo but found the process to be restrictive and felt disconnected from the data. As a first-line analytical tool, I found it inflexible, attempting to recode or categorise was difficult and time-consuming. I attempted this three times before deciding I needed a method with greater flexibility as I felt my way through the data. Next, I printed and cut quotes from the transcripts, arranging them physically in front of me. This was the most useful method of familiarising myself with the data as I was able to see everything at once and felt I could see patterns emerging more clearly. However, it was impractical for the long-term process of writing up and did not yet feel as though the data was fully organised. Using the physical mind map of quotes, I began to build an Excel spreadsheet, which led to the ultimate categorisation of my data. This gave me the flexibility to move data as required but also keep it all organised and together. By using separate tabs for each theme and then co-ordinating them into sub-themes, it became easier to write in a synthesised manner. The data were eventually coded into five themes: Adjusting to and living with LTCs, Accessibility and physical environment, experiences of using health and social care services, communication and information, and engaging with others. Each theme has a number of sub-themes, explored in the following chapter, Findings.

3.10 Ethics

This research was submitted for approval to Manchester Metropolitan University's faculty research ethics team. Ethical approval was sought and granted on 13/05/20 (ref: 17754).

Conducting any research with human participants requires close scrutiny over any potential ethical issues. Additionally, researching older adults is considered to have increased ethical considerations. However, Jamieson and Victor (2002) consider that not all older adults are considered 'vulnerable' and recommend in most situations treating research with older adults no differently than research with younger adults. In line with the Mental Capacity Act (2005), capacity will be assumed. Although this research involves those who have physical conditions, mental-health conditions and those unable to provide informed consent will be excluded.

Given that this research took place during a global pandemic careful consideration was given to ensure the safety of the participants and appropriateness of the research.

3.11 Consent

Consent is paramount in ensuring participants are informed, not coerced and able to participate. All participants consented to take part in the research and to the recording and storage of data before the research started. However, Hughes et al., (2008) have suggested that in qualitative research consent is complex, a participant information sheet was provided (appendix 3). The methodology employed within this research was purposefully designed to be participant-led and was, therefore, not possible to provide full information on the topics being discussed to the participants in advance. To safeguard participants from feeling coerced into talking about topics they may not have been comfortable with, a clause was established advising that they should not talk about anything they do not want to and would be able to withdraw from the study at any point up to the submission of this thesis should they wish. Additionally, as principal researcher, I had to demonstrate a degree of judgement as to how comfortable a participant was and whether to pursue the discussion further. I made it clear to participants at the beginning of the study that they were not required to answer any questions they were uncomfortable with and used open-ended questions so they could guide the conversation, leaving topics for discussion under their control. I was also mindful of my own comfort. I maintained a journal throughout the data collection process, noting what was happening before the interviews that may have impacted them, for instance, a new lockdown had begun on the day of one of the interviews. I also reflected afterwards on how I thought they had gone and things to improve or consider next time.

3.12 Reflections Before Data Collection

My pre-thoughts and understandings before entering the research process are detailed earlier. However, the nature of both this research and the world as we know changed during 2020 with the COVID-19 pandemic. The literature review on COVID-19 emphasised this had profound implications for the participants I had sought to interview and made recruitment amongst this group particularly difficult. Consequently, as discussed earlier in this chapter, it also influenced my choice of method how I conducted the interviews. My participant recruitment and data collection were heavily delayed and influenced by the pandemic and this section will explore my thoughts and feelings as I was finally able to progress into data collection.

I have maintained a job in healthcare alongside this research process, I was keen to do this as I felt it connected me to the real world and the very people who I hoped would benefit through the impact of my findings. In early 2020, I was working as part of a general surgical ward when it became apparent that COVID-19 would require significant intervention to manage its spread. As lockdown began in March 2020, I watched management rally to reallocate staff based on their abilities and training. As a professional, I found myself before the Head of Nursing for palliative, end-of-life and bereavement care and redeployed to a specialist team. As a novice researcher, I found myself floundering. I should have been recruiting participants. However, I found organisations hesitant to reply or commit to gatekeeping for my study as they were concerned for their future, the safety of themselves and their communities, and preoccupied with transforming their services onto the internet.

In these early months of the pandemic, the dominant political and media rhetoric centred on the vulnerability of older adults to COVID-19 (Monahan et al., 2020), and those who also have a long-term physical health condition (Robinson, 2020). The constant headlines in this regard concerned me, firstly the impact it would have on older adults themselves and secondly how it would impact my research.

Data is inevitably framed by the time and conditions from when it is collected, so I knew Covid would inevitably feature within the research. However, I was aware that I needed to be careful not to assume all the participants would want to talk about it or even consider it a significant factor in ageing and long-term conditions. Beginning the interviews in the summer of 2020 I was still working as a part of a specialist end-of-life care team. My role involved supporting those at the end of their lives, in addition to their families who often due to covid rules were unable to be with them. I attended an inordinate number of deaths in this period with the vast majority being from Covid, and again the majority of those being of older or chronically unwell people. At this time, I was constantly straddling between healthcare professional and researcher. During analysis, I could see this reflected in the data and the prominence and space I gave to participants to discuss the impact of Covid with me, despite it not being part of my research aims. I hoped data collection would prove not all long-term conditions meant increased vulnerability to COVID-19 and that the participants would have unique insights about ageing at home during a lockdown. It would be easy to assume that by spending longer periods indoors participants' perceptions of the home and ageing in place could have been altered. However, I acknowledged that the participants being both older and with a long-term condition could have been isolated to the home pre-pandemic (Baker et al., 2018).

I have considered that it would be equally important to capture my own reflexive stance as a means of contributing to the research as much as it would be a means of checking researcher bias. Building on the work of Koch (1998) who uses reflexivity as a way of developing rigour in qualitative research, this thesis will utilise the researcher's voice in addition to the participants to build a picture of researching during a pandemic.

3.13 Chapter Summary

This chapter has justified the methodological and analytical approach in relation to the research aims. The chapter began with a discussion on the conceptualisation of the study, reiterating the knowledge gap identified in the literature review. The complexity of involving older adults in participatory methods was discussed given society’s propensity to overlook them. The narrative constructed argues for a methodological approach that would facilitate their voices as central rather than marginal.

The discussion moved onto the paradigm for research and how constructionism offers an opportunity for no singular voice to be overlooked or considered inferior. In doing so a comprehensive discussion was dedicated to the multiplicity of experiences, particularly for those with LTCs. I also considered the rationale for exploring AI as a methodology and consequently why it would not be used exclusively but instead to inform this research. I have also explored reflexivity and its importance to both this research and its ontological stance. The following chapter presents some reflections as I entered the data collection phase of the research.

Chapter 4: Findings

4.1 Chapter Overview

In this chapter, I consider the findings from the analysis of the interview data. As part of my reflexive stance, my reflections are woven throughout the chapter to capture my thought process and challenge existing bias. At conception, this thesis intended to move away from deficit-oriented methodologies and sought to strengthen the narrative of positive interactions in health and social care. However, both the physicality and mentality of ageing and illness are profound and by not exploring the negative along with the positive we risk erasing the narrative of this hardship that is so closely entwined with illness. The findings were overwhelmingly positive, and the older adults had excellent insight into what was supportive and helpful to them. However, the participants did identify some areas they felt could be strengthened with some changes which reaffirmed my decision to include negative experiences as influenced by Johnson (2011). The experiences of the participants are explored and contrasted against the experiences of other participants to reaffirm the multiplicity of experience underpinning social constructionism (Burr, 2015). There were five main findings of this research each of which has several subsections. This chapter will look at each theme in turn and conclude with a summary. The themes are: adjusting to living with LTCs, accessibility and physical environment, experiences of using health and social care services, communication and information, and engaging with others.

In this chapter, I present an introduction to the participants (please see table). I felt that the stories and experiences of the individuals were guided and shaped by the nature of their conditions and their experiences. Therefore, this chapter will explore how living with an LTC impacts different areas of the participant's lives and shapes how they think and feel. The chapter begins by exploring the initial onset of their LTCs, and how this changed the participants' lives and everyday experiences. The discussion will then look at the participant's social needs. The interviews supported the idea that becoming older and having an LTC can impact an individual’s social life. The chapter will then examine the participant's experiences of this, and how important maintaining social connections is. Finally, as I familiarised myself with the transcripts, I realised that the participants all had different mindsets about their conditions and their outlook on life. The final part of this chapter explores how individuals have framed their conditions and how this impacts the way they live their lives.

4.2 Participant Table

Table two outlines the participants involved in the study and details relating to them. Pseudonyms have been used to protect the participant's identity but have been chosen based on cultural and age appropriateness. The choice of information collected and presented in this table is purposeful, and intended to be vague enough to avoid identifying the individual but to provide information to make sense of their narratives. For instance, for some participants the nature of their condition and the amount of time that has passed since diagnosis is interwoven into their narratives and experiences. It is necessary to concede at this point that I did not collect ethnicity data for my participants, again, this was intentional. This study aimed to understand what works well for participants and to elevate the voices of the participants. Therefore, I felt it wasn’t for me to say whether ethnicity was an influencing factor on whether something was helpful, but if it was, I felt confident that the participants would raise this.

Table 2: Participant information table

Participant number	Pseudonym	Age Range	Information on living arrangements	Long-term health condition/s	Time since the first diagnosis	Medium of data collection and length of interview
1	Peter	66-70	With partner Homeowner Family home	Hypertension	2 years	Video call 52 minutes
2	Alice	66-70	With partner Homeowner Accessible bungalow	Myeloma, kidney failure, osteoporosis	12 years	Video call 45 minutes
3	Sue	66-70	Alone Homeowner Family home	Ulcerative Colitis, previous breast cancer with ongoing complications	18 months	Video call 33 minutes
4	Rosa	71-75	With partner Homeowner Family home	Sarcoidosis, Diabetes, glaucoma, osteoporosis, arthritis	20 years	Telephone 55 minutes
5	Jeff	81-85	With partner Homeowner Accessible flat	Amputation (leg) above knee, circulation problems	10 months	Video call 46 minutes
6	George	86-90	With partner Homeowner Family home	Stroke, circulation problems, leg amputation below the knee	11 years	Telephone 50 minutes
7	Ian	76-80	Alone Homeowner Family home	heart disease, kidney disease, bowel disease, scarring of the liver	30 years	Telephone 48 minutes
8	Linda	66-70	With family Homeowner Family home	Depression, back injury, sciatica, hearing loss	45 years	Telephone 51 minutes

4.3 “I one day just couldn’t stand up on that leg, literally.” – Adjusting To And Living With LTCs

This theme was constructed out of the initial conversations I had with participants about how their conditions started and how they impacted day-to-day life. The sub-themes here show that LTCs can begin and progress in a multitude of ways but parallels can be drawn. However, I also contend that individuals process this change differently based on their social surroundings and personal mindset.

4.3.1 The Onset of Long-term Conditions

The participants were open to talking about their conditions and were keen to share how their LTC started and progressed. Listening to their stories, each participant had a unique story that manifested in differing ways and had varying implications. The nature of how the LTCs started amongst the participants was fairly evenly split between those with a sudden onset of ill health, and those for whom it developed over a longer period. Many of the participants who experienced a sudden onset had been previously well and independent, and they told me that for them, the diagnosis was often associated with shock. For instance, Alice sneezed one day and the significant back pain she experienced afterwards led to her diagnosis of myeloma[2].

The sudden change from health to illness was devastating for some participants, including Alice who told me it meant that they needed to make significant mental, emotional, and physical adjustments that they were unprepared for. I interpreted that Alice’s account was consistent with being in shock and that initially, it had manifested as denial. This was also apparent in Peter’s account of becoming unwell. He described being transferred to the hospital in an ambulance after experiencing a significant cardiac event.

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[2] “Multiple myeloma, also known as myeloma, is a type of bone marrow cancer. Bone marrow is the spongy tissue at the centre of some bones that produces the body's blood cells.” (NHS, no date: online)

> My ambulance trip to the hospital, which came as a complete shock. I suppose I wasn't totally conscious of what was going on. Whether that was deliberate closing stuff down I don't know. I remember it because it was 5 o'clock on a Monday and the traffic was bad so they said we'll put the blues and twos on, and I said oh that's perfectly reasonable, but actually it was because I was in so critical condition at the time. So, all those times I just wasn't taking it on board. (Peter: 130).

Both Alice and Peter appeared unable to comprehend the seriousness of their conditions in the early stages of becoming unwell. My experience as a health and social care professional meant I was drawn to this as it compared with my experiences supporting others, and the literature that suggests that people can struggle to make sense of illness (Conrad and Barker, 2010). In practice, I have witnessed many people undergo a shock diagnosis that could be life-changing and I was interested in what the participants felt was helpful in this situation. As a practitioner, it was evident that supporting people to remain calm and reassured but conveying the seriousness of an illness could have significant implications for a person's experience of their condition. Jeff was another participant for whom life changed very suddenly, he described one day feeling fine and the next unable to stand.

> I one day just couldn't stand up on that leg, literally. The previous day I'd been in the garden doing things. As much as I could, the leg always gave me a bit of trouble. Just one day I couldn't stand up on it, two days later I was in hospital and never got back to my house … So, there was no forewarning or preparations for the fact that I couldn't even get back into my own house. (Jeff: 238).

Jeff's account differed slightly from Alice and Peter's experiences, in that he knew he had an LTC but in the longer term, it was stable and largely unproblematic. For him, his shock came with a sudden deterioration in health which led to an emergency leg amputation. Rereading the interview transcript, I felt that Jeff knew he had a health condition but did not seem to be aware of the implications of it and how quickly a change could occur. Additionally, he described being wholly unprepared for the fact that as a result of his amputation, he was never able to return to his home. In this instance, his change of living arrangement was also a shock and emphasised to me the unpredictability of health. It also coincided with literature that suggests support should be offered to people with new diagnoses of LTCs to help them with the adjustment process (Naylor et al., 2012). George had also undergone an emergency leg amputation after doctors had been unable to clear a blockage in his artery:

> It was a botched-up job the artery disintegrated while they were trying to remove the blockage. And it was panic station it was down to theatre. Terrible pain, terrible pain. That was it. But there was a period after that happened when I probably had 2010, I was in hospital from about January to probably end of March. (George: 191)

George's account of his amputation and the onset of his subsequent disability differed from Alice, Peter, and Jeff's. He described the amputation as unexpected but not shocking.

Although he had not expected to lose a limb as a result of his condition, he was the only participant not to discuss the negative implications it had had. I had become used to, in practice, in the literature I read and from the preceding interviews to hearing how LTCs had been an unwelcome addition to people's lives (Francis et al., 2018). Therefore, I was surprised to hear George describe his sudden health change as a blessing and a positive life event. In contrast to the findings of Francis et al (2018) which emphasised that LTCs can leave people marked by loss, George believed his amputation was a sign from God to be more present with his family.

The other four participants described their conditions as the result of a long-term decline in health. Although the change to managing a long-term health condition was not sudden, it still had physical and emotional implications. These accounts also reiterated to me, however, that whilst all a long-term decline the process of becoming more unwell was not a homogenous one and varied on social conditions as much as the individual medical condition. Ian described to me how the combination of treatment side effects and lifestyle choices had negative implications for other aspects of his body and his health:

> I had a quadruple bypass in 1988. Then I had a triple bypass in 2014 which was complicated. It included repair to a mitral valve and the use of a lot of anaesthetic and antibiotic burned up my kidneys. The bowel disorder and liver disorder are products of a recent illness. (Ian: 29)

Ian's account resonated with me about the many different ways a person's health could change and deteriorate, whether from lifestyle influences such as smoking or overuse of medication damaging organs. The exacerbation of Ian's symptoms came from having multiple LTCs and lifestyle factors. Initially, Ian described the decline in his health as being the result of a knock-on effect one condition had on another. By having one biological system impaired it had caused issues for others. However, as the interview progressed and we discussed this further, Ian disclosed that he didn't feel resentful towards modern medicine but instead accepted that his illness was likely his own fault. He described feeling supported by services but expressed regret at his inability to take his health seriously.

> What they do, they do well, and they do willingly. If there was anything to be changed it would be my lifestyle when I was a young man. (Ian: 124)

The NIHR (2021) has highlighted the growing interface between multimorbidity and lifestyle factors, indicating how they can adversely impact each other. This indicates that Ian's experiences are likely to resonate across a wider portion of the population. Sue also disclosed receiving her primary diagnosis as a result of a knock-on effect from other health issues she had faced. After being treated for cancer, she was diagnosed with ulcerative colitis[3] and Crohn's disease[4]. Sue felt that her conditions were largely manageable, however, and primarily was relieved to be living with them rather than with cancer. Unlike Ian, however, Sue had limited personal agency for controlling her probability of developing an LTC. Rosa also described having limited control over her

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[3] "Ulcerative colitis is a long-term condition where the colon and rectum become inflamed …. Small ulcers can develop on the colon's lining, and can bleed and produce pus." (NHS, no date: Online)

[4] "Crohn's disease is a lifelong condition where parts of the digestive system become inflamed." (NHS, no date: online)

health, she was diagnosed with sarcoidosis[5] which was linked to genetics rather than social factors. For Rosa, her experience of adjusting to and living with an LTC was overshadowed by the time and difficulty she endured to obtain a diagnosis:

> It was not diagnosed for 10 years; I was suffering silently. Because I did all the tests, and they couldn't find anything what is causing me this trouble and they said. And then I thought it was in my head there is no problem and then I thought I got depression because it went worse and worse, I couldn't do anything. I was lethargic I was stuck in bed for long hours. I couldn't sleep I couldn't look after my daughter. For ten years I lived that way. Then accidentally, I was diagnosed with this illness. (Rosa: 48)

Rosa was another participant who told me that her health declined over time, and what started with seeing floaters in her eyes[6] devolved into significant physical symptoms. I had not heard of sarcoidosis before speaking with Rosa, so after the interview spent some time researching it to try and understand more about her responses and experiences. Rosa stood out for me as the participant who was struggling the most with her diagnosis, though this was primarily because if she had been diagnosed early enough it could have been cured. This is consistent with Milne (2012) who emphasised the difficulty in attaining a diagnosis for certain conditions and the negative impact that has on an individual's outlook. I empathised with Rosa during our conversation, her frustration was palpable, and she struggled to identify positive aspects of her care and experience of living with an LTC. However, having researched sarcoidosis I realised how difficult it is to diagnose due to the generalisability of its symptoms. This was not of comfort to Rosa who described living in considerable distress, however, it made me think about preconceptions of modern medicine. Was it that Rosa had assumed that doctors had all the answers, and reality had not matched this expectation? When I asked about her LTC and how it impacted her life, Rosa described a sense of betrayal, disappointment, and mistrust toward health services.

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[5] "Sarcoidosis is a rare condition that causes small patches of red and swollen tissue, called granulomas, to develop in the organs of the body. It usually affects the lungs and skin… a few people find their symptoms develop gradually and get worse over time, to the point where they become severely affected" (NHS: online)

[6] Floaters are small dark dots, squiggly lines, rings or cobwebs in your vision (NHS, 2020: Online)

> My doctor, he let me down me you know. If he referred me in time my sarcoidosis could have been caught early…. So really let down. I feel if I knew because I trusted my GP you know. At that time, I actually wasn't well because of this issue and because of the illness, I could not make the right decision to go again and find out. I was waiting for him; my mind was not alert. Sometimes I feel I have been very unlucky. I would ask once and if they did not respond I did not ask again. But I had to pay a big price, my whole life has been ruined for the last 30 years. It's getting worse and worse. It's an ongoing thing and it'll only get worse. (Rosa: 146)

I noted in my reflective journal at the time that Rosa had expectations of omniscience amongst medical professionals. This was consistent with my own experiences in practice, whereby there has become an expectation for medicine to have all the answers. Whilst it is not my role in this research to apportion blame or exonerate a particular party, I did feel that Rosa's deep sense of hurt was tangible and had framed her ability to adjust to and live with her condition. Additionally, Rosa talks about not being able to go and find out for herself and about her mind not being alert which is consistent with Miserandino's (2010) spoon theory. The theory explains how people with LTCs only have limited energy to explore everyday life, in this sense what would be helpful for Rosa is assistance in navigating an often complex and disjointed system of healthcare (Banerjee, 2015).

Linda was the final participant I interviewed, and I felt she represented a unique case in the group. She told me that she had several long-term conditions, although her arthritis was age-related, her other conditions were attributable to her workplace. Linda is a frontline NHS worker and described a back injury that occurred at work decades ago resulting in sciatica. However, she also disclosed developing a respiratory illness from poor working conditions.

> I started with [job role] 6 years ago, up until 2 years ago we worked for 4 years in a dirty portacabin. It was that bad I had to get [union] in and health and safety, I was only there 3 months and I started with ENT problems because of the black mould and dirt. (Linda: 39)

I was surprised by Linda's comments as my own experiences of working within the NHS were in clean clinical conditions, yet I was equally aware that occupational lung disease remains highly prevalent in the UK (Taskforce for Lung Health, 2023). Linda was the only participant still working full-time; however, her respiratory condition placed her at significant risk when she later contracted COVID-19. For Linda, being diagnosed with another condition was significant as she was concerned it would impact her ability to continue working. Heading into data collection I had not expected many of my participants to still be working, and I had also overlooked how causes of poor health could include the workplace and associated occupational illnesses. Linda described how her condition had now improved but that she was now struggling with long-covid due to the ongoing impact the black mould had had on her lungs.

Moss-Morris (2013) describes adjusting to illness as a complex construct and encapsulates not just the mental health changes associated with diagnosing an LTC but also the impact it has on health behaviours and everyday life. My findings broadly support this and provide examples of how adjustment can differ based on personal and social structures. Additionally, the participant's experiences reflect the varying trends across UK society and cemented my earlier criticisms in the literature review that not all conditions could be prevented with lifestyle changes. However, these findings tell us that the early diagnosis and full understanding of a condition supports older adults to feel in control and empowers them to make choices on how to adapt and live with their conditions.

4.3.2 Maintaining Social Connectivity

Before starting the interviews, I had immersed myself in research that linked ageing and poor health with increased social isolation. George was one participant who recognised the impact of growing older and a shrinking social circle and told me that some of his friends had died and that meant he didn't experience such a good social life. However, George also described maintaining an active social life within a faith-based community which was extremely important to him. He described how the church community frequently met within his home and therefore, his LTC did not prevent him from socialising with others. On the other hand, Rosa's experiences supported the traditional view that experiencing poor health could act as a barrier to engaging with others (Francis et al., 2018). She told me:

> I don't do any social activities. Because I think over the years, I lost the confidence to mix with people. When people come to my house, I am terrified, and it has got worse with lockdown. Only there is some friends that want to come I am terrified. It is funny sensation because I'm like what should I say? It makes me scared you know. (Rosa: 112)

Rosa appeared to me to be insightful about her isolation, she knew she was isolated and wanted to change that. However, I noted in my reflective journal that she presented as under-confident and would likely need support or encouragement to change this. As we were talking, Rosa asked me for recommendations as to how she could improve her social networks. I was surprised by Rosa's request as she had been signposted to my study by a community organisation that facilitates exactly that, yet it appeared she had not made this connection herself. Rosa's interview took place during a lockdown period in 2020, because of this she explained that her fear of mixing with others had been exacerbated by Covid.

> It's been very dreadful because I don't see much people but because of COVID I hardly see anyone now. It's been more difficult for me to speak to people now because of COVID... I think I'm losing the confidence in the lockdown, I'm becoming more isolated. It's been so long now that I don't know whether I could make contact with someone new unless it's a carer or someone to come to the house to help me. (Rosa: 278)

Without follow up it is unclear if Rosa's fears led to a long-term decline in her desire and confidence in interacting with others. She did, however, describe herself as isolated and discussed her struggles in conversing with others, explaining that trying to socialise made her feel foolish. Rosa's account of being isolated was painful for me to listen to, I encouraged her to get back in contact with the community organisation I had contacted her through in the hope it would improve her situation. When I compared the experiences of the other participants against Rosa's account of isolation, I noticed that the others described being normally well-connected, but isolated during Covid lockdowns. I was surprised that no one else disclosed feeling lonely normatively as the literature I had experienced presented this as a given, both for older people and those with LTCs (Francis et al., 2018). This finding suggests that becoming older or having an LTC does not equate to increasing isolation. However, it is also significant that older people are aware that maintaining social connections is important to sustaining their health and wellbeing and therefore, critical to successful ageing in place.

It was, however, unsurprising, that the participants focussed on the impact of lockdowns on their mental health. Heading into the interviews for the study, I knew that COVID would feature as the interviews were conducted in the period after the first UK lockdown and up to the beginning of the second lockdown in the autumn/winter period of 2020. All the participants described voluntarily opting to shield whether due to age or health meaning that their social contact even between official lockdown periods was significantly impaired or self-restricted. Jeff described his experience due to his age as ‘In isolation, in a cell, however, you want to put it!’ (Jeff: 59).

Several participants explained that they would not have bothered to shield based on age alone, they felt that it was the health status of themselves and their partners that encouraged them to do so. For example, Jeff told me that his health conditions meant that he was classed as vulnerable and perceived as needing hospital care if he contracted COVID-19 which would lead to fewer intensive care beds. Rosa discussed feeling more vulnerable and not being able to go shopping. Her world had shrunk to her house and garden, and she no longer saw anyone other than her husband who was awaiting an operation. She said, ‘I feel like I’m stuck on this little island now for a year’. I felt that Rosa was struggling with identifying positive aspects of her life throughout the interview. In this instance, I noted in my reflective journal that Rosa was extremely lucky to have access to a private outdoor space during lockdown, but she hadn’t recognised this. This is significant to my findings as it demonstrates that it is easy to see negatives but less so to reframe and see positives in our situations.

From interviewing the participants, it was apparent that Covid had exacerbated health anxieties amongst the participants, and it was this that contributed to a growing sense of isolation during lockdown. It is worth noting that media rhetoric on older people at this time was particularly sensationalised and was likely to impact the way the participants felt (Harper, 2020). However, Jeff also explained to me that he felt his fears were accentuated by those of his partner and friends:

> It's had a dramatic impact since as it has for most people. My partner didn't really want to go out. I had friends who quite literally locked themselves away, did everything via the internet. Just made the decision they were going to keep away from everyone. So, there was that isolation aspect, the fear of people coming into the house and carrying it. The really feeling that in society as a whole that a lot of people hadn't grasped the real threat of this disease. It could hit anybody and dramatically. (Jeff: 272)

Jeff's concerns are consistent with findings from Philip et al. (2020) who found many people's main concern was of infecting or losing loved ones rather than the risk to themselves. This was an important finding as it demonstrated the strength of desire people had to protect loved ones whilst maintaining relationships with them. Although this statement is important in the context of COVID-19, it also demonstrates wider implications for considering LTCs. It suggests that older adults may prioritise the well-being of others more than themselves, including choosing to age in place for the benefit of others or to maintain close connections rather than based on their own needs. However, further research would be needed in this area to positively assert this.

Being connected with family and friends was frequently cited as crucial to the participant's well-being. However, the impact of being isolated from family and friends was evident throughout the interviews with several participants describing themselves as becoming or feeling depressed. Peter told me he felt depressed and having previously experienced depression when he had retired, he could tell the difference between feeling down and being depressed. Ian explained feeling down about not being able to connect with his family and grandchildren. Sue also explained that she felt okay about not meeting other people but was worried it may impact how she felt if it continued for longer.

What was unclear at the time of data collection was whether these feelings of isolation and depression would have long-term consequences for the older adults or whether they would allay with the lifting of restrictions. Inevitably during the interviews, I spoke to the participants about their experiences of lockdown, as this had permeated home, social and health care. However, whilst some participants had concerns about contracting the virus, they mainly framed this time by the disconnection from their families. Covid was a frame for the participants to realise the extent of the impact friends and family had on their well-being. For them, what made the most difference was not formalised health and social care but the relationships they had with their loved ones. Alice illustrates this point as she describes how she had previously regularly cared for her grandchildren and was finding the separation from them particularly painful. She told me that a new grandchild had been born during lockdown and she was upset not to be able to bond with her and had only seen the baby once outside through a porch window. Other participants did not live close to their families and described learning to use online platforms such as Zoom and Skype[7]. Peter positively reframed one of his answers to me during the interview. He initially described feeling socially isolated but then thought about it and instead revealed that he felt fortunate to be able to see his family's faces and socialise by using online platforms such as Zoom. George also told me that using Zoom had been revolutionary, and he was able to maintain the connection to his church and religious groups. He also described how the pandemic had encouraged his use of technology which he would now continue to use post-pandemic if his health prevented him from being able to socialise in person. This is consistent with evidence by Weil et al. (2020) who have noted COVID-19 as a way of reframing technology and increasing its use for older

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[7] Zoom and Skype are free online video calling platforms.

people. Alice also explained to me that she had learnt to Skype as a means of mitigating her social isolation and maintaining some of the childcare responsibilities she was missing with her grandchildren. Whilst the pandemic certainly led to increased isolation at the time of lockdowns, preliminary post-pandemic studies are indicating that it also increased digital literacy and learning amongst older people driven by a desire to connect with others (Sixsmith et al., 2022).

Social connectivity is closely linked with positive health and wellbeing outcomes (Bruggencate et al., 2018). This study has contributed to knowledge by finding that being older and having an LTC does not equate to social isolation. Additionally, reflecting on the interviews, I realised that maintaining a connection with others far outweighed any other concern for the participants during the lockdown periods. Technology was a common theme in this section, likely due to its importance in maintaining connections during the Covid lockdown periods. George emphasised how important technology was in enabling him to maintain social contact in the event his amputation prevented him from physically being able to leave the house. This is important for the future direction of services for older people. The increase in uptake during the pandemic (Sixsmith et al., 2022) means that older adults are more technologically literate than previously, and opportunities should be made available to them online. However, this section also demonstrated that not all the participants were able to appreciate what was working well in their lives and Rosa struggled to find supportive practice in almost any aspect of her life.

4.3.3 Personal Mindset and Adjusting to LTCs

As I was transcribing and analysing the interviews, I realised that the participants approached transitioning to and coping with older age and illness/disability in different ways. Rosa, in particular, was overwhelmingly negative about their experiences and appeared, to me, to be struggling the most. While George was overwhelmingly positive about his experiences and described his amputation as the best thing to have happened to him. The other six participants described personal struggles whether due to the diagnosis, symptoms, or changes to their lives. However, they all seemed to find a motivating factor that drove their desire to live with their LTC rather than simply exist with it. Rosa was the sole participant who was overwhelmingly negative in her discussion of her illness:

> It has really ruined my life. I had to give up my work I thought I was depressed you know; I could not do anything. The doctors said there is nothing wrong. Then I couldn't cope with everything... It affected everything you know it really ruined my life, my job, my quality of life. (Rosa: 81)

It is notable that Rosa also had the most difficulty in attaining a diagnosis and validation for her symptoms (it took ten years) and had been symptomatic for a considerable amount of time despite many tests. This had led to depression, and she described being stuck in bed and unable to care for herself and her daughter. In many ways, Rosa's experience reflects that of a contested or invisible illness (Milne, 2012), as she had to fight for a decade to be given a diagnosis whilst having her symptoms downplayed by medical professionals. Research indicates that people who experience this challenge to attain a definitive diagnosis often experience poorer mental health due to the lack of validation and support regarding their symptoms (Armentor, 2017).

The nature of the symptoms and the extent each participant's condition impacted their life were variable. I began to wonder, was the participants' outlook related to the level of disruption LTCs had on their lives or due to their own mindset and framing. George was the only participant who remained entirely positive throughout his interview. He described receiving a leg amputation as revolutionising his life for the better.

> My family's been a very important factor in my coping with disability.
> Interviewer: In what way?
> George: A huge way because they just, I'm a proud father. Now particularly because I've been slowed down. I think to some extent having the amputation improved me as a person. It's about, almost God said yes, you've been a bit wild and what have you, I think now you're getting on a bit you should slow

> down and be a bit more considerate. That's one of the good things that's come from the amputation and the false leg. (George: 71)

During the analysis, I started to link some of my thoughts around the impact personality and outlook had on how the older adults transitioned to having an LTC and how they learnt to cope with it. From this, I drew comparisons to the anticipatory principle of AI, which asserts that we learn from what we imagine for the future and that if we imagine the future as being positive then we are more likely to strive to make this a reality (Bushe and Kassam, 2005). The participants in this study who felt positive about living with an LTC reported much more positive experiences as part of their narratives. However, not everyone was able to adjust as quickly or positively as George and several participants disclosed that they found the transition to be difficult.

> I think it's more to do with living in the knowledge that you've got a severe illness or disease or whatever you want to call it and having to adjust to certain things. Adjust your way of thinking, adjust your way of living, adjust your life plans from being long-term to, well I better do that now just in case kind of thing. It's hard to put into words … I think when you realise that it's you and it's you that's got it, not your pal or someone in the street. It has an impact within you that it's difficult to explain. Gratitude to things change, your plans change, your objectives change. And your attitude to problems and situations changes, you know they either become exaggerated and more important or become irrelevant and less important. So, there's a change in approach and your attitude to things. A lot of people I wouldn't say they give in to illness, but they let it dominate them. I've never done that. I've just continued as normal as possible. (Ian: 135)

Ian's words reflected my thought process, could maintaining a positive mindset have influenced the experiences of the participants? Alice also felt her outcomes and ability to cope came directly from her frame of mind. Her myeloma, although in remission is not curable and is considered life-limiting. Despite this, she appeared determined throughout her interview to maintain a quality of life, something that I specifically noted in my journal at the time.

> So I think the fact that despite everything I've continued to see people is quite important to me. But I wouldn't like to think I'm negative about my life really though. Despite all of these medical problems, I'm a very busy person I do a lot

> with my life. I run a support group for people with myeloma and that keeps me working. (Alice: 232)

Alice, like Ian, maintained that a positive mindset was important to achieving a good quality of life. This contrasted sharply with Rosa's description of her experiences and her failure to address any positive aspects of her life. I started thinking more about the internal drivers that impact how we construct managing health and well-being. I realised that Rosa's inability to recognise positive aspects of her life and overall negative assertions align with some of the critiques of positive or asset-based approaches. I realised I had assumed that in adopting a particular mindset health could be altered positively (Daly and Westwood, 2018). However, there is evidence that having a positive frame of mind can improve resilience to the challenges associated with poor health, and additionally, having resources to mobilise can better a situation. For instance, many of the participants spoke of things they could control that gave them some agency over their health or well-being. Ian and Peter described this as being retrospective. They acknowledged that their health behaviours had attributed to their diagnosis but accepted this and altered their habits to reduce future risk:

> I'd not looked after myself as well as maybe I should have done, so I used to smoke, and I stopped smoking with absolutely no issue when I was in hospital. Just lost any interest, breathlessness, in smoking. So, I smoked, and I drank, and I exercised quite actively but intermittently. So, I didn't quite abuse my body, but I didn't look after it as well as I could have done. And I could have done a lot more damage than I did. (Peter: 171)

In contrast to Rosa who felt everything to do with her health was out of her control, Peter and Ian sought areas that they could control and made changes accordingly. However, I acknowledge that the nature of the conditions between the three was different and was likely to have a bearing on this outcome. Jeff and Ian's conditions could have been prevented with lifestyle changes; however, Rosa's condition was genetic and therefore, outside of her control. However, I felt there was a sharp contrast between Rosa's apparently defeatist attitude and the mindset of the other participant who seemed to be saying, well I have this condition, but I won't let it stop me. In this sense, I felt that Rosa was reliant on external forces to help and drive her.

Instances of this are presented throughout the findings, but notably, she feels that medical professionals did not do enough, and she hasn’t heard from any services and therefore wasn’t able to make any changes to her life. This links back to the anticipatory principle, as Rosa felt overwhelmingly negative about her future and struggled to find positive aspects of her life. Whereas the other participants looked at what they could do themselves to improve their condition and actively sought support.

> It took about 3 months before I started to feel a little bit better. I was determined to do so, and I did things like walk to the end of the cul-de-sac that I lived in at the time and back and that would exhaust me. And then the next time I’d go a street along and I’d gradually do a bit more. (Alice: 133)

Alice described the chemotherapy process as brutal and commented at one point that her consultant had described her as having a particularly bad time of it. This comment from Alice made clear that the support of professionals could impact a person’s thought process and consequently their experiences. Rosa felt she was not believed or supported by professionals whereas Alice described how reaffirming it was that her consultant was supportive and understanding in what she went through. Alice described being strongly motivated to recover from her chemotherapy because it was important to her to feel like her old self and maintain a quality of life. As I thought about this more, I began here to question my preunderstandings. Was it that the participants had a positive outlook that drove them towards rehabilitation or was it that they had a motivating influence, and incidentally how much of a role did other people play in this? Alice, in her quote above, describes being motivated to get better, she identifies maintaining friendships and keeping active as being important to her and this appears to drive her to push forward. Similarly, earlier in this section, George describes how his family made him appreciate life and what could be achieved from it, therefore preventing him from seeing his disability as a barrier. It became clear that other people were as motivating a factor to get better as was personal independence (Jowsey et al., 2014). As I read back over the transcripts, I realised that Linda identified a different personal motivating factor. Having witnessed a sudden health decline in her grandmother following retirement, Linda stated that she intended to stay well so she could continue to work.

> I'll work until then [age 70] and perhaps retire and do one or two shifts on the bank a week. Because dementia runs in my family. My gran, she was only retired 6 weeks and she started dementing because she'd worked since she was 12 and had 7/8 kids and always worked. She demented 6 weeks after she give up, she started leaving the gas on, disoriented time, place, and person so. So, I'll carry on as long as my health, just doing a couple of nights post turning 70. Keep the old brain cells ticking over. (Linda: 258).

Linda had used her previous experiences to shape what she wanted for the future, framing herself as an expert by experience. She understood that cognitive decline was possible if you don't keep active in older age (James et al., 2011) and this motivated her to keep working and consequently change her health behaviours so she could continue to do so. Linda described previously having been 18 stone and as a result, had needed to walk with aides and witnessed a decline in her health conditions. She felt that if she had not lost the weight, she would be unable to continue working and subsequently be unable to pay her mortgage. Linda reported taking control of her health and weight by changing her lifestyle and opting for a gastric sleeve which means she now feels well, able, and independent. I felt that Linda's drive for a better life was motivated by a variety of factors, she wanted to continue to work for her well-being, she had financial pressures that meant she needed to work, and she didn't want to be reliant on mobility aids. Ian was another participant who recognised that he felt embarrassed by the side effects of his health. He used this as a motivating factor to take control of his health and work towards getting better. After spending a period in hospital, he realised he could not cope at home but was embarrassed about what others may think of him if he raised this.

> Sometimes I just, I would be watching tele and it would be bedtime and I just didn't have the strength to go up the stairs. I didn't tell anybody at the time, but I just used to sleep in the armchair. Gradually I got my strength back, gradually. (Ian: 115)

Ian used his social embarrassment to motivate himself to engage with rehabilitative services and return to his previous abilities. However, towards the end of the interview, Ian made a comment, that I think has stood out to me more than any other.

As the interview was drawing to a close, I asked Ian if there was anything else that he wanted to share, anything he felt that was important to him that I may not have asked about. He replied:

> My ambition is, and you can laugh or not. My ambition is to live for another 4-6 years so I can see all four of my grandchildren go to and finish university. That's mine. I don't have any personal ambitions anymore; I've filled all those. For me, it's about my grandkids. (Ian: 207)

I thought about that sentence for a long time after the interview ended, and I found myself repeatedly drawn back to it. After the interview, I wrote in my reflective journal that it made me feel sad. I had interpreted Ian's comments to mean that he was unable to find gratification in his life outside of seeing his grandchildren. However, after some reflection, I realised that Ian had described being motivated by embarrassment and talked extensively about the importance of his social life and seeing his friends. Therefore, there were other motivating factors in his life, and I had likely taken the comment in isolation to the wider context. I have since come to understand the comment as Ian describing his grandchildren as his motivation to remain well and continue to live his life as fully as possible despite his health conditions.

4.3.4 Summary

In summary, these narratives support the literature review findings that illness and ageing are not homogenous experiences (Harper, 2021). Adjusting to a LTC was an important part of the journey for older people, they described the different ways this happened for them and how they adjusted their lives accordingly. The participants also had different wants and needs as their conditions and mindsets varied and each experience was unique. However, it was important to them to be motivated to adjust and live with an LTC.

The findings identified two major factors that influenced the participant's motivation to manage and live with their conditions, this was personal drive and interaction with others. The personal aspect was driven from experiences, they wanted to be able to do things they previously could do, or they recognised that if they could not make changes they would be limited in the future. On the other hand, the impact of others relates to the constructionist principle of AI. The viewpoints and behaviours of others have the potential to shape our reality. Supportive relationships with professionals to help with the adjustment to LTCs led to improved outcomes, this is explored further in section 4.5 experiences of using health and social care services. Remaining socially active was also an important driver in thinking positively about living with an LTC. The participants acknowledged that age and health changed their ability to do this, but socialisation was important to feel they had a good quality of life. Wanting to continue to engage with others was also an important motivating factor to engage with rehabilitation and become as well as possible. Having and protecting social connections was paramount to feeling positive and working towards better well-being.

I identified that maintaining social connections during the pandemic was a major challenge and form of distress for the participants, more so than the risk to their health. Consequently, several participants identified using technology as a facilitator to this and felt they became more technologically literate as a result. This is consistent with existing research (Sixsmith et al., 2022) and underlines the need to encourage digital literacy or not discount its usability for older people. There is also learning here that older adults are not averse to change if it has benefits for them, particularly as an enabler for social participation.

This chapter highlighted that managing an LTC and becoming older was not easy for the participants. However, the participants were able to find positives in the situations and for the most part continued to live their lives as they did pre-illness but with some modifications. It was interesting to note the importance of having a driving factor for the participants. It appeared that being motivated manifested a more positive mindset and better well-being outcomes.

4.4 “I get told off now for doing things, told to wait but I can do it myself now!” – Accessibility and Physical Environment

Being able to access people, services and the local community had a significant impact on the participants and their wellbeing. Accessibility is commonly associated with the physical environment; however, it was clear from the interviews that usability was also important to the participants.

4.4.1 Physical Environment

I will begin by exploring how the participants felt their physical environment helped and hindered them. I will then explore the various accessibility themes that the participants highlighted as important in living with an LTC. The literature review identified that many long-term conditions are associated with increased physical needs, therefore, I expected physical environment and accessibility to feature in the interviews. The participants had varying degrees of physical needs, and this was reflected in the different ways they discussed physical accessibility. However, they did all raise the physical environment as a topic of importance to them.

Jeff and George had both undergone leg amputations and self-identified as having a high level of physical accessibility needs.

> I was able to use a dentist I had to do a transfer as they call it. It had to be private, my own dentist was up a flight of stairs and I think that is a factor with something like an amputation. Its access, its accessibility wherever you go, being able to physically get there and get in. (Jeff: 84)

Jeff went on to describe how he had needed to change his dentist from an NHS provider to a private one as the NHS facilities in the area were not wheelchair accessible. I reflected that Jeff was fortunate to have the resources available to him to be able to seek private care. Manchester’s’ high levels of deprivation mean this is unlikely to be a reasonable answer for all older adults with accessibility needs (Wall, 2021). However, Jeff did specify that this was not a universal experience, and he recognised that services were generally accessible, and he rarely encountered this issue. This was echoed in the experiences of the other participants who were keen to emphasise the importance of local services. Ian described living in a community where everything was close together. Therefore, although he could no longer drive his GP was down the road, his prescriptions were delivered to his home, and he uses informal support from family and friends to attend hospital appointments. Ian was keen to highlight how home delivery services were tantamount to overcoming physical inaccessibility and made a big difference in his life. Home delivery services were also praised and utilised by Rosa who indicated that she too was unable to drive and felt that bringing shopping home on public transport was too strenuous for her. Around 40% of older adults do not drive or have access to a car (Age UK, 2019b), therefore, I was unsurprised that many participants acknowledged a reliance on public transport and informal support to access services and the local area. George had a leg amputation and described needing to use ambulance services or wheelchair taxis to get out in the community. He praised the availability of these resources as key to maintaining his social independence and accessing clinical appointments. Jeff also had an amputation but described how it was more challenging to access support in his area:

> the other thing is if you’re in a wheelchair it's actually getting anywhere. I have a contact with the wheelchair taxis. There is the organisation in [area] where you can book but all these systems they are very heavily, not compromised, committed for things like disabled children so that’s connected with the school etc. So there are limits on accessibility and getting access to transport if you need transport. (Jeff: 95)

I recognised here that the nature of the participant conditions impacted what a participant's priority was in terms of accessibility. For Jeff and George who were unable to drive as a result of their amputations, access to transport was key to being able to go out into the community. This aligns with the Greater Manchester Age

Friendly Strategy (GMCA, 2018a) which has prioritised transport on the basis that is fundamental in supporting older people to stay connected.

My findings have also shown that accessibility goes beyond physical mobility. Sue described that easy access to public toilets was essential in managing her Crohn's and colitis symptoms. Sue had no mobility limitations and could walk as far as she needed, however, she disclosed often needing access to a toilet with little warning.

> It affects me in that it’s very difficult to go out because I need to plan going out around toilets. If I go for a walk, I need to go to the toilet so I’ve started taking Imodium before I go for a walk. I cycle so It’s the same thing, so it affects exercise as much as anything. Public toilets are a nightmare. Finding a toilet is just so bad. Having the facilities that you need in a public toilet is a nightmare too. (Sue: 41)

There is a dearth of academic literature surrounding the availability and accessibility of toilets for older people and those with LTCs or disabilities. However, Fenney (2019) has highlighted that a lack of public toilets leads to increased social anxiety and isolation. Manchester City Council does have a website[8] dedicated to identifying public toilets across the city, but it only lists five across the whole city centre. Salford also has an online list, but this is broken down by area indicating a greater number of toilets available[9] compared with Manchester. What this demonstrates is that there are disparities across Greater Manchester and that as Sue has illustrated, not enough public toilets to stem social anxieties. Sue did, however, concede that she had recently acquired a radar key which had increased her access to public toilets. This made her feel more confident in accessing the local community.

Physical accessibility was not just important to the participants within the community, the findings show that people recognise the benefits of having an accessible home. Several authors (Brim et al., 2021; Ouden et al., 2021; Sixsmith and Sixsmith, 2008)

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[8] https://www.manchester.gov.uk/info/500004/events_and_tourism/2360/public_toilets_in_manchester

[9] https://www.salford.gov.uk/health-and-social-care/help-to-get-out-and-about/accessible-toilets/

indicate that the major downfall of the ageing-in-place agenda is the unsuitability and inaccessibility of the home. Alice for instance described how they had chosen to move into a bungalow as her condition meant she was unable to navigate stairs:

> When I was really poorly, I couldn't get up and down the stairs without help, and I just thought given that myeloma is not curable it will probably come back at some point. I didn't want to be at that stage where I couldn't get to bed, and you know I couldn't get up and down the stairs again on my own. So, I suggested that we move to a bungalow. So, we actually bought a bungalow 18 months ago.… this house is much more conducive to being able to cope if I'm not well because we're all on the same level. (Alice: 280)

Alice's thoughts represented a growing realisation amongst academics that when thinking about ageing in place, an older adult's primary attachment was to their locality rather than to an individual home (Pani-Harreman et al., 2021). Additionally, Alice along with Ian emphasised that the availability of accessible housing stock was small and needed improving to increase choices for older people:

> I did at one point think of moving. My wife died 17 years ago and that left me in this house, this house has 5 bedrooms, 2 lounges. It's far too big for me. There was a short period where I looked for a bungalow. But I couldn't find one, so I just abandoned the idea. So, I've unless something happens and I have to go into a [care] home or whatever I don't intend to move, and so that's that. (Ian: 188)

This aligns with GMCA's investment in the accessible housing project (GMCA, 2020), which has recognised this gap in the market and is seeking to address it. However, I also noted at the time of the interview that whilst Ian wasn't wanting to move home, he was not averse to moving into a care home. This contrasts with the literature reviewed in chapter 2.2.1 which suggested that older people did not want to move into care facilities (Chapman, 2019; Pierson, 2008; Timonen, 2008) and yet Ian showed no hesitation at this.

Jeff was another participant who had sought accessible housing, he had managed to find one but described having to move in with his partner while he waited for it to be built:

> I've already moved from familiar surroundings but I'm with somebody who has lived here for a very, very long time since she was a child. So, I've got that as a, it softens the blow so to speak. My intention is to move to a development where you've got an apartment within a building that is wheelchair accessible. The apartment has so you can actually get in the place, you can get around, you can get in the bathroom, you can get to the toilet yourself, you can actually have a shower. It's all fine by wheelchair. So they are specially built, they have wider doorframes etc. so I also have supporting services there if you need them…. Yes, it is the functionality that's the most important for me, I think I could cope with a new location providing I had the independence and that would be the independence to explore that new location. (Jeff: 206)

Jeff was lucky to have a partner whom he could turn to and who happened to have an accessible home to accommodate his wheelchair. The informal support that this was providing is largely hidden from data as it is a temporary arrangement outside of formalised services. However, it was important to Jeff as it allowed him to remain living in the community rather than needing to temporarily move to an assisted living facility. Jeff's perspective was also interesting in the wider scope of ageing in place. Above I have noted how Ian and Alice were drawn to their community as their notion of ageing in place, however, Jeff discloses that he has moved away from his community to live in an appropriate setting. Jeff describes wanting to be part of a community and feeling he can adapt because his partner is already part of one in the area and he could integrate into that with her help. However, Jeff also singles out the importance of independence in choosing a home, this was reflected across all the participants who saw this as tantamount to their wellbeing. These findings support that accessibility is key to promoting independence and ageing in place.

4.4.2 Ease of Use

Reading over the interview transcripts it was a common thread that the participants conceptualised accessibility beyond the physical environment. The participants described different positives and areas for improvement, which varied based on the nature of their condition and the area in which they lived. For instance, when asked about what improvement would most benefit her, Rosa felt that changing the appointment system in primary care would make her GP more accessible to her:

> It is very difficult though you know the GP practice, I don't like to phone them. You're too, I ask someone to phone for me. It's too difficult it's busy busy busy then they put the music on. I get so mad, I can't do it anymore. It's a bad experience for me. I used to love this practice but now all this change and all these things happen I don't have the love for them anymore. Unless it's an emergency I don't go anymore. You have to call when you're in pain you know and it has to be early in the morning. It's too early for me to be up in the morning when I don't sleep well. That is another problem you know. I try not to go or to phone. My husband phones for me sometimes. (Rosa: 192)

Rosa's experience resonated with me, and I reflected that is a well-documented barrier to accessing primary care across all age groups. However, Rosa was the only participant to raise this as an area for improvement and other participants noted that they found professionals easy to access. Alice for instance, described how when she was told she had cancer she was given an appointment with a haematologist for the same day. Alice felt strongly that the consultant providing the time to do this was immeasurably helpful to allay her fears and support her with her diagnosis. In contrast to Rosa, Alice also identified that her GP was very accessible, and she was always able to get the appointments she needed:

> I also have been very fortunate with GPs and the GP practice that I'm at. Even during COVID twice they've seen me, you know I'll ring them in the morning, and they'll see me the same day. (Alice, 104)

Alice did, however, identify that changes could be made in terms of information sharing. She felt that the healthcare system was difficult to navigate as her condition fell under multiple specialities. She described having to double up on medical interventions and tests:

> I think one of the things I'd like to change. Because for haematology I'm under [NHS Trust] but for Renal I'm under [hospital]. The two hospitals although they're part of this [Trust] their information isn't shared with each other. So if I have bloods taken for haematology clinic they can't see the results at the renal clinic. So sometimes I'll literally have bloods taken twice in the same week just because the clinics kind of have merged. And also sometimes I'm the one saying to them well I've had this done because they can't see my record. So if I was able to change one thing it would be that everyone in the health service could log in to one system and see all the health records. (Alice: 163).

Banerjee (2015) also makes this point, that for people with multiple LTCs the health and care system can be difficult to navigate. This makes the usability of the healthcare system difficult, with Alice stating that she often doubles up on interventions such as blood tests and needs to be an expert by experience in place of the medical professionals having the desired information. I reflected post-interview that the complexity of Alice's condition contributed to her fractious care. Although other participants reported having multiple LTCs, Alice was the only participant who reported this issue. Despite this, my findings suggest that more investment is needed to improve the integration of health and social care and consequently, improve its accessibility.

Several times during her interview, Sue described accessibility in the context of being free from preconception and discrimination. She reflected that whilst community resources such as public toilets were becoming more accessible, it was her own stigma and fear of reprisal that prevented her from using the facilities she needed whilst out in her community.

> As far as toilets or going out I have a radar key now and a sunflower lanyard. But I don't feel confident with either of these, like oh there's nothing wrong with you you're walking ok when you're going into a disabled toilet. I'm trying. I really am trying. But my diffidence makes me think I shouldn't be doing this (Sue: 133)

Sue’s fear of repercussion was consistent with Bailey et al. (2019) who contend that both globally and in the UK, there is a significant stigma towards older age and poor health. Sue went on to explain that she had never actually experienced any negative repercussions of using a disabled toilet. What Sue feared most was the preconceptions of others, and yet it was her own preconceptions that appeared to be having the most impact on her. She described creating these social anxiety barriers in other aspects of her life, notably how health professionals would treat her for being in a same-sex partnership:

> I’d always had this fear that my partner wouldn’t be allowed in to see me as next of kin. So, when I had cancer that was my biggest fear and that was alleviated right away. So, she comes with me every time and we don’t make it obvious. Well, it's obvious anyway but we don’t go in and say well we’re the only gays in the village sort of thing. (laughing) I have to say I think everyone’s really accepting, I haven’t come across anything that’s really made me uncomfortable as far as medical services are concerned. (Sue: 228)

Sue’s experiences align with Christie (2018) who acknowledges that while the LGBT community have historically faced stigma from healthcare services, there has been a significant contemporary shift in acceptance. Additionally, GMCA has committed to an LGBT action plan (LGBT Foundation, 2017) to combat inequalities faced by the LGBTQ community. The lack of stigma Sue has faced is supportive that these inequalities are reducing. Sue felt that stigma was a barrier to accessing or using a service, feeling that a service was inclusive meant she was more likely to engage with them and feel supported.

4.4.3 Summary

Accessibility was a common theme throughout the interviews but appeared to impact some participants more than others. Physical accessibility was more likely to be discussed by those with increased physical needs and framed as an area for improvement. Accessible housing in particular was identified as needed to support older people to remain independent in addition to an increased array of housing choices.

Physical accessibility is the traditional definition of accessibility, and overall the participants described their communities and services as being easy to access. However, the findings show that we need to expand our definition of accessibility when looking at ageing and LTCs. It was important to the participants that support, and resources were easily obtainable and usable in addition to being physically accessible. Being able to access help means being able to get an appointment as well as being able to attend the appointment. In addition, people and in particular professionals needed to be accessible to the older adults so they may seek out help and advice. The older adults were aware of how pressured services were and consequently were extremely grateful for the professionals they were able to access. It was also important that they were able to access family, friends, and social activities. I have also found that loved ones are providing a mostly hidden informal care role in accessibility from providing transport to and from services or arranging appointments for those who find the system difficult to navigate. The participants recognised the role of informal care in facilitating this access and were thankful it was available to them.

4.5 “They’re what they should be, they’re professional, they’re attentive, they know what they’re about.” – Experiences of Using Health and Social Care Services

The background research and literature in Chapter 2.3.2 highlighted that older adults and those with LTCs were much more likely to have contact with both formal and informal health and social care services. The participants described varying levels of contact with services, depending on their conditions, overall health, and inclination. However, they described mainly using health services to manage their conditions, with social care utilised more in a community and social aspect than as a support service. Social and community services are explored in more detail in section 5 – engagement with others. This section will explore three key themes that arose from the participant's experiences of using services: quality of services, availability of services, and support for managing conditions.

4.5.1 High-Quality Health and Social Care Services

When I envisioned this research, I consciously linked the use of social care to older adults. This was based on my own experiences working in the sector and the literature which indicated that older people with LTCs are primary consumers of social care (Glasby, 2017). However, as I discussed services with the older adults it transpired that few were using formalised social care services. Therefore, this section predominantly features healthcare. One of the interview prompts I designed, asked the participants to identify or comment on a positive aspect of a service they used. As I went through the transcripts as part of my analysis, I realised that nearly all the participants linked good quality services with the staff working there.

> The GP is very attentive, they're good quality staff. At the slightest sign of any disorder, they make sure I get the right service. For example, my blood reading recently was very high which could have led to blood clots. So, they made sure I went from the surgery into hospital to be treated. They're what they should be, they're professional, they're attentive, they know what they're about. (Ian: 92)

> the medical care has been without exception excellent all the way through. And I've developed a really good relationship with the rheumatologist and the renal specialist. I have also been very fortunate with GPs and the GP practice that I'm at. (Alice: 103)

Both Alice and Ian understood that it was through the actions of people that they were receiving the follow-up they required, though the underlying referral structure did support this. The approachability, respectfulness and professionalism of health and social care professionals were frequently identified as being either the best or worst part of a service. I have captured both the positive and negative here to show that in some areas of GM, they are doing things right and that other areas could learn from this. I think this is best illustrated by two conflicting accounts from Sue and Alice. They both described how they often face delays when waiting for medical appointments. Sue disclosed having medical anxieties and that the lack of communication over delays could be very distressing for her:

> I think I get very nervous at clinics; I would like the appointment to be on the time that it says rather than waiting. I mean I do understand the reasons behind it, but it would be nicer if you could walk in and call your name and be done…. Any sort of waiting just thinking I've got to go to the hospital is enough to get me wound [up]. Just sitting in a waiting room counting people off like oh I was there before them. (Sue: 165)

However, Alice described delayed appointments from a positive lens. She recognised that the professionals have people's best interests at heart and that those delays could be because they're showing compassion for someone in a difficult position as she once was.

> To be honest with you whenever I went to his clinics they always overran. But I never actually minded because you felt you know like the day I was diagnosed I got to see him and I didn't have an appointment. So, I broke into someone else's time so I could never complain if that happened. (Alice: 153)

Therefore, despite Alice having to wait to see a professional, she recognised and sympathised that with another person the compassion and flexibility shown could be influential in their own journeys with ill-health. This is consistent with Francis et al. (2020) who identified not feeling time pressured in appointments as being important to older adults. This again links back to the importance of the people who staff services. Someone, whether the consultant or administrative staff, had decided to accommodate Alice and therefore, was able to offer significant reassurance about her cancer rather than going home and having to wait for answers.

Peter was another participant who identified his personal experiences with services as positive and supportive. However, he had anecdotal evidence that this may not be the same for all older people:

> I am a fairly personable person, and I was professionally comfortable in dealing with consultants and whatever. I felt as though I was listened to. I'm not sure, this is the supposition bit. I'm not sure that my experience would be a typical experience and I'm not sure that all patients and I know from experience sort of talking to other people and certainly people that I'd worked with, clients for a lack of a better word. My experience was very different to that experience by people who are less able to operate on a level that medics do. (Peter: 181)

Peter described feeling lucky that he had these quality professional relationships with staff, and it was important to him that he was taken seriously and that his views were considered. Despite this, he still felt that it was important to highlight that he did not think his experiences were universal and he was keen for me to understand this. I felt that Peter's concerns were illustrated in Rosa's experiences, who didn't feel as though her voice and opinions were being heard or respected.

> I would ask once and if they did not respond I did not ask again. But I had to pay a big price, my whole life has been ruined for the last 30 years. It's getting worse and worse. It's an ongoing thing and it'll only get worse. (Rosa: 146)

What the participants most identified they wanted was to feel they were using quality services. They each defined quality slightly differently, as above, Peter and Rosa felt that being listened to and supported by staff was important. However, the participants recognised that many services struggled to provide this time for them because of systemic staffing pressures.

> I have to say I'm quite a fan of the services. I used to work in hospitals so I'm, I see it from both sides really. When I was first diagnosed, I think I feel what didn't work very well was that sometimes the nursing care was a bit iffy. I don't know what it is but you'd ask a nurse for something and they say they'd go and get it and two hours later you'd have to ask again because you didn't get it. (Alice: 99)

Alice was keen for me to understand that she did not like complaining about services. She was unhappy on this occasion as she was unable to care for herself, however, she reiterated to me how busy the team was and how she recognised that the fault did not lie with the individual staff members. This is consistent with Morris et al. (2023) who identified staff shortages as a key driver of dissatisfaction within the NHS. Concerns surrounding the lack of funding and support for health and social care services were raised by other participants also. They had linked adequate staffing with quality services and recognised that this was a major challenge. Jeff described how he was hesitant to push for support knowing how busy the staff were:

> You realise how tied up people were in different ways. You've no idea what the stresses were on their own situations so one didn't press. I think in general yes more help in the sense of accessibility to ask about things and talk things over and get advice. This is what you get if you go private for something you get the time. (Jeff: 151)

These findings suggest that some older people may refrain from seeking help, feeling that their needs may not be great enough or that they would only place additional strain on services. Drawing on this, I began to wonder whether those already in contact with services, may not request additional support due to witnessing it under strain. Some participants described seeking private support to help meet their needs, however, this was restricted to those who were able to pay. Additionally, the need to seek private services varied by area, some participants were unable to access any rehabilitation whilst Peter described the physio in his area as exceptional:

> I was referred to physio and it was absolutely superb. I was going to the physio gym in the hospital. Pretty sure they said you could go as much as you wanted to, but I went once or twice a week. And it was like having your own personal trainer. I've got friends who go to private physio and stuff and there was this NHS service that was just superb. (Peter: 195)

Public services can be of excellent quality, and when they are, they have a significant and positive impact on the lives of older people. However, these findings show that the availability and quality of services varied across the region.

4.5.2 Availability of Services

Building on Peter's comments in the previous section, I realised that many participants were discussing how important it was to have services available to them. Being able to use services, whether primary, secondary, or rehabilitative made participants feel supported and their conditions more manageable. Rosa described how she felt overwhelmed by her condition as it was uncommon, and they struggled to identify the service she would need to access:

> The optician said you go to your doctor and tell him we found something we don't know what it is. So, I went to my doctor in [area] you know my GP. I begged him please send me to the hospital, please if not I'll go private because I couldn't see. (Rosa: 59)

This research identified that there were gaps in service provision across the region and that participants were frequently utilising private services to address this. Earlier in section 4.4.1, physical environment, Jeff had also described needing to use private services because of accessibility needs. I reflected then that he was fortunate to be able to do so. The participants in this study have demonstrated that older people are increasingly turning to private services as the NHS is not meeting their needs. However, I was concerned that given the economic profile of older adults in Greater Manchester, many would not be able to pursue this and could be disadvantaged (Wall, 2021). Although these experiences are not reflected in the accounts of the participants of this study, it is likely many older people were not receiving the support they needed due to gaps in service provision which is widely supported by contemporary literature (Chapman, 2019, Dunatchick et al., 2019; Vlachantoni, 2019). Peter talked about how having multiple conditions meant he didn't fit the criteria for traditional single-condition rehab services. He recognised that his adjustment to his condition and rehabilitation would have been a much better experience had he had a support group to turn to.

> In terms of my personal experience, the bit that would have helped me most would have been if there had been a community rehabilitation service for

> people with like you know chronic conditions. It kind of fell between lots of stools I think…I suppose, it's a realisation this, I would have really welcomed something like that that would have supported me to get better. Either to come to terms with my condition and learn how to better it. (Peter: 200)

It became clear that Peter was searching for a formal healthcare solution to his needs rather than looking towards the community. As the GM ageing strategy (GMCA, 2018) identifies community support for health as a key priority I was keen to understand if other participants felt their experiences aligned with this. Alice described seeking a community rehabilitation program through the social prescribing scheme at her GP:

> As I started to get stronger, I knew of something, sometimes people call it exercise on prescription if you've heard of that before. There's one in Bury it's called [name]. And I knew about it and my GP referred me to it. So, they worked out a program for me in the gym and I had a sheet so when I went, I had a program each week, so I knew what I was doing in the gym. They also recommended that I do tai chi which I talked to my consultant, and he said that was fine …. Anyway, I've been doing tai chi ever since. I still do it. I've been doing it for about 13 years. (Alice: 190).

These comments from Alice demonstrate that help didn't need to be from a formal NHS or social care service, and that support was available in local communities. However, I felt what was most notable about Alice was that she had to ask for a referral and find a service for herself. Ploeg et al. (2009) suggest that it can be difficult for older adults to know where to seek help but that those who do know experience better outcomes. There is learning here that signposting is important and had Alice not sought this opportunity for herself she may never have accessed it. As it was, Alice talked about how important it was to have the service available to her not just as a social activity but also to rebuild her physical strength and balance post-chemotherapy. George also described how important it was to his rehabilitation that he could access a support service:

> I was going to a disability centre, which I still go to actually, it's mainly for people with disability which affects walking or what have you. The disability centre, which is a new centre now, before it was scattered around but now it's all in one base. New build, all the facilities. When you go there you see lots of

> people with legs missing and it’s there for other things too. But it’s mainly for people with amputations. I probably had a new leg after about would have been about October. It’s quite remarkable getting it for the first time because you’ve been from basically being reliant on wheelchairs being driven around. (George: 197)

I was interested in how George had first come to access the disability centre and he talked about being referred by the hospital before he was discharged post-amputation. Knowing that there was support waiting for him when he got home and was ready to access it, was important to George in not feeling out of his depth. He described his amputation as life-changing and suggested that having services available that support mental, emotional, and physical well-being is important. My findings suggest that it was important for the participants to engage with others who had similar conditions, George said: “(It’s) Not everybody who suddenly gets surrounded by people with legs missing.” (George: 239).

Being connected to those with a similar health condition fostered a sense of camaraderie which reduced isolation and meant that ideas for managing conditions could be exchanged. Alice’s experiences also illustrate this as she disclosed how beneficial it was to help in establishing a support group for people with blood cancers:

> I think it’s helped me to realise that there were other people with it. Because it’s so rare and I know 3 people who have had breast cancer, but I’d never heard of anyone with myeloma. Most of the people who are diagnosed say the same that they’ve never heard of it, they’ve never heard of the illness. People have heard about leukaemia, but they haven’t heard about myeloma. So, I think now, to be honest, I get more out of it because I was a manager and an organiser and an administrator. So I quite like the organisation stuff. I found it quite hard when I gave up work because I was used to being busy and doing things like that. Psychologically it was quite difficult not to have a role in life, so this gives me a role. I do most of the organising. (Alice: 260)

Novak et al. (2013) reiterated the importance of community support groups and identified them as key to the self-management agenda. Having rehabilitation and social support groups available based on specific conditions appeared to me to be more impactful mentally than physically. Often LTCs are incurable but removing the feeling of isolation seemed to be more important to those who attended such groups. I questioned Alice on how her support group had been established and she talked about how one of her nurses had had the idea and helped her set it up. This again suggests that it is the people staffing services rather than the structures who are most important to enacting positive change. These findings demonstrate that staff are aware of gaps in provision and often act autonomously and proactively to support their patients.

Social care services were infrequently mentioned throughout data collection. This was predominantly due to a lack of interaction and need between the participants and these services. However, the participants all displayed an insight into the prognoses of their conditions and recognised that they may one day need to access social care. Several participants expressed concern that when they come to need it, there might not be any social care available to them. Linda told me that she was fearful of being left without care:

> I just think more money needs to be ploughed into social care for all age groups, but especially for the elderly. Like private care, once your money runs out that's it, you're dumped, you're dumped at the nearest A&E. (Linda:249)
>
> Because I still work full-time because I've got my mortgage till, I'm 70, so I'm taxed on my wage, I'm taxed on NHS pension, and I'm taxed on my old age pension. So, a third of my money goes on tax and I think I'm entitled to the aftercare, I'm entitled to someone to come here and build me a toilet. (Linda: 253)

Linda's account concerned me and made me think about how a lack of care service availability could mean participants do not seek or receive the help they need. This was consistent with findings in the literature review and the increasing numbers of older people with unmet needs in the UK (Brimblecombe et al., 2017). Peter and Alice, also spoke of their concerns for social care service availability, but for social rather than physical needs.

> it's the availability of support, there's an erm local I don't know what you'd call it it's not a community centre. Anyway, there's a local organisation that once a

> week does a blokes get-together, and they eat together, or they did before the pandemic. Yeah, eat together played dominoes together or whatever, I'd just spend a couple of hours socially. It's for isolated men, isolated older men particularly. And I think the availability of stuff like that is really important. And the kind of promoting of stuff like that is really important and I guess there's more of that on a kind of voluntary community basis than there used to be, I think. Partly because in response to the fact that there is not as much adult social care provision as there used to be. Partly because there is not as much money as there used to be. (Peter: 264)

> There used to be rangers in the area, and they used to organise lots of walks which were about an hour, hour and a half. That was just perfect for me, not too ridiculous but the fresh air and the exercise and I used to go with a friend. But unfortunately, the austerity measures at local authorities, there used to be 8 rangers and there's now 1 and a half so they don't do the walks anymore. (Alice: 199)

It was evident to me that Peter and Alice were concerned about the impact of austerity on local services. Both they and Linda recognised that accessible social care was paramount in being able to continue living in the community as their conditions progressed. They valued the availability of these services, recognising the positive impact they have and how they would be needed as conditions deteriorated, but felt disempowered to advocate for change.

4.5.3 Support for Managing Conditions and Symptoms

The participants all described that an important aspect of using services was support for managing their conditions. Kalankova et al. (2021) make this point in their research and assert that meeting health and social care needs is imperative in realising better wellbeing. Some participants recognised that they had experienced additional health conditions that impacted their primary diagnosis, and it was important for them to address this. Linda talked about having a muscular-skeletal condition that deteriorated significantly due to being overweight. She was able to undergo surgical intervention for this and was thankful for her improved quality of life as a result.

> I had a gastric sleeve because I wanted one and I had to have it. My stomach was ulcerated and bleeding. So now instead of weighing 18 stone with a stick, I now weigh 12 stone and I don't walk with a stick. (Linda: 31)

It was important to Linda that she was able to undergo this procedure for improvements in both mobility and quality of life. However, I also recognised that the surgical intervention would have reduced the likelihood of her developing other long-term conditions due to her weight (Keramat et al., 2022). Although the primary conditions described by the participants were not treatable, they did acknowledge that through pharmaceutical and professional maintenance their symptoms were not compromising their quality of life. Ian explains that he largely feels very well in himself but that this is changeable:

> Some days I feel as right as rain and other days I don't. I wouldn't feel as right as rain for example on a cold and wet and windy day. Because that usually brings some, not pain, but I don't feel as well in that type of weather. By and large, I'm stable but like everything else, I have good days and bad days. I don't have days for example where I'm racked with pain, heart pain or angina or anything like that anymore because the medication is a barrier to that. (Ian: 60)

Although by nature LTCs are incurable, Ian's quote recognises that this does not mean that interventions can't be made to improve the day-to-day impact. Peter also praised the attentive care of services that had stabilised his condition:

> The consultant at [hospital] was brilliant and my goal was to get back to 5 a side. And he supported me through that, through that journey. That was definitely my goal and he basically said we'll get you back and he was very positive about my previous history having been, laid a decent foundation to health and wellness. So, he discharged me in January he said something like referred, diagnosed, treated, cured, discharged. And that was kind of erm I'd dodged a bullet basically. I'm back to normal and that was good, that really reassuring. (Peter: 156)

Although the participants still attended regular clinic appointments and took some medications, generally they were able to lead a good quality of life. However, it is not possible to manage all conditions to a point that they are not noticeable in everyday life. Both Jeff and George had undergone leg amputations, for them it was most important that services were able to increase their mobility and independence.

> I've talked to X which is the centre for prosthetics and that sort of thing. They've left me thinking about whether a prosthetic would help. So, the other area that one has to look at is mobility do you have a wheelchair, what sort of wheelchair, do you have a scooter? Do you hire it, or do you buy it? So, there's all questions around getting out of the house when I can because of course I haven't been able to do that leave the house. (Jeff, 52)

George also expressed the importance of being able to attend this clinic as it gave him access to specialist care. In hindsight, I wish I had discussed this service more with Jeff and George. I suspect that the clinic is particular to Greater Manchester and therefore, older adults outside the region or living further from the centre may not be able to access the same benefits. Jeff and George both recognised how fortunate they were to live close to this centre and that consequently they were provided with a prosthesis quickly. They also both described how the centre improved their wellbeing and independence as their services and prompt responses reduced their need for informal care.

4.5.4 Summary

As explored in the literature review, a prevalent contemporary rhetoric is that health and social care have added years to life but not life to years (Glasby, 2017). Whilst the experiences of the participants highlight areas for improvement, they do not necessarily support this statement to be true. Health and social care services were largely described positively by the participants. They were particularly supported by rehabilitation programs that helped them regain independence and wellbeing. Additionally, having services available to them meant that they reported lower levels of unmet needs. Their accounts did however demonstrate that they were aware of the pressure services were under, this was something that concerned them and could act as a barrier to seeking help. However, the main finding of this section is that people are at the heart of services. Friendly, supportive, and proactive staff make a service and having a good relationship with them is tantamount to feeling confident and well.

4.6 “It's information, that is the real thing you want. That’s for all the services. It’s knowing about them and knowing where to go” - Communication and Information

During the interviews, I asked the participants about their conditions and the services they access. Their answers suggested that information and communication had a significant bearing on the way they perceived the quality of services, and how they managed and interpreted their health conditions. Although I did not directly ask about this topic it was a dominant theme when the participants were asked either, what the best thing about a service was, or, what was one thing that if changed would make the most difference to them. This was significant as on reflection I realised that this meant the participants had been able to take the conversation in the direction they wanted to and were self-identifying what was important to them without a prompt from me.

4.6.1. Feeling Informed

The need to feel informed was identified across all aspects of the participant's lives and had significant implications for how they felt and dealt with their conditions. Some participants such as Peter identified this as they had felt concerned and out of control when this was not achieved. Peter was hospitalised following a cardiac event and was subsequently diagnosed with atrial fibrillation (AF). However, when he attended a follow-up appointment with his GP, he learned that he had been given a second diagnosis.

> my GP said we’ve not done anything about the underlying hypertension. Which I’d not been aware of. (Peter: 66)

Hypertension is a causative factor of AF, but by not disclosing to Peter that he had this condition, the services were disempowering Peter. He described how being given this knowledge gave him a sense of control as he knew there were changes, he could make to his life to manage this condition. Additionally, this knowledge gave Peter the means to process his diagnosis and he felt that once he knew he had a condition his cardiac event was explained rather than 'out of the blue'. Francis et al. (2021) identified that feeling uninformed was the greatest inhibitor of self-managing conditions. Sue also disclosed that feeling uninformed had led to negative experiences of services for her. She expressed feeling anxious when having medical investigations and said that feeling uninformed about what was going to happen was a significant contributor to this. Sue identified that for her it would be most supportive if she could have all the information about what to expect from a consultation in advance so she would know what her options are in advance of the day and prevent her worrying:

> that just completely freaked me out. I'd just gone silent then and my head was down. My partner had to speak for me. After she's saying it won't hurt her and blah blah blah. Then she said well, she can have it under general anaesthetic so basically all that stress could have been alleviated. (Sue: 90)

Participants told me that appointment letters often follow a standard template and do not always include information relating to what to expect from an appointment, Sue's account reflects the distress that can be caused by this. Rosa also indicated that she had experienced interactions with medical services, where she did not feel fully informed of what to expect. When attending her GP after feeling unwell she felt let down when she did not receive any follow-up:

> No, he was not taking me seriously at all or he would have referred me to the eye hospital. That was the thing they asked him to do. I asked him and I was waiting for him, I didn't have the thought that I should go back and ask again. I trusted that he would do it and he didn't. (Rosa: 159)

I was mindful that I only had Rosa's account of this interaction and there might have been a reason that this referral did not happen. However, I also appreciated that if a referral was not needed this should have been made clear and rationalised to Rosa who could have managed her expectations and understood why it had not happened. I felt that the mistrust that developed from this experience could have been avoided or at least mitigated by clear communication. A key finding of this study is that feeling informed is essential to empowering older adults to manage their conditions and know where to seek help. Rosa describes how feeling disempowered made her give up seeking help which had consequences for both her physical and mental health. These findings suggest that by ensuring older adults feel informed we could reduce unmet needs and improve active help-seeking.

Feeling informed was also raised by participants in a positive light and the participants recognised the difference it made to their care when they felt informed and empowered. For instance, when asked what the best thing about a service was, Alice answered:

> I think the thing I value is that they will discuss a thing with you, so you can ask them a question and they will give you answers in a sort of layman's terms which I can understand because I'm not medically trained. But also, they treat you as though you are an intelligent human being. Now it may be because I've worked in hospitals, but I'm not frightened of consultants. So, and with the renal people for example, when I have blood taken you can actually look at your results on the screen. So, when I go to clinic I've looked at the results of the bloods taken a week before and I can ask the consultant questions and I can even say I've noticed my total blood count has gone a bit high so should I reduce my, I have injections to stop me getting renal anaemia, so should I reduce my injections. So, I just like being treated as an intelligent individual. (Alice, 111)

In this instance Alice was enabled to learn about her condition in an easily understandable format, she was also empowered to have some control by being able to see her results and implement self-directed change. I noted the difference between this conversation and the one I had had with Peter (discussed above) where he was unaware of his diagnosis. Alice presented as empowered and informed as opposed to the confusion that Peter conveyed. I was also particularly drawn to Alice's description of being treated like an intelligent individual, and with hindsight wish I had explored this with her further. In this interaction, Alice was treated as a co-producer of care rather than a passive user. Additionally, the professional respected that Alice was an expert by experience and placed her in a position of power to make decisions around her care. Alice conveyed how important this was to her and attributed it to her excellent therapeutic relationship with the staff.

When I looked over the transcripts from the interviews, I noticed that although Peter and Alice had initially described opposing communication methods from professionals, they had reflected that what did work for them was establishing an effective communication style between themselves and the professional. For example, Alice was given a life-changing diagnosis of myeloma, instead of trying to ask questions immediately, she was given time and space to process this and return to ask questions.

> I think when I was first diagnosed, I got told that I had myeloma and I had vaguely heard of it, but I didn’t really know anything about it... Although it was a devastating thing to be told you have blood cancer, he [the rheumatologist] was so helpful, and he just said come back next week with your questions. I’m quite an organised person and I typed out all of my questions and I started asking him and then I said to him I may as well give you the sheet, and it was about 20 questions, and he went through the whole lot of them. So, I really felt very reassured by him and very supported. (Alice, 141).

I recognised that this appeared to have a therapeutic effect on Alice, she felt informed about her condition and also affirmed that the people involved in her care had respected her as a person. The way that information was communicated to the participants and the difference this made to them is explored later in this chapter.

4.6.2. Finding Information

Knowing where to find information came up in many of the interviews and was important to support the participants in making informed choices. Several participants demonstrated being technically literate and would use the internet as a first port of call for information:

> I wasn’t clear about taking Imodium. There’s so much stuff on the internet about ulcerative colitis and Crohn’s. you can be really misled. It’s quite mild mine compared to what you read. People are taking 10 doses or more a day. It also says on the leaflet if you’ve got IBD don’t take Imodium so (laughs). I clarified this, I’ve only just clarified this with the nurse that it's okay to take it. (Sue: 122)

These findings affirm that older people can be technically literate. Sue was able to navigate the internet for the information she needed and knew that she needed to analyse the quality of the information rather than simply accept it. Being able to search for information independently gave participants a sense of independence and reduced their reliance on services. It was also important that Sue had a designated point of contact for her IBD as she was able to quickly seek reassurance on her findings without needing to book a full primary care appointment. She recognised that this was a more effective use of everybody’s time and didn’t feel she was unnecessarily bothering her GP. Owen et al (2022) make a point in their research that signposting and support to navigate the health and social care system is critical in delivering better patient outcomes and reducing unmet need. The participants reflected on this and asserted that it was important for them to have a designated point of contact.

> I think once you make contact with the right organisation, the people themselves are very helpful. It’s actually knowing where to go for any particular bit of help. If you’ve not actually got people around who know the systems it’s very difficult, you don’t know what help there is there and how to get to it. (Jeff: 75)

Rosa recognised her needs was increasing and disclosed to me that she was thinking of moving to supported living but hadn’t done so because she didn’t have the information, she needed to navigate the move:

> We talk about it sometimes. Go to a nice place because I find it difficult on the day to day with cooking, I cannot do cooking or cleaning. Sometimes I feel that I can go to a place where, but I don’t know much about these elderly people's home, but I’d like to know more like how to find a good one if I had to go. (Rosa: 217)

Throughout Rosa's interview, I felt overwhelmed by how much she appeared to be struggling, she frequently sounded despondent and lacked any direction for seeking help. I reflected long after her interview as I felt I should have done more than just encourage her to reconnect with the organisation that had connected us. However, I was struck by how much her lack of information had disabled her. The experience made me realise how easy it could be to become lost in a system and how many older people may not access support for similar reasons. A few weeks later when I interviewed Jeff, he echoed my thoughts that a point of contact for information would help navigate the health and social care system. Jeff had received an emergency leg amputation and had gone from being able-bodied and independent to disabled and dependent within the space of a few hours. Given the extent of these changes, he required significant intervention in the early stages of his recovery and discussed how he navigated this:

> It's information that is the real thing you want. That's for all the services. It's knowing about them and knowing where to go. And then if you've got to go private you want a good one. So, you know you've got a grant for a carer for half an hour each day but what is a good company and there are a hell of a lot of companies out there. It's the information that's the hard thing. You end up picking up things haphazardly from friends, family, neighbours. But you could do with something stronger than that, a sort of centre point at which you could ask for information and recommendations. Now I know that would be very difficult for people to start recommending say a specific firm, things like that. But it's getting that information, finding the right help and then you're not paying good money out for inadequate service. You want quality services.
> Interviewer: So a lot of reliance on word of mouth?
> Jeff: I think it's not just a lot it's almost total. How do you find a good company? Unless it's a personal recommendation there's no other way of doing it. And the quality is variable. (Jeff: 160)

Jeff emphasised to me the importance of maintaining social connections, which before the interviews I hadn't connected with information sharing. By having a network of friends around him who were experiencing similar milestones Jeff was able to informally information share and hear first-hand accounts of service quality. Word of mouth was influential although there was concern over the reliability of information and quality of services on offer. This was acknowledged by Rosa who was connected with a local older person's community organisation that was able to offer local signposting services. She described how she could call them with a request for support and they would provide her with a list of organisations to contact. Additionally, it was important for Rosa that they remained available during COVID-19 as she did not feel able to navigate the internet for information. However, as I questioned Rosa further on her desire for assistance and the intervention of this organisation it transpired that she was not acting on the advice and support they had given her. When I asked her about this, she talked about lacking the confidence to advocate for herself rather than not wanting to act on the advice. There was not a one-size fits all approach to signposting for older adults. Some wanted pointing towards support so they could interrogate it for themselves, and others wanted someone to navigate the system on their behalf. Being able to access information empowered individuals to meet their needs, however, there was a clear postcode lottery on services. It was after speaking with Jeff that I recognised the importance of Rosa being connected with this organisation and how it could transform the information-seeking experience.

> I felt that once you find the right people, they're there, they're supportive, that's the key to it. It's finding, it's getting to the right people. (Jeff: 118)

The point of interest here is that what the participants want, is to have access to a person to help them navigate rather than a list or website. Part of feeling reassured that they had the correct and most applicable information was that it had come from someone who had put it together in a personalised way. There was an exception here and that was that many participants identified better signposting for the NHS, but next to none for social care. Jeff and George in particular emphasised this as they had an automatic referral to a limb loss unit for any medical questions but received no signposting or follow-up from social care.

4.6.3 Communication Style

It became clear that the way information was offered and communicated made a difference to the participants. Although I didn't ask the participants specifically about this, each of them raised an experience of it, whether good or bad and discussed its impact on them. Some of the accounts contrasted with each other and demonstrated the variety in the quality of experience that the participants had. For example, Peter felt jargon was overused by medical professionals and it impeded his ability to understand the information he was being given. However, Alice specifically noted that she valued that the medical professionals in charge of her care were careful not to use medical jargon and instead were clear and concise.

Another crucial factor raised was the way information was communicated to the individuals. The way they were treated and communicated with was important to the participants and greatly impacted how they felt about the service itself. For example, Linda became unwell due to a lack of sleep from switching between day and night shifts and sought help from her occupational health team.

> I was speaking to a different person every time and the one before this one that I spoke to last year had been supportive of me. But this one she was very clipped in the way she spoke to me; she was, I didn't feel there was any empathy. There was no unconditional positive regard if you will, she was very clipped, very abrupt, very business-like. I told her about the 15 [hours] sleep in 72 hours and she just said no. (Linda: 99)

The interactions participants had with staff impacted how they felt about the services, with participants specifically noting that poor staff equated to poor service. When I questioned Linda further on her experience, she described being more affected by how she was spoken to than the refusal for help.

> If she'd have been nice with me, had been courteous. I would have said ok well that's your opinion, I'll have to go down a different route thanks for speaking with me. But she was just arrogant and so clipped she just controlled the whole conversation. (Linda: 109)

Jeff recalled having a similar reaction whilst in the hospital recovering from having his leg amputated. He felt that whether due to a lack of time or being used to dealing with less able patients meant that the physiotherapists developed a patronising approach to his care.

> In the hospital, you had the physios come in and I must admit they just ignored me, you're doing what you're supposed to be doing and he's going press, press, press, press, press, and I said no don't treat me like a child I'm an adult. You told me what to do, I'm doing it, don't go press, press. (Jeff: 136)

Staff approachability and respectfulness were directly equated with the participant's willingness to engage with a service. The result of this experience meant Jeff engaged a private physiotherapist as a way of avoiding dealing with these practitioners and the way they spoke to him. These experiences were not replicated across the board, however, and Alice was keen to highlight that she valued her consultant making her feel like an 'intelligent individual'. Owen et al (2022) reflected that feeling respected leads to better outcomes for patients as they are more likely to seek support from the practitioner. Peter believed that the means of communication had implications for his physical well-being as well as his emotional well-being. If he had been aware of the seriousness of his condition and become panicked his arrhythmia could have deteriorated with significant implications for his health.

> And when I described this to my GP, he said well I don't know personally what that must feel like but it must be terrifying because basically, you were drowning in your own bodily fluids. He sussed that talking straight to me was the best way really (Peter: 136)

Mitsi et al (2018) concur with my findings and support that effective communication and empathy are critical to developing effective therapeutic relationships. In contrast to Peter's 'patronising' experience with physiotherapists, the GP in this instance reaffirms his experiences and treats him with a level of intelligence.

The means of communicating information also arose during the interviews. As this research took place during Covid the participants had witnessed a substantial move toward communicating via technology. When asked how COVID-19 had impacted them, several participants referred to virtual appointments with medical professionals.

> I suppose in a way it's easier talking over the phone about it because I'm not as embarrassed. (Sue: 72)

Sue was broadly optimistic about this move and felt it opened a line of communication. Additionally, as someone who struggled with a fear of health services and procedures, telephone appointments removed some of her anxieties. However, while Ian appreciated that the telephone consultations were a necessary product of the pandemic, he felt they weren't as comprehensive as in-person consultations.

> The telephone consultations were alright, they were alright. You can't expect miracles when someone's doing their best down the phone, they can't see you, they can't sense your reactions, they can't sense your eyes that sort of thing. (Ian: 178)

Many of the participants valued face-to-face conversation and recognised that professionals are more likely to identify nuances through this. At the time of the interviews, there was enduring media speculation that telephone appointments had contributed to significant numbers of missed opportunities for diagnosis and treatment amongst the UK population (See: The Guardian, 2023; Sky News, 2023). None of the participants felt this had happened to them, however, I sensed Ian's account concurred with the media narrative in that he felt the telephone consultations to be less thorough that face to face ones.

In the wake of the first UK lockdown, all communication from health and social care services outside of households was provided via technology. Some services adapted well and others less so. George described being unable to attend his local church during the lockdown and sought an alternative church that streamed a Catholic Mass online from Ireland which he enjoyed. All services were forced to move online due to the pandemic, for some this was a positive and had improved their accessibility. For George who had a leg amputation, streaming mass at home was much more accessible to him. He also felt he enjoyed the online mass more and was able to interact with people all over the world and had made the decision to continue to attend online post-lockdown. George and other participants told me about how much more significant technology had become during the pandemic in helping them keep in contact with family and friends.

4.6.4 Summary

Information was important to the participants in several ways, it made them feel empowered and gave them some autonomy to manage their conditions. Poor information-sharing procedures contributed to negative experiences for the participants, and they recognised the benefit of knowing who they could contact for help. The participants were not a homogenous group and wanted this to be reflected in the level of control they had over information and how they could use it. However, it was consensus that they would prefer contacting a person for information rather than seeking it online or through lists. A crucial aspect of signposting and information sharing was the style and means of communication that the professionals employed. This directly impacted how the participants thought about a service. Quality and supportive therapeutic relationships were built when the participants felt listened to and were treated as intelligent. Having a supportive and positive relationship with health and social care practitioners was important for the participants and boosted how positively they felt towards services.

4.7 “My family’s been a very important factor in my coping with disability.” – Informal Support and Connecting with others

Family and friends were a pivotal part of the lives of the participants, they each felt strongly about being connected to and supported by those around them. Jowsey et al (2014) support that family and friends are integral to the wellbeing of people managing LTCs. The interviews gave a strong impression of how social support networks impacted the participants' physical and emotional wellbeing. This section explores the impact of others in three areas: informal support, community, and social activities, and ageing in place.

4.7.1. Informal Support from Family, Friends, and Communities

Entering this research as a ‘professional’ in health and social care I expected that most of the discussion would be on formalised services. What became apparent throughout the interviews was that health and social care services did help the participants and have a bearing on their well-being. However, many participants were more strongly motivated and influenced by their family, friends and communities who gave them support in an informal capacity. This is supported by Jowsey et al (2014) who link better self-management techniques with those who are supported and motivated by family.

All the participants described needing informal support since the onset of their conditions. This was undertaken by partners, children, friends, and neighbours. However, the extent and nature of support they needed varied depending on their condition and was prone to change over time. For instance, Alice disclosed that when she started her chemotherapy, she needed a wheelchair to get around and was unable to get in and out of bed. As a result, her husband gave up work to care for her, however, after some time and rehabilitation, she felt her needs had decreased and she was able to mobilise independently. Swinkels et al (2022) support that earlier retirement is increasingly sought to provide informal care. For others, the level of informal support required was significant and ongoing. Jeff had collapsed at home due to a blood clot which led to an emergency leg amputation. Afterwards, he described realising he would be unable to set foot in his own home again and relying on his partner and daughters to organise his care, his home and his belongings. Jeff found this process very emotional and was thankful for his daughters' support:

> Making decisions about what you keep and what you can't keep and being told what you can't keep…Most of my possessions, my furniture it was just guess what one would need in an apartment, and she was the one who said to use the iPad. She would say look what do you want of these items, she'd scan round the bookcase, and I'd go yes, no, yes, no about keeping things. It's very difficult because you don't really know given time what you would want to keep. You just have to make a blanket decision and let most of it go. (Jeff: 248)

Without support from his daughters, Jeff would have been reliant on the local authority to help organise his home and its contents. After the interview finished recording Jeff reflected on this and discussed how important it was for him to know there were people he could trust. He expressed concern about having strangers come in and help, whether with moving or personal care needs which is consistent with Doekhie et al (2019) who purport that trust is a key factor in accepting care. It was clear that having loved ones perform informal care came from a place of trust, however, Jeff's experience demonstrates that there are emotional aspects of change that friends and family are better suited to support people with. Similarly, Peter whilst generally well in himself felt he would prefer care coming from his wife:

> I am just lucky that I have a very, very supportive partner who if I needed looking after would look after me. You can't replace that. You can't find that. (Peter: 250)

However, Peter described a change in dynamic at the start of the Covid pandemic. Initially, it was unclear who would be clinically vulnerable, and to what extent. Peter expressed that he didn't feel vulnerable, however, his wife disagreed. He was happy to be at home and his wife did the shopping. Although Peter's wife was also an older person and considered at risk by the UK government, it was she who took on the additional care roles during the pandemic as she did not have an LTC. I was interested in the fact that whilst both were vulnerable due to age Peter was encouraged to isolate more intensively due to his largely stable heart condition. There were differences in conceptions of socially constructed categories, such as age, as the participants often recognised the implications of being ‘older’ but didn’t always ascribe the same meaning to it that they felt wider society did. Peter goes on to explain this:

> However positive I might feel toward older people and I don’t identify as an older person. And I remember when I was approaching 50 and the definition of older people was like reducing to 50 or that and I was like WHAT *shouted*. Life doesn’t begin at 40 it probably begins at 60 but then ill health comes about. So, I don’t particularly identify as an older person, but I appreciate that I am. (Peter, 260)

What was apparent from this is that the participants did not necessarily behave in a certain way because society told them to. Instead, they would often modify their behaviour or lifestyles to adapt to situations as they arose. For instance, Ian and Peter only stopped smoking after they experienced cardiac events. Covid also acted as an incentive to change behaviour with Alice explaining her desire to keep well due to her increased risk from her chemotherapy. Several participants described Covid as a catalyst for needing more care, notably, with shielding in effect many people needed extra help with activities they previously managed independently. Rosa described her husband as providing informal care over the 20-year period she had been symptomatic with her condition. This ranged from caring for their daughter to supporting Rosa with her physical and emotional needs. However, she felt that covid had increased her husband's vulnerability and as a result disclosed that she no longer felt informal care was sufficient to meet their needs. She told me that she needed a carer as they couldn’t manage. She had lost her confidence due to her illness and didn’t want to live on her own and indeed perceived that she wasn’t able to. It was clear throughout the interview with Rosa that she was struggling to manage day-to-day, and she made several comments throughout to suggest she needed additional help. However, it was COVID-19 that had been the catalyst for acknowledging that they could not continue how they were. By being confined to the house Rosa had realised that now she couldn't access help, how much she needed it and had previously relied upon it. Ian also described noticing changes in his level of need during the pandemic. He discussed relying on his neighbours and the community for support. I was surprised when Ian explained his neighbours were his main support network as he was the seventh person I interviewed for this study, and until that point, all the participants had described informal care being undertaken by family. Although Ian was close with his family, and they lived nearby he still relied mainly on his neighbours.

> Ian: the lockdown has shown people in their true light, the helpful and unhelpful.
> Interviewer: Absolutely
> Ian: my family visit me, but they don't do anything day-to-day to help me like my neighbour. I mean I go to my daughters for my Sunday lunch and things like that. (Ian: 48)

In my practice and the literature, I had generally only read and heard about the impact of informal care on family and reflected after this interview that help from friends and communities is often overlooked and underexplored. I was also struck by the impact of the pandemic on changing the nature of informal care. Emerging data suggests that the care burden of female partners has increased during the pandemic (Power, 2020). However, for those who live alone, it is likely the pandemic has increased the number of neighbours and communities undertaking informal care in place of families who could not travel. Therefore, it is important to have connections within the local community as well as wider connections, which supports the directive of ageing in familiar communities (Weber et al., 2023).

It was noticeable throughout the interviews that the participants were being supported mentally and emotionally as much as they were physically. Having worked in the health and social care sector I had supported people in this manner, however, the emotional support that the participants recognised as most important came from family and friends.

> I think the thing that I found most unexpected but not really directed at a service is that when I became ill how many of my friends were supportive. People who I knew but I wouldn't say close friends who got in contact to see how I was. And that really surprised me, pleasantly of course. And still to this day, I keep in contact with a lot of ex-colleagues and things. (Alice: 176)

Extensive literature informed me that reducing social circles were prevalent and highly likely with older adults who had long-term health conditions (Berg-Weger & Morley, 2020). However, Alice's account directly challenged this. She described expecting to lose contact with friends because of her illness but was pleased when this didn't happen. Although checking in with loved ones was a small sentiment, Alice was quite emotional during her interview as she recalled how important it had been to her and how it had given her the strength to keep going. Family and friends were also described as a significant coping factor by Peter, Sue, and George.

> I lost a lot all at once because of my health issues. I'm sure you've got some sort of question for that, but had I been on my own it would have been awful. It's only the fact that I'm married, being married to [my wife] kept me going. So basically, whatever experience I've got and this understanding that I've got my actual experience of it would have been horrendous had I lived on my own. (Peter: 112)

> We don't live together but she's been to every appointment and taken notes. You know with the cancer she was just fantastic because I had chemo, and it wasn't the greatest experience for someone to be watching that. (Sue: 105)

George stood out to me from the other participants. Whilst he noted his family as a coping mechanism like the accounts above, he disclosed that he felt his disability was a message from God, telling him to appreciate his family. Whilst some participants had accepted and made peace with their conditions, George was unique in this participant group for seeing and describing his disability as a gift. Throughout his interview, George was very reflective of his previous lifestyle and repeatedly referred to his selfishness in comparison to his wife's selflessness. For George, his disability had transformed his life and was a tool to connect with his family and open his eyes to see how much they love him.

4.7.2 Communities and Social Activities

There is extensive literature linking social participation with improved health and wellbeing outcomes for older adults (Aroogh and Shahboulaghi, 2020; Cheng et al., 2020; Lofgren et al., 2022). The participants independently described being part of social groups as being important to them. Volunteering was a significant aspect of being socially connected as it gave the participants a sense of reciprocity, they spoke of the sense of purpose it brought to them. Peter spoke fondly of how it improved his self-worth after being forced to retire on health grounds.

> Volunteering is very good for the volunteer too. So, I was getting a lot out of volunteering, and I suppose I was getting a lot of self-worth and knowing or believing I was actually supporting people to feel better about their lot. (Peter: 96)

Many participants described needing to retire due to their health or disability, however, volunteering posed a flexible means to continue to utilise their skills. Sue gave me an example of volunteering as being empowering and provided her with an opportunity to create social change.

> I actually got money from ambition for ageing to go into care homes or sheltered accommodation to advertise the fact that it's okay to be gay…. it's finished now but it's just come to an end. So yeah, we did meet up and it's quite a diverse group of people... So, we just, they built up a package of how to inform people about equality basically. And that’s disseminated to the older people’s network and [region mayor]. (Sue: 202)

As a queer person, she was concerned that social care services were not prepared to meet the needs of the LGBT community. Voluntary opportunities gave her the means to change this and connect with other people. The wellbeing impact of volunteering is well established (Lum and Lightfoot, 2005; Anderson et al., 2014) and Rosa was a participant who felt that engaging with it could boost her confidence.

> I’ve got a dream that if I can meet some people and help it will be a better quality you know. But I do not know if I can do any volunteering because of my health you know. But I wonder, I think sometimes like once a month about going somewhere and a mix of people or something. I like the thought of that when the lockdown and this shielding is over. (Rosa: 250)

There is a clear draw towards volunteering as a form of social activity in addition to productivity. Remaining socially active is also established as being associated with increased well-being and reduced social isolation (Aroogh and Shahboulaghi, 2020; Cheng et al., 2020; Lofgren et al., 2022). There was a strong desire amongst the participants to engage in social activities and connect with other people. I noticed reading over the interviews that they self-identified the positive impact of social activities on their wellbeing. For Alice, social groups were critical in supporting her emotional wellbeing. After being diagnosed with myeloma, she discussed how losing her job and her independence to a condition with little recognition was isolating. She acknowledged that establishing and running a myeloma support group improved her quality of life by giving her purpose and support.

> We set up a meeting and invited them to come to this meeting. We had 14 people at first in the meeting and since then we have gone from strength to strength…. Because myeloma tends to affect people who are older. So, I was young really to have it at 54 so a lot of people in our group are in their 70s so we tend to do things during the daytime as you know some elderly women 75+ don’t like to go out at the night time. (Alice: 242)

Alice specifically indicated that it was important to her to be able to use her existing skills, for instance, her organisation, as part of this role as it minimised the loss of her paid job. Filling free time with activities was a key driver for the participants, they felt that when they were busy, they felt less ill or lonely. Ian described filling his time with activities to meet his social needs after his wife had died.

> I play bowls *laughing*. I go for a pint with a pal of mine. I do go to church when it's available, but it’s restricted at the moment. I’m in associations if that’s what you mean also, I’m in the bowls club, I’m still a member of the golf club. I’m in a body called the Catenian Association (Ian: 66)

Groups meet on different days, and they helped for, a structure to the participant's week that gave them a sense of purpose. LTC's impacted the ability to participate in some activities, for Ian, this meant he could not play golf but he maintained his membership so he could access the social facilities. Therefore, highlighting the importance of social groups pre-diagnosis and how activities can be adapted to maintain connectivity. Ian also identified that it was important to him to maintain his religious and spiritual needs through associated groups. George also identified being able to attend religious groups as important.

> I've got, my Christianity is much better than it was. We do pray a lot. We did even before, I would say it was a gradual process, we do prayer meetings. I had a lot of friends who were interesting in socially meeting. And it improved my faith and my belief in the purpose of life, so that's a big factor in my coping with my disabilities. (George: 128)

Without this group, George had concerns about how he would meet others and keep busy, as following an amputation he had needed to give up his sporting hobbies. This made me think about the wider impact of social activities, as George had engaged with his prayer group primarily for his religious needs but ended up being able to meet his social and emotional needs also. Rosa was the one exception amongst the participants, she described the deterioration in her health and how isolating had meant she had become fearful of other people and knowing how to navigate social nuances. Despite this, Rosa had been put in contact with a local organisation for older people and was starting to imagine the difference this would make to her life. I wrote in my notes at the time that there was a shift in her tone when she talked about her dreams of engaging with others more and how much more positive, she sounded.

4.7.3 Ageing in Place, With Others

I wanted to understand whether the participants had thought about ageing in place, whether it was important to them and why. Throughout the data the participants were talking about ageing in place but without identifying with this specific label. As Jeff explains, the concept was familiar to them although the terminology was not.

> I understand that, so basically encouraging people to stay where they are or in some cases encouraging people to stay where they are because they have familiar friends, contacts, tradespeople. I've seen people try to go somewhere and literally die. So, I think I understand the concept. (Jeff: 198)

The notion of remaining connected to people and places was consistent throughout the interviews. Although some participants had explored ageing in place for accessibility (as explored in section 2), the majority described wanting to remain close to their family and social support networks. This adds weight to the GMCA (2021) priority for building accessible community homes for older adults.

> we've only moved half a mile and were in the same area. Local friends are still local friends if that makes sense. (Alice: 285)

Alice had downsized to a more accessible home and described wanting to be near her friends. When I asked her if this was important to her, she explained that being close to her grandchildren to assist with childcare was a priority.

> My daughter who lives locally has 3 children and we used to sometimes help out. The third one was only born this month but the other two we used to help out with occasionally as she works full-time. We didn't sort of have them all the time, but we did have them after school some days. I wanted to be able to continue that because it helped her, and we enjoyed seeing the grandchildren. (Alice, 292)

Ian also mentioned that being able to see and help care for his grandchildren was intrinsic to his decision to remain living where he was. However, he disclosed that after his wife died, he did look to move to a smaller house but was unable to find anything suitable in the local area.

> Unless something happens and I have to go into a home or whatever I don't intend to move, and so that's that. As far as the community is concerned things are alright in the community. I've got my own activities, I've got my own pals, I've got people helping me so that's ticked that box as well. So, I've got no plans to move to another setting now, I'm too old. (Ian: 190)

Ian’s account made me consider the changeability of the mindset around ageing in place. The decision to stay or move could be impacted by several factors, but also as Ian demonstrated could change over time. Before entering this research, I had considered that an individual may change their mind on ageing in place if their needs increased and they needed more support. However, I hadn’t considered that people may want to move but choose not to. I asked Ian why he’d changed his mind.

> it’s the realisation that I’m quite happy with this lifestyle. I’ve got pals, I’ve got people that will help me. I can go on holiday whenever and with whoever I choose. There’s no point at this stage in life going to a new place, new circumstances, new people. No. I’m ok for where I am. I don’t want to move away from my family either so. There was in two stages after [partner] died my mindset was far different to what I am today. (Ian: 197)

Ageing in place was still an imperative for Ian, however, he demonstrates that current homes may not be ideal on a physical level, but this can be superseded by the social options they provide. Social connections were an evident priority for seeking to age in place. However, some participants have chosen this based on proximity to friends and community rather than to family. Peter described his family as being scattered across the country and only seeing them sporadically throughout the year. Despite this, he expressed strong ties to his local area and was driven to age in his current neighbourhood rather than move closer to his family.

> I was born in Manchester, brought up. Where everyone knew each other, I used to run errands for elderly neighbours etc etc so I’ve always had a deep belief in community and supporting people at home as long as they are able. And I certainly want that to happen to me. (Peter: 247)

Evidence suggests that older adults were more likely to relocate near to children if they had an LTC or were living alone (Artamonova et al., 2020). Peter did have an LTC but was living with a spouse, however, I was interested in how his account juxtaposed with the other participants with children. Although Peter described missing family, particularly during the lockdown periods, neither Peter nor his wife was motivated to move closer to their children. For them, connection to the place and local people was more important and acted as an enabler to greater independence. The phenomenon of connection to community over family is underexplored in existing literature as a deciding factor for ageing in place. The importance of community and location for choosing to age in place was also raised by Linda, although for her being close to her family was equally important:

> Oh yes, I'd like to stay here and live because I've lived in this area since [the 1980s] … I get on very well with the neighbours so should my niece or stepdaughter move out I'd be alright. We're not in each other's houses but I know that should I need to knock on any of the houses they'd help me if I was stuck. And I know people round about like one of my colleagues lives across the road, [name] lives about 10 minutes' walk away, [name] I can see his house from here he's from [team] in the office next door. I've got quite a good network, and my sister only lives 10 minutes' walk away and my family. My son is 10 minutes away in the car. (Linda: 153)

Linda framed her desire to remain in her home because she felt surrounded by people she knew. It was also imperative that someone would always be on hand to offer help should she need it, it made her feel connected rather than isolated. Jeff was the only participant who had relocated because of his condition. Being unable to return to his home, he had temporarily moved in with his partner whilst awaiting specialist accommodation to be built. When I asked him about the decision to move to a new area, he advised that he only did so because his partner had connections to the area. Rosa described a similar mindset, she admitted that her physical needs were increasing, and she knew she would not be able to manage at home forever. Rosa specifically discussed wanting to live in a group home where she could have her physical needs met but also connect with others. In this sense, while she was currently ageing in place, it was not her goal to do so. The decision not to age in place is often cited in literature as being made on health grounds, or due to the unsuitability or dissatisfaction with the environment and community (Hillcoat-Nalletamby and Ogg, 2014). However, these findings suggest that older adults may choose to move to supported living because of the perceived benefits of socialisation. Rosa's desire not to be lonely was more significant than her desire to age in place, and she cited Covid as the catalyst for realising this:

> It’s quite hard now because of the lockdown and things we are not managing. Because there is no way out, but we need some help. That’s why I feel like escaping you know if I go to live in a different place. I don’t know anything about that, but I want to know more about the opportunity and what it’s like you know …. I don’t want to live on my own because you know my husband, he supports me; I can’t live on my own. If something happens to my husband, I don’t want to think about it because I’ll be lost. (Rosa: 241)

The fear of being lonely once being widowed also has a clear impact on Rosa’s decision-making here. It is interesting that she recognises the benefits of expanding her social circle for this reason and discusses that it would be easier to do now rather than if she is widowed.

4.7.4 Summary

Being connected to other people positively impacted the lives of the participants in several ways. Firstly, having friends and family to provide informal care was integral to managing LTCs in the community and meant that the older adults felt they were being supported mentally as well as physically. Secondly, maintaining and developing social connections contributed to the older adult’s sense of wellbeing, by providing routine and emotional support. The findings suggest that social interaction gave the older adults a sense of purpose and motivated them to remain well. Lastly, other people with a huge influence on decision-making around ageing in place. For many of the participants being close to loved ones and maintaining a close relationship with them was the primary reason for wanting to age in place. However, wanting to be around others could also be a reason to not want to age in place. Feeling isolated is a significant fear for older adults and they actively seek and engage in social activity to prevent this.

4.8 Chapter Summary

Within this chapter, I have considered the findings from the interviews. I have provided an overview of what older adults feel is important to them in ageing in place and have identified five themes. My study shows that current health and social care service provision is supportive and has evidence that the quality of a service hinges on the people who staff it. Exploring this further, it was important to have clear and concise communication between the participants and the services and this contributed to a more positive overview of the service. However, signposting to services and help locating support and information could improve wellbeing and access to services.

My study shows that older people seek to remain socially active and engaged and this has direct implications for their mental, physical, emotional, and spiritual wellbeing. Having a range of accessible social activities improves social connectivity and reduces isolation. Fostering social connections is important to create an informal care network, and this comes from family, friends, and the wider community. My findings have emphasised that the desire to age in place is primarily motivated by a sense of community and wanting to remain engaged in existing social networks. However, the choice to not age in place can also be driven by wanting to move towards better social opportunities. In the next chapter, I will discuss the main findings of this study and relate it to current literature and policy.

Chapter 5: Discussion

5.1 Overview of Chapter

In this chapter, I discuss the key themes that I identified in chapter 4, considering them within the theoretical framework and with reference to relevant literature. This chapter considers how my study’s findings challenge existing narratives on what is important for older people as they age in place with Long-Term Conditions. In Chapter 2, I reviewed relevant literature on ageing with long-term conditions which revealed that factors such as austerity, socio-economic inequalities, and an overwhelmed health and social care system, were contributing to higher rates of long-term conditions (Chapman et al., 2018; Dowling, 2022). Ageing in place has become the gold standard framework for reducing pressure on services and encouraging people to remain independent and active in their communities. However, little was known about what older people themselves feel is important to maintaining a quality of life (Meyer et al, 2006; Sixsmith et al., 2017). In particular, there is a lack of evidence about how older people’s wants and needs compare with current local and national policies and drivers (Chapman, 2018). In Chapter Four, I explored the findings of my research and demonstrated that there remain environmental and structural challenges to ageing in place which align with current policy targets such as building age-friendly homes (GMCA, 2021; Local Government Association, 2022; Menezes et al., 2021). However, the participants felt that people were more impactful than structures in creating a sense of place attachment.

This chapter is in three parts and will explore what the findings demonstrate in relation to my research aims and how they relate to contemporary literature and policy. In 5.2 I explore how appreciative research methods present an alternative lens for research and how by exploring what works well, we could change the narrative on ageing in place and reveal hidden intricacies in supporting this in practice. Next in section 5.3, I will consider how the findings provide a basis for rethinking ageing in place. Finally, in 5.4 I will discuss wellbeing, contrasting the participant's experiences of what supports this against current political and academic narratives. Throughout the sections, I will consider how the findings compare with current policies and strategies for promoting ageing in place.

5.2 Changing the Narrative: Positive Reframing

The narrative within the United Kingdom from people with lived experience and professionals in health and social care around ageing with LTCs is largely negative and although experiences are extensively documented it usually comes from a deficit orientation (Francis et al., 2021). At the outset of this research, I presented a desire to move away from these traditional deficit-oriented methodologies and proposed that positive reframing could uncover narratives that were previously unheard of or discounted (Bushe, 2010). In this section I will explore positive reframing, firstly exploring how the negative aspects of living with an LTC influenced how the participants framed what they thought works well, before exploring the participant's use of positive reframing.

5.2.1 Drawing Positives from The Negative

In Chapter Three I set out a critical discussion of appreciative inquiry (AI) as a methodology which uncovered several challenges of utilising a purely positive approach to research. There were well-documented concerns as to the rigorousness of AI (Bushe and Kassam, 2005; Clouder and King, 2015), and dismissed appreciative methodologies as reductionist by failing to encapsulate the whole picture (Patton, 2003). However, the experiences of the participants in this study directly challenge this view. They were able to recognise positive aspects that contributed to their wellbeing as well as recognise barriers and the reasons behind them. Johnson’s (2011) notion of the shadow of AI was also important to the participant's narrative as they compared positive examples of supportive practice against negative ones, whether from their own experiences or anecdotally from others. Capturing this shadow in my research has generated richer data (Bushe, 2010), allowing participants to voice where support is needed whilst also appreciating how supportive systems and people generally are.

Before starting this study, my pre-understanding was that older people would be able to independently appreciate and recognise good or supportive experiences. Whilst this was the case in some scenarios, as illustrated above, it was apparent that the participants also used negative experiences to frame what was important to them. When asking questions during my interviews it was normative for the participants to answer in the negative and emphasise the challenges they have faced since the onset of their conditions. However, using provocative propositions appeared to help them format their thoughts from this isn't going well to, how can it go well. In doing so, the participants didn't ignore their negative experiences as some critics of appreciative approaches have contended (Patton, 2003), but instead used their negative experiences to inform their thoughts about what could help things change for the better or what would be most transformational to them. One way this was displayed was through an example given by Alice, who recalled that attending medical appointments could mean lots of waiting around to be seen due to clinic delays. However, she didn't mind waiting because when her myeloma was diagnosed, she was given an appointment that was squeezed into an existing clinic at the last minute to help her understand what her diagnosis meant. This was something Alice referred to several times in her interview and she emphasised the importance of not feeling she was alone in managing her condition. Mangset et al (2008) discuss how being treated with respect and feeling valued by medical professionals influences how satisfied patients are with their services and motivates them to engage in rehabilitation. Additionally, Moudatsou et al (2020) and Swift et al (2021) link the notion of feeling valued and listened to with improving outcomes post-diagnosis. Sue gave a contrasting account of a similar situation and described the long waiting times at clinics as contributing to her anxiety about what would happen in the appointment. She felt that reducing wait times would be the best thing for her. These examples draw on the shadow element of AI, there are negative elements of their experiences that influence the participant's construction of what is working well. Furthermore, reflecting on these contrasting accounts with Van de Haar and Hoskings' (2004) relational stance, they present an example of how multiple realities exist when constructing an idea of what works well. The examples raised by participants throughout the interviews often gave conflicting accounts of what works well; however, they did identify similar or overlapping areas of what was important to them. The contrast in realities evidence that not every older person has a similar need, however, we can recognise that there are fundamental micro themes that must be right to support them. The above examples support existing findings across literature that personalised healthcare and quality therapeutic relationships are important to making older adults feel supported (Francis et al., 2020; Mitsi et al., 2018).

Capturing the shadow aspect of AI was valuable to frame an understanding of how the participants came to define what was important to them. The needs of the participants were constructed on two social levels, the first through lived experience, and the second anecdotally through the lived experiences of others as co-constructed knowledge. Firstly, the participants described how having experienced something negative meant they were able to frame what they wanted from the future, as they were able to understand how different interventions or interactions could have altered their journey or outcome more positively. An example is that Jeff felt patronised by some of the healthcare professionals he had encountered. Therefore, it was important to him to be spoken to with respect and feel listened to. Conversely, Peter explained that this was important to him, not because he had had a poor experience himself, but because he knew people who had been spoken down to by professionals. These layers represent the different levels of discourse that build our overall construction of what it means to age in place with a long-term condition (Burr, 2015). To consider personal experiences as a singular truth would erase recognising the influence that others have on our ability to construct what we need and what we believe to be supportive (Crotty, 1998). It is not enough to recognise that how we understand or feel about an LTC is socially constructed, we must also consider how the social interactions of older people influence their ability to interpret and recognise positive experiences. This is supported by Burr's (2015) theory of discourse in social constructionism, suggesting that through a complex interweaving of discourses, our personalities and beliefs are constructed. This was reflected in the narratives of the participants, where there were contrasting experiences, for instance, some were easily able to access their GP and others were not, and the wider changes that they wanted to see were broadly aligned. Thus, demonstrating a mostly unified social construction of what works well or should work well to support ageing in place with long-term conditions in Greater Manchester.

To conclude, the participants were informed and insightful about what works well for them, however, they also relied on co-constructing knowledge through their interactions with others. Socially constructed knowledge about positive and negative experiences shaped what the participants felt was needed to better support them in their own homes. From this, it was interesting to observe how what works well was framed by the negative experiences of both the participants themselves and the anecdotes they recalled from others. This meant that despite differing experiences amongst the older adults they had similar wants and expectations from services.

5.2.2 Thinking Positively

In this section, I explore how appreciative methodologies, and the overall positive frame of this research influenced the dialogue with the participants, including how some participants were able to engage with thinking positively and how some struggled. Then I explore the wider impact of positive thinking and how it intersects with supporting ageing in place.

In Chapter One, I highlighted that my own negative experiences and the dominant negative narratives on ageing were fundamental to my choice of choosing to pursue a positively framed study. The interviews with the participants showed that this could, however, be challenging and that using an appreciatively influenced methodology is not always accessible or favourable. My findings highlighted that for most participants this was just simply an unfamiliarity with this form of research, they had expected to discuss what was not going well, however, they did manage to engage with thinking positively and identifying what was working well. The caveat here, however, is that one participant, Rosa, consistently struggled to identify what was working well for her throughout the interviews. Personal, social, and practical factors, all influence how we construct what works well (Burr, 2015; Wurm and Benyamini 2014), however, my findings illustrate that these same factors can impede an individual's ability to recognise positive aspects. Rosa was unable to recount any examples of what worked well to support her health and well-being, and on the balance of comparison with the narratives of other participants, she described a much poorer quality of life and sense of personal well-being than the others. Extensive research has linked positive mind frames with better physical and mental health and even extended longevity (Brothers et al., 2021; Heller, 2012; Klusman et al., 2020; Wurm and Benyamini, 2014). In Chapter Two, the literature review emphasised that older age comes with a wealth of negative stereotypes and is inextricably linked with poorer physical health (Brothers et al., 2021; Robinson et al., 2020; Porter et al., 2020), therefore, it is unsurprising that for Rosa it was difficult to think positively. From the perspective of the other older adults, there were contributory factors that helped them feel positive about themselves and their future, that was a positive mindset and supportive relationships with professionals (Mangset et al., 2008; Moudatsou et al., 2020, Wurm and Benyamini, 2014). Alice was an example of someone for whom there were supportive therapeutic relationships (Moudatsu et al., 2020), a positive mind frame (Brothers et al., 2021) and the drive to seek out and engage in rehabilitative activities (Wurm and Benyamini, 2014). However, Rosa was an example of someone who did not meet these criteria, she disclosed a dissatisfaction with all the health professionals she had encountered and felt she had been ignored and overlooked which meant that she lacked motivation to seek help and support as her health deteriorated.

Previous negative experiences appeared to be a barrier to positive reframing for older adults, whereas being motivated to be well was important to challenging negative assumptions and working towards better outcomes. Naseem and Khalid (2010) contend that positive thinking is most impactful when applied throughout a stressful situation as it is effective in reducing perceived stress and creating positive coping mechanisms. As a subjective observer reading over Rosa's interview, I was able to recognise that she did in fact have many supportive factors in place in her life, yet she was unable to distinguish this herself. For instance, she was in a stable and supportive marriage with a husband who assisted her with her care needs and was accessing a local community group that helped her navigate the health and social care system. I recognised that this could be what Rosa sees in terms of what supports her but her difficulty in expressing this could result from several factors. Firstly, there is frequently an implicit inability to recognise our own discourse (Burr, 2015), in this sense what is usual for Rosa becomes a given rather than an appreciated addition to her life. This thesis has therefore, emphasised that the sociological landscape of how we construct support for older people on both a structural and personal level shapes living with an LTC. and how the underlying assumptions Rosa has shaped the way she frames her own narrative (Conrad and Barker, 2010). Secondly, Rosa presented as extremely isolated throughout her interview and repeatedly emphasised her loneliness. This supports Crotty (1998) who contends that our ability to construct reality relies on interaction with the world. Connecting and comparing with others is fundamental to creating new and nuanced understandings of self and others. Despite Rosa's obvious difficulty in identifying positive factors that are supportive to her, I still consider her to have participated in an appreciative study. Bushe (2010) asserts that appreciative inquiry should be thought of more as generative and that is something that sits better with this research. Rosa had difficulty naming positive factors, however, her account has shaped this discussion on what being and thinking positively means and how it can be used to shape our understanding of supporting ageing in place for people with LTCs.

The complex debate of why and how some people can think positively, and others cannot, extends beyond the scope of this study. However, what this research has emphasised is that we can support ageing in place through positive mindsets. In Chapter Two I explored some of the existing literature on ageing in place, and the main criticisms of it are that it is not practical for everyone and that it poses detrimental implications for those with poor physical and mental health (Sixsmith and Sixsmith, 2008; Ouden et al., 2021). However, if the existing research available in conjunction with the results of this study poses that positive framing could improve physical and mental health then it offers a new dimension of how we could support ageing in place (Brother et al., 2021). A significant finding of this research has been the impact of positive reframing. It has been extensively researched and intersects with critical disability studies and the movement for reconsidering how we frame disability (Martz and Livneh, 2015; Reuman et al., 2013; Smith, 2021). However, positive reframing is considered a technique rather than a methodology and its applicability outside of disability to other forms of 'deviant' behaviour (Friedson, 1970) is underexplored. This research considered that a person could reframe how they interpret or understand an LTC by looking at what they do have rather than don't. This was evident in the case of George, who considered his amputation as a blessing. Rather than focussing on the physical limitations it had brought to his life, he saw it as an opportunity to slow down and spend more time with friends and family. He reframed his focus on the people around him and what they brought to his life rather than seeking external gratification through his work and sporting achievements. I feel, however, that positive reframing is not for everyone. Health and ageing are incredibly emotive topics and when situations go wrong, they can do so with catastrophic outcomes. It can be difficult to find positives amidst great loss and it is important to recognise this so as not to erase these experiences and feelings (Moudatsou et al., 2020). Indeed, Wurm and Benyamini (2014) proposed that those who were prepared for difficulties but remained positive in their outlook had better outcomes than those who were positive to the point of not recognising that losses are inherent. Also, it is unlikely that as a fallible human race, we will inevitably make mistakes or choices that negatively impact our lives, and it is important to recognise this and learn from it to continue to grow and improve. Consequently, I concur with Carter (2006) and feel that positive methodologies are not a panacea and have a place alongside deficit-oriented research rather than replacing it. By considering both perspectives we can appreciate the entirety of an individual's experience and recognise both what could be better and what could be supported to continue.

Despite this, this study demonstrates that positive reframing and positive mindsets occupy an important place in answering the question of how we can support older people to age in place with LTCs. Positive reframing can be encouraged and developed through interventions such as cognitive behaviour therapy offers the ability to teach optimism and coping strategies which are inherent in learning to live with and manage an LTC (Wurm and Benyamini, 2014). In recognising the impact that this has we can understand that successful ageing in place could be supported by both structural policy, supportive professionals and challenging negative stereotypes by promoting individual optimistic views and behaviours.

5.3 Rethinking Ageing in Place

This section will explore the aim of the study, to explore ageing in place, and look at developing new understandings of how older people perceive this in relation to living with a long-term health condition. This was considered by exploring the participant's perspectives of what was important to them and how their lived experiences had shaped this. The narratives of the older adults manifested into a singular interwoven theme: redefining and conceptualising ageing in place.

5.3.1 Redefining and Conceptualising Ageing in Place

In exploring ageing in place as part of my literature review in chapter 2.2.1, I critiqued that existing literature tended to situate ageing in place to a person’s specific home. There is a body of literature such as that on place-based belonging and place attachment, which situates ageing in place in the wider community (See: Lubruson and Gomez, 2022; Woolrych et al., 2021). However, the majority of the literature on ageing in place failed to consider a wider definition. Through my interviews, I asked older adults about ageing in place and what that meant or looked like to them. Ageing in place was not a phrase or a view that the participants were familiar with and yet throughout their interviews they referred to it both implicitly through their descriptions of wanting to remain connected to their social infrastructures and explicitly through discussing their housing needs and wishes. This research has challenged current assumptions about how older adults feel about their living arrangements on several levels.

The participants generally described a desire to remain in their community rather than their home. Alice discussed how her home was not compatible with her health needs or her mobility, so she moved to a new home on the condition that it was in the same neighbourhood allowing her to remain connected to friends and family. Lubruson and Gomez (2022) argue that place attachment is critical in the decision to age in place and is signified by the two different but interwoven dimensions of home and neighbourhood. Returning to the literature, there has been a relative shift since the commencement of my research, whereby contemporary publications are increasingly seen to support this wider definition of ageing in place rather than constraining it to one particular home (see: Buffel and Phillipson, 2023; Rose et al., 2022; Webber et al., 2023). This is important as this research has recognised that older adults conceptualise ageing in place as ageing in the wider community rather than simply their current home, therefore literature needs to recognise this wider concept and the nuances that come with it. For instance, there was a significance attached to the connection between being socially connected and feeling well by the participants. When choosing where to age in the community, social connectedness was routinely described as being paramount when considering housing and whether to move. Buffel and Phillipson (2023) describe social infrastructure as being equally as important as physical infrastructure for supportive ageing in place. Understanding this provides a lens through which we can target support for ageing in place. A well-documented example of this is the requirement for and availability of disability and age-friendly homes in all communities (GMCA, 2021). Ian described how he recognised that his own home was too big for him as a widower with long-term conditions, but how he was unable to move due to a lack of suitable properties within his support network. Ian’s example also reflects that with established social infrastructure comes a source of mutual support and often increased levels of informal care that are essential to supporting ageing in place in a time of austerity (Rose et al., 2022). Jeff described how he knew people who had moved area and had died quickly. He attributed this not just to the loss of informal social networks but also the lack of social insiderness that came with living in a community known to the individual. Specifically, he described a lack of known tradespeople and external help agencies as being detrimental to the ability to age in the community. These narratives add weight to the existing national and local calls for more accessible housing options for older people (Centre for Ageing Better, 2022; GMCA, 2021).

The narrative of the participants in my research emphasised that ageing in place is not as simple as deciding to remain living in their current home, and then doing it. They interpreted ageing with long-term conditions to be dynamic and recognised that consequently ageing in place needed to be a flexible concept based on intrinsic and external needs. This represents a shift in the definition of ageing in place and emphasises a dynamic definition that focuses on change over time rather than the fixed goal established in the literature of remaining in their current home (Brim et al., 2021; Sixsmith et al., 2017; Vanleerberghe et al., 2017). Jeff needed to move to a flat after his leg amputation as he was unable to navigate his existing home. He talked about being attached to his previous home but was accepting of the change and felt that it would be a way of increasing his independence rather than a negative move. Many of the participants described how they would like to stay in their current property but would be open to moving to a higher level of care such as a residential home should their health necessitate it. These comments are in opposition to the narrative that is normatively expressed in literature, whereby older adults are recorded as stating they wish to avoid residential care at all costs (Lebruson and Gomez, 2022; Rose et al 2022). Indeed, Rosa described wanting to look for a residential home as she felt this setting would be more beneficial to her than remaining in her own home and struggling to meet her own needs. Rose et al (2022) described ageing in place as a product of the satisfaction paradox, whereby older adults may interpret their quality of life in their own home as better than it is, in reality, to avoid moving. However, the results of this study reflect that this may not be the case across Greater Manchester. The participants were open to moving on the condition that certain aspects of their life including independence and social connectivity could be maintained or improved. These views appear to challenge existing assumptions about how older people prioritise decisions on living arrangements. The evidence from this study highlights that older adults recognise their preferences but contrast them against their social circumstances to make an informed decision. Moreover, this provides important context for policymakers, both local and national, giving a strong rationale for creating accessible homes in all communities.

There are certainly limitations to these conclusions not least that all the participants were homeowners with property as capital which gave them both security and more options regarding future care needs. Buffel and Phillipson (2023) documented that the austerity agenda, COVID-19 and the more contemporary cost of living crisis have widened inequalities in communities, particularly for older, disabled and low-income individuals. The result is that there is increasing precarity and tenability for many people to remain living in their own homes, whether due to affordability or safety (Age UK, 2022). The older people in this study who own homes have the option of selling property to raise funds or seek more suitable care, however, this study has not captured the viewpoints of the older adults for whom this is not an option. The willingness to move may likely vary amongst groups who are being forced to move due to practical or economic rather than health factors. Furthermore, the finding that social infrastructure is key to ageing in place has repercussions for lower-income areas. These neighbourhoods tend to be disadvantaged in terms of resources and access to local structures that encourage social togetherness (Buffel and Phillipson, 2023) and therefore people who are not connected to their local community may also elicit a divergent view of what it means to age in place. Consequently, it is important to acknowledge that wealth and financial status place significant constraints on the choices older adults are able to make around ageing in place. Those in more advantageous situations have access to increased options and opportunities on where they age which impact their physical, emotional and mental health.

Another limitation of these findings is that this research has fixated on individuals who live with others and receive informal care from them. Lebruson and Gomez (2022) identified that informal care was an important aspect of ageing in place and was essential to allowing older people to remain living in their own homes. In this research, Rosa had no family locally and a restricted social network and was able to recognise that the best thing for her would be to move somewhere with an increased level of care. This example demonstrates that the interplay of friends and family is more than just a draw to remain local, the absence of them can act as a catalyst for deciding not to remain at home.

5.4 Ageing in Place with Long-Term Conditions: What Do Older People Want?

This section explores the findings concerning Research Objective Two: seeking to understand what is working well for older adults. Existing research outputs have been broadly similar, in that what needs to change is well documented (Bottery, 2019; Glasby 2017) but what older people want or recognise as important is less so. The use of the appreciative approach in this study sought to uncover what is working well in the older adult's own terms and acknowledge their expert by experience status. A common theme was that structural support is necessary however, people are more impactful and influential in how older people perceive their care and support. This section first explores the idea of people as the most important resource and then considers how older adults' wants and needs compare with contemporary policy to support ageing in place with long-term conditions.

5.4.1 People Are More Impactful Than Structures

In my study, I used an appreciative method (Curtis et al., 2017; Jack et al., 2019b) to explore what older adults' thought was most helpful and supportive to them when ageing in place with LTCs. I have gained a nuanced understanding that whilst structural and environmental accessibility and availability is an important part of this, it is overshadowed by the importance of having supportive people in their lives. My research demonstrated that feeling connected and supported by other people was beneficial to older adults' health and wellbeing particularly through promoting their independence and feeling respected as an individual (see Section 4.7). My research supported existing literature that in addition to community and social groups there was a prominent role for informal everyday interactions with friends, family, communities, and professionals (Macdonald et al., 2021; Zhaoyang et al., 2021).

Informal support was considered by the participants as being more important to them than formal services. However, when formal services were accessed the people who staff them were more important than any other aspect as they valued the interpersonal interactions and feeling listened to and supported. Older adults with long-term conditions are well established as primary consumers of health and social care (Glasby, 2017), the responses to the interviews in this study reaffirmed this as the participants confirmed they have frequent contact with services. Existing literature has explored this link, primarily from the perspective of what is missing or what needs to be improved (See: Kalankova et al., 2021; Ouden et al., 2021; Zhou et al., 2019). My findings illustrated that whilst the participants felt there were some improvements to be made to services to make them more supportive, generally they were thought of positively (See section 4.5). However, what became apparent was that there was a dynamic interplay between how services were perceived and the staff who ran the services. Feeling listened to, respected, and informed influenced the older adult's perception of services, with Kornhaber et al., (2016) having established these qualities as being fundamental to developing therapeutic relationships. This was further supported by Rosa, who subjectively described the antithesis of these traits in professionals she encountered as the only participant who described poor quality services. The importance and impact of therapeutic relationships are well documented in literature (Kornhaber et al., 2016; Mitsi et al., 2018), however, the importance of it with respect to older adults is under-explored. Jack et al., (2019a) recognised the importance of therapeutic relationships in improving older adults' engagement with formal services and in turn improving their self-esteem and quality of life. Engagement with formal support services was a common theme in my research, and the voices of the participants challenged my underlying assumption that everyone wants help or support to better their lives. Whether it was a conscious choice not to engage with services, is unclear in this research as the participants did not expand on their thinking specifically in relation to this. However, they did explain some reasons why they would not seek external support, such as, they did not want to put pressure on services, did not meet specified criteria for services, were unable to make contact or know who to contact, and not being aware of services. Existing literature on help-seeking behaviours in older adults is dominated by conditions such as hearing loss and mental health which conclude a strong emphasis on stigma as a barrier (Meyer et al., 2014; Polacsek et al., 2019). Aside from the physical and environmental barriers which are widely reported across varying research topics (see: Saeed et al., 2020; Townsend et al., 2021) there was also a human factor that could impede older adults' access to services. Knowing who to contact and feeling able to approach them for help was something that the participants identified as important to them. However, it was evident from the interviews that there was also a more interpersonal aspect of help-seeking behaviour which included being motivated to seek help. Whilst some of this motivation occurred on a personal level with Alice describing the desire to return to a level of independence, others described seeking help to allow them more time with family and friends. These results are in keeping with other studies which identify having social support and supportive therapeutic relationships as being an important driver for help-seeking behaviour and engagement with services (Jack et al., 2019a; Langford et al., 2018; Tan et al., 2023). However, there remain gaps in knowledge and further research is needed to understand why older adults may not be proactively seeking help and exploring their perceptions of what would be beneficial in improving this.

Informal support and services were valued highly by the participants, and they attributed more significance to formalised help. Formal services were recognised as important to participants for managing symptoms of conditions, curing short-term illness, and engaging in rehabilitation, which is consistent with existing research (Aspinal et al., 2016; Carrier 2016; Jack et al., 2019a). However, informal support gave the participants a stronger sense of independence and well-being. Research has established that informal support is fundamental to engaging in rehabilitation and better outcomes post-serious injury or illness (Chang et al., 2020 Langford et al., 2018; Tan et al., 2023). Additionally, informal carers had an established level of trust, which older adults valued over accepting a stranger into their lives in a caring role (Broese van Groenou and De Boer, 2016). However, the older adults in this study recognised that informal care was not without flaws and discussed the impact it had on their loved ones. Rosa went so far as to identify that her husband was no longer able to be her carer and recognised that while she appreciated his help, she was seeking formal support to relieve the burden on him. The impact of informal caring is well-documented (Chou and Kroger, 2020; Dury 2014; Greenwood et al., 2019) as is the need for it to relieve the burden on oversubscribed health and social care services in the UK (Bambra, 2019; Bottery, 2019; Colombier, 2018). However, current policy trends fail to account for informal care predominantly targeting intervention at an individual level rather than the wider families or communities. This includes The NHS Long-Term Plan (2019) which stated an aim of increased support and recognition of informal carers but did not formulate a plan on how to achieve this.

5.4.2 Policy Implications

The participants in this study presented as informed, proactive, and knowledgeable about their conditions and spoke with conviction about how they wanted to be supported. Throughout the interviews, the participants demonstrated a detailed and informed understanding of the systems and communities in which they live and use. This has important implications for policymaking and research on ageing in place as they were able to describe supportive and often simple changes that would make a difference in their lives and increase their well-being. However, despite their knowledge and ideas, only one participant recalled being asked to participate in an event where their ideas could be heard.

The literature review in Chapter 2.4 identified a growing body of research that emphasised the importance of engaging stakeholders in policy creation to ensure its suitability and applicability (McNally et al., 2015; Owen et al., 2022; Wiles et al., 2022).

Additionally, the UK government commissioned a report on engaging the public to create open policymaking (House of Commons, 2013) which would allow the public to influence policy. However, the experiences of the participants highlight that this is not currently reflected in practice and reality. This supports the plethora of evidence suggesting that public engagement in policymaking is feasible but not currently facilitated on a global or national scale (Chapman, 2019; Hunter et al., 2016; McNeil et al., 2016). The participants in this study knew what they wanted from services and more widely in terms of support, but they described lacking meaningful opportunities to air this and be heard. The GMCA Ageing Hub was established to promote healthy ageing across the GM region yet is run by organisations rather than by individuals who are ageing in the area albeit with the intention to co-produce action plans with residents (GMCA, 2023). Within GMCA there are opportunities for individuals to join panels, research, and discussions to make their voices heard, as indicated by Sue who had engaged in a project to increase LGBT accessibility across social care. Exploring this opportunity further it was revealed that Sue was offered this project due to her connection with an LGBT group, when exploring other engagement opportunities on the GMCA website they each related to predetermined topics rather than opportunities for generalised idea generation or feedback. This is indicative of an undercurrent of power dynamics with existing research concluding that such opportunities to engage with policy-making are tokenistic and ambiguous rather than authentic and generative (McNeil et al., 2016; Chapman 2019). Additionally, by limiting public consultation to fixed predefined topics, participation may only come from specific groups rather than from proportional representation or underrepresented people and communities (McNally et al., 2015; Kolade et al., 2022).

Research in health and social care has long established a disconnect between the priorities of patients, professionals, and policymakers (Cheraghi-Sohi et al., 2013; McNeil et al., 2016). Nationally and locally assumptions and key factors have been selected as a focus for improving the experiences and outcomes of people in terms of ageing and health. Looking locally at GMCA, they identified their ageing priorities as increasing access to work and volunteering, reducing frailty, and improving exercise amongst older people (GMCA, 2018a). Whilst all valid research-backed agendas, it is unquestionable that all three of these priorities can be linked to an underlying neo-liberal preventative agenda. Unquestionably, prevention has a role in maintaining our health throughout our life and research suggests it could improve outcomes for older adults (Aspinal et al; 2016; Glasby 2017; Kuh et al., 2014). However, local policies appear to have taken a narrow view of what could be considered prevention by seeking only to explore personal factors such as increasing fitness (GMCA, 2018a). As reflected in this research many of the LTC's reported by participants of this research such as myeloma, IBS, and sarcoidosis in this research cannot be reduced by this preventative targeting in the same way that stop smoking campaigns can reduce lung cancer rates. Other conditions reported by the participants could be reduced with prevention but by taking evidence-backed holistic approaches, which consider wider social indicators for poor health such as housing, education, and poverty (Bambra, 2019; Buffel and Phillipson, 2023; Centre for Ageing Better, 2017). This was evidenced in the participant's desires for increased disabled-friendly housing options in their local communities, and reflecting on anecdotes of the variable availability of services. However, the current GMCA strategy (2018a) fails to account for this entirely. Their housing priority is on accessible housing and ageing at home rather than on the quality of housing available across the region. However, the UK Government (2023a) have published a policy paper on healthy ageing which identifies housing quality as a key priority, but at the time of writing, there is no formulated plan on how this is to be achieved. Looking next to policy priorities both local and national on older adults remaining in work (GMCA, 2018a; UK Government, 2023a), Linda's experiences demonstrate that whilst is commendable to recognise that older people should be able to choose to stay in work if they wish, we must consider the implications of workplace safety on older workers and their health. There is a strong policy focus on preventive illness and disease, yet this research emphasises that people could continue to develop LTCs regardless of changes we put in place, we cannot completely eradicate ill-health. However, given the extent of these findings from the relatively small sample of 8 participants, there is scope for considerable further research in this area.

My study demonstrates that we need to challenge our assumptions about what older adults with LTCs want. When comparing what the participants felt would be supportive for their wellbeing with current GMCA ageing priorities (2018a) there were some priorities that weren't applicable, some that were somewhat applicable and some priorities that were not mentioned in the policy. Firstly, the policy outlines a focus on improving activity and reducing frailty (GMCA 2018a) which aligns with wider policy strategies on a national scale (NHS England, 2015). However, this did not fit with the participants in this research who described themselves as being relatively active. 6 out of the 8 were involved in frequent physical activity and 7 of the 8 were active generally. I do not claim to have a proportional sample of older adults across the GM region; however, it is important to note that despite having an active lifestyle they had all developed LTCs regardless. One policy aim that did align with the older adults' views was the intention to remove the separation between health and social care (GMCA, 2018a; NHS Digital, 2019). There are widespread calls across policy and research to integrate health and social care and increase service accessibility (Bottery, 2019; Glasby, 2020; Reed et al., 2021) which is consistent with some of the findings in this study. However, the health vision sets out to help older people into work, obtain an early diagnosis, and improve outcomes for people with dementia (GMCA, 2018a). This is at odds with the priorities of the participants in this study. They knew when to seek support or advice from services but didn't always know where to seek help or how to access it. Additionally, several participants identified a lack of consistency between health and social care services, which feels unsurprising given that at the time of this study local policy had positioned them under separate strategic plans with little overlap in agenda (See: GMCA, 2018a). However, since then there has been the publication of legislation introducing Integrated Care Systems (DoHSC, 2022), which sets a precedent to bring together planning responsibilities between the NHS and local authorities. Despite this, evidence is starting to emerge that barriers remain under this system and members continue to find integration difficult and complex (Sanderson et al., 2023). Lastly, the findings of this study determined that older adults felt that feeling connected to others was by far the most significant factor in improving well-being. Although there are strategies and policy directives in place to encourage socialising, the national policy paper on healthy ageing (UK Government, 2023a) states that this should be around active contribution through volunteering and peer mentorship. Conversely, the older adults in this study referenced socialisation primarily from a sense of camaraderie and feeling supported. This was particularly present in the older adults' descriptions of wanting access to friendly, compassionate, and accessible professionals. These findings although small scale suggest that focussing on the experience of ageing from a social rather than health perspective could mean more engagement and improved outcomes for older adults.

Whilst professionals and policymakers are seeking to improve the reality of ageing in place with LTCs, this research indicates that the policies or changes do not always have a real-world impact or align with the needs of older adults. My study highlights that the specific local GMCA policy was not addressing the needs of these particular participants and the wider population of older adults in Greater Manchester needs to be considered to effectively put in place a policy that supports older adults with LTCs to age well in place. Engaging older adults in the process of developing policy is more likely to achieve responsive rather than reactive policies and enable better health and well-being outcomes (Kolade et al., 2022; Wiles et al., 2022). Further study would be needed to understand why older adults' voices are not being given this credence or power-sharing opportunity and how we could improve this.

5.5 Summary

In this chapter, I have considered my findings in a wider political and theoretical context. I have identified that approaching research with an appreciatively informed methodology can uncover nuances in existing knowledge without erasing the negative influences that are still essential to be addressed. I have considered how a personal mindset is important in pursuing well-being and how agentic forces such as the influence of others can increase or reduce positive outlooks. I have also explored how current thinking around ageing in place and what older adults need to support healthy ageing may not align with the wants of older adults. Lastly, I have demonstrated that contemporary policy on both a national and local level does not align with what older adults feel is important to them and that rethinking current policy to include the voices of older adults could create improved health and more responsive practice.

Chapter 6: Final Thoughts, Impact, and Conclusions

6.1 Chapter Overview

This chapter is structured starting with a summary of the research findings and how this maps to the research aim and objectives. I will then consider the contributions to knowledge this study makes and its implications for policy and practice. I will move on to a reflexive account of my experiences in undertaking this research before concluding with the limitations of the study.

6.2 Summary of Findings

In this section, I summarise the key findings of this study in relation to the research aims and objectives.

This study aims to explore what is working well for older adults living at home with long-term physical health conditions.

Following a review of existing literature in chapters one and two, research around ageing and health was identified as generally coming from a deficit orientation. I adopted a positive-oriented approach to research, underpinned by asset-based and appreciative models to develop a narrative of what is important to older people and what they feel is supporting them and their conditions as they age in place. Using semi-structured interviews allowed the older adult's perceptions to be accounted for in their own words, which was missing in much of the literature reviewed.

The participants were able to identify an abundance of positive experiences that made a difference to them. They expressed clear ideas of what was most important to them and were able to identify supportive practices. Social interactions were fundamental to their wellbeing and were considered in several ways, most importantly informal support was a significant enabler to being able to age in place with an LTC. Participants were reluctant to engage with formal social care services but recognised how informal support both physical and emotional added value and wellbeing to their lives. Maintaining a social network and feeling connected to others was also a significant factor in the older adult's wellbeing. Whether through community groups, informal spaces such as pubs or health support groups the older adults stated that feeling connected contributed to feeling happy and well and gave them an incentive to remain healthy. This study also uncovered that for the participants, interpersonal interactions with health and social care organisations had a significant impact on their well-being and concept of services. These social interactions impacted how an individual felt about the services they used and were a dominant factor when deciding if an organisation was supportive. Those who had good experiences with services and felt supported by the people who worked there were more likely to report increased well-being and better physical health outcomes. Therefore, it became apparent that the people who staff a service are as important as the work and support the service is providing.

Becoming older and having a long-term condition does come with a sense of loss, each of the participants drew on this in their narrative and described how the negative aspects of LTC's had impacted them. These negative aspects are appreciated in the findings chapter and are considered in keeping with the shadow of AI (Johnson, 2011). In capturing this my study emphasised that it is possible to have a positive-oriented study while acknowledging the importance of the deficit aspects and how they shape a person's experience. This includes how the negative experiences mirrored and supported what the participants identified as important and supportive. Additionally, the use of positive methodologies enabled the participants to think differently about their experiences. The feedback from the participants during the interviews suggested that being asked questions such as what works well or what is most supportive made them think differently about their experiences. Several participants during their interviews made statements to say they hadn't thought of their services from a positive standpoint before, indicating that participating in this study facilitated a more positive frame of mind and therefore has the potential to have a positive impact on their health and wellbeing.

Finally, the participants' experiences indicated the power that positive reframing has on transformative outcomes and empowering people to continue to lead fulfilling lives. It was a significant finding that being motivated and having a positive frame of mind towards taking control of their condition has the potential to support better experiences, wellbeing and outcomes. From the discussion chapter I concluded that to live well with a LTC, an older adult must want to take control of their condition and think not about what they have lost but what they can still achieve. However, from the interviews, I realise that this is a complex process, and more research would be needed in this area to understand how older adults could be motivated to have positive mindsets towards LTCs and ageing.

RO1: To examine the provision of health and social care for older adults with long-term conditions in Manchester within the context of devolved health and social care budgets and integrated services.

The health and social care services provide physical, emotional, and social support for the participants across a variety of settings. In section 1.2 I discuss the introduction of devolution across the Greater Manchester (GM) region. Devolution has rapidly become a popular policy direction across the UK and is seen as a partial solution to tackling regional inequality and supporting older adults. In this study, I did not specifically ask about devolution and only one participant referred directly to it. Although they did not overtly refer to devolution or its local management structure, GMCA, the findings from this study reflect that there had been little change in the quality or availability of services since its introduction as the themes closely related to outcomes from studies before devolution. Additionally, several participants referred to the closure or pressure on services since the introduction of the austerity agenda, indicating that devolution is currently not able to counter the effects of this.

A prominent finding of my research was that current strategies by GMCA were not aligned with what the participants described as important to them. For instance, the GM Age Friendly Strategy (2018) seeks to improve health through physical interventions such as improving access to sports and promoting a healthy diet, in conjunction with increasing the uptake of home adaptations. However, the participants in this study regarded themselves as being as physically active as they could with their conditions and felt that preventative approaches were given more weight than the rehabilitative services they sought. The concept of ageing in place and GMCA strategies for this were also brought to the forefront. The current GMCA strategy encompasses the dominant narrative from the literature that older adults prefer to age in place and is seeking to support this by building new and accessible homes (GMCA, 2021). This did align with the needs of some of the participants who indicated being unable to move to more suitable housing due to a dearth of availability in their area. However, the overall narrative from the participants in this research was that ageing in place was not necessarily their goal. For the participants it was more important to live somewhere conducive to their physical health needs, however, they indicated this needed to be in their own communities and close to social networks. Which suggested they had a wider interpretation of ageing in place that expanded beyond a specific building. Therefore, investment in a range of housing options including care settings should be invested in across the region to promote options within communities. The findings of this study also supported the narrative that older people are not always genuinely consulted for their input and opinions to drive both local and national policy (McNeil et al., 2016; Chapman 2019). The mismatch between the current GMCA agendas and the wants and needs of the participants in this study emphasise this. GMCA routinely state in their publications that older adults have been consulted, however they rarely state how this consultation has taken place and in what way the older adults' thoughts have influenced their resulting policies (see: GMCA, 2024). Therefore, increasing older adults' participation in policy making is necessary as is clarity on the nature and scope of that participation to increase transparency.

The findings of this study aligned with outcomes from existing research that took place outside of devolution. Therefore, the extent to which devolution was impacting the lives of older adults is questionable. Research explicitly evaluating the efficacy of devolution would be necessary to measure its impact. However, overall findings from this study suggest that older adults in Greater Manchester are not necessarily seeing any additional benefit from it than those living in non-devolved areas. However, I acknowledge that this may not be the case, and that devolution may be making a difference in the lives of older people in ways that are less apparent or on subjects not discussed in this study. One clear outcome from my interviews was that older people know what they want, and they want their ideas to be heard. Therefore, one recommendation of this study would be for GMCA to have more direct contact with those people whom they want to support. Engagement sessions both to make ideas heard and feedback on changes and developments would bring older people closer to understanding how the local authority is supporting them. Finally, this consultation with older adults should be clear in the publications they produce, bringing increased transparency to how older adults are consulted and how this influences the policy and action.

Integrating health and social care services is a significant aim of not just the devolution agenda but numerous policies including the NHS Long Term Plan (2019). The research indicated that services were not always appropriately integrated, and gaps in provision persisted. Participants identified undergoing repeat procedures and interventions due to a lack of information sharing between partner organisations. Additionally, the participants held health services generally in high regard but remained suspicious of social care and described information on it as hidden and hard to access. In 2022 integrated care systems (ICS) (DoHSC, 2022) were introduced across England to improve integration in health and care. However, as this occurred after my interviews took place (in 2020) the impact of them has not been captured in this study. Despite this, there were several examples of services making a positive difference with onward referrals to specialist services and participants appreciated support in navigating this system. Additionally, the participants whose needs were being managed by one NHS

Trust or clinical commissioning group (CCG) experienced better outcomes and felt the system was easy to navigate. However, in contrast, social care service provision varied greatly across the region and depending on the needs of the participants. There was little integration evident, with participants disclosing a complete lack of knowledge on how to access and navigate local services. One participant disclosed using a community service that supported people to navigate this, which others described as being needed across the region.

RO2: To develop knowledge of what is working well for the older adults in Manchester and how we can continue to deliver this.

By locating this research within a positive frame, I did not seek to erase the challenges of ageing in place with LTCs but emphasised success stories were possible. I have shown that it is possible to engage older adults in appreciative methodologies and that they understand the rationale for doing so. However, the study has demonstrated that a positive personal mindset is a core component of being able to recognise success. The ability to think positively is complicated by both internal and external circumstances. My findings suggest that a lack of support and trust can hinder an individual’s ability to see successes and make them more likely to focus on what isn’t working.

My findings suggest that both medical and accessibility advances have enabled a significant increase in the quality of life for individuals. In particular, the quality and availability of services that reduce the day-to-day impact of conditions and enable people to live as independently as possible. Several participants were particularly thankful for the availability of rehabilitative services, while others lamented that they could not access some in their area and had to manage their rehabilitation. This was important as the primary aim of the participants was to remain socially active and connected. Feeling well and being able to access social spaces is essential for promoting wellbeing and must be protected to maintain quality of life. As part of this, there was emphasis drawn to the need for accessible transport and having choice over a wide range of activities to engage with. The participants valued the services they access and saw maintaining them as important by voicing their concerns about the austerity agenda and its impact of closing local services and reducing transport options.

In contrast to existing research, my study has indicated that the people were valued and recognised as having a positive impact rather than structures and systems. Namely, that services could not be considered of good quality without having friendly, approachable, and respectful staff. Additionally, the participants identified they could not age at home without informal support from family, friends, and the wider community. There is something to recognise here about how people are affected by structures and individuals, therefore, supporting the time practitioners can give and the support family and friends can provide would be an important part of system change. It also contributes to the understanding that by reducing social isolation we can improve physical, emotional, and social outcomes for older adults who are ageing in place with LTCs.

Finally, the participants identified that help, supportive services, and social opportunities should be visible and accessible. It was important for them to feel informed of their options and know where they could seek support or opportunities to enhance their wellbeing. Having this knowledge gave them a sense of independence and control over their health which they valued given that often their LTCs could feel debilitating. Although to caveat this, it was also evident from the interviews that some older adults may choose not to seek help or support for a variety of complex reasons including feeling burdensome or not wanting to add pressure to strained services. However, it remains that individuals have the right to change their minds and information must be accessible to them should they wish to participate in the future.

RO3: **To establish a participatory approach accessible to older adults with long-term conditions.**

This research objective I feel was the most ambitious of the five, and only tenuously met. I set out to utilise appreciative inquiry (AI) in this research and wanted to develop its possibilities within community settings, however, as the study evolved it became clear that this wasn't the right fit (as discussed in section 3.6.2). By using AI's positive orientation but also accepting that negative experiences happen, and acknowledging they're equally valuable for learning where support could and should be, this method captured wider experiences than typical AI studies to date. This was in keeping with recommendations made through Johnson's (2011) shadow of AI.

There have been some significant limitations to achieving this outcome, namely through the impact of the COVID-19 pandemic. This study did not achieve the engagement of older adults in a truly participatory experience. Participatory methods work most effectively face-to-face where everyone can come together, however, lockdowns prevented this from happening. This has resulted in a mixed success for this outcome, on one hand, the approach was more accessible as people could join the study from their own homes either by phone or videocall. This reduced any physical or communication barriers that could be experienced by necessitating a face-to-face meeting. However, on the other hand, the ability of the individuals to come together and drive the project was hindered. Overall, it has been a deficit of this study that it was not as participatory as intended other than the inclusion of choice around the format and direction of the interview. The participants were offered to come together in a participatory second phase however they chose not to do this. Despite this, participation was considered in the methodology of the data collection which was designed in a semi-structured fashion. The use of prompts rather than set questions meant that the older adults were free to adapt the conversation to what was important for them to talk about, rather than what I had determined we should discuss. A further participatory inclusion was the use of the shadow of AI, which meant participants did not need to exclude negative aspects of their narrative but were able to instead explore them and how they shaped their current outlook on what was important.

Moving forward, the method used here was not infallible and requires more thought and development if a truly positive and participatory design was to be achieved. However, it has provided the groundwork in establishing that quality data can be achieved through remote collection and positive-oriented methods are both sensical and accessible for older adults to engage with.

RO4: **To explore how older adults could contribute to the ageing in place agenda.**

The literature review revealed that the expertise of older people was often overlooked in favour of professional expertise and evidence-based practice. However, this research has uncovered that 'experts' in all fields often have agendas that do not align with the wants and needs of older people. By placing more emphasis on experts by experience, this research pilots its potential for improving personal and socioeconomic outcomes for older adults. The expert by experience status of the participants was evident throughout the interview and they demonstrated excellent insight and rationale into what works well. Applying some of the literature, this personal contribution to knowledge has often been overlooked in favour of 'professional' expertise. However, my research shows that older adults appreciate being treated as 'intelligent individual(s)' (Alice: 111) and have experiences they wish to share to contribute towards an improvement agenda.

I have shown that similarly to current research narratives, the individuals valued ties to people over ties to a specific home. Additionally, my research argues that the participants were not opposed to entering social care services, and prioritised independence and socialisation above their current home. My research has contributed to literature by arguing in contrast with current narratives, participants do not universally view ageing in place as the goal. However, I recognise that studies conducted across a greater diversity of participants and in other areas may not reflect this view. It remains a notable finding and supports the notion that a singular ageing-in-place strategy would not work for all.

As discussed earlier in the chapter, this research demonstrates that older adults should also be consulted on local policy and intervention. The disparity between current GMCA agendas and what was identified by the participants in this research was significant. By consulting those who live the experiences we are seeking to improve there is potential to increase health and wellbeing and prevent increases in unmet need and social inequality.

As indicated earlier, older adults want to be involved in making decisions about services and communities that matter to them. AI is built on the notion that the people who do are the people who know best what is needed for change. Therefore, opportunities to engage with GMCA and service providers should be made available to older people. This would enable their ideas to be fed back which could create both higher quality services, and increased well-being for older people whilst also acknowledging that older adults are both knowledgeable and valued members of society.

RO5: **To inform future direction and provision of health and social care for older adults with long-term conditions in Greater Manchester (GM).**

The provision of health and social care for older adults in GM is underpinned by the Greater Manchester Health and Social Care Partnership (GMHSC). My research argues that some of their identified priorities including improving access to health and care services, do align with the needs of the participants. I also observed that in line with GMHSC Taking Charge policy (2020), regional inequalities exist across GM. Continuing to invest and review in this is paramount to ensure equity amongst those living in the region. I have evidence that a core focus in this regard should be on improving accessibility and the availability and visibility of information.

However, I contend that many of the GMHSC policies do not necessarily align with what was important to the participants in this study. The policy does not include support for those with LTCs and instead frames personal prevention as key to improving life expectancy (GMHSC, 2020). This study demonstrates that many LTCs are not the result of personal lifestyle factors, and some individuals are unable to prevent becoming unwell. Failing to address or acknowledge this, risks erasing their needs and misses the opportunity to better support people with LTCs. The participants in this study, however, are not representative of GM as a whole and this research would need to be expanded to ensure that policy directives align with the needs of a more diverse sample of the area. All the same, it indicates that tailored support for older people is complex given the variable needs, particularly in more diverse areas such as GM. Several points arose from my study that could inform the future of health and social care, they include: Feeling listened to and respected by professionals, including acknowledging personal thoughts and concerns, giving time and opportunities for questions and support, and, being able to access health and social care services, whether due to environment, availability of appointments or service provision. Early diagnosis is crucial but so is aftercare and rehabilitation. Finally, building therapeutic relationships is key to both feeling supported and seeking support in the future.

My research has contributed to the literature on involving older people in research and policy that concerns them. This study contends that involving older people in the decision-making process is beneficial to the efficacy of services and the well-being of the individuals themselves.

6.3 Contributions to Knowledge

6.3.1 Appreciative Methodology

I originally set out to conduct this research in the style of Appreciate Inquiry (AI), however, soon into the process of designing the study it became apparent that the rigid hierarchical structure would not map to unstructured community research. Change and development of ideas in AI were reliant on having a figurehead who as part of the fourth phase could enact the change that was recommended. This was not achievable when the scope of this study was to explore widespread provision rather than a singular service. Therefore, an appreciatively informed approach was designed and used to capture what works well in a more general way across a wider range of services. This section explores the merits of using this hybrid approach.

Returning to the beginning, the literature review identified a lack of positive statements surrounding what is working well both across health and social care and in particular for older people (Reed, 2010). Therefore, my research findings are framed by an appreciative approach to the study which enabled an examination of what is important and working effectively for older people managing LTCs at home. An appreciative approach moves away from traditional deficit-oriented methodologies actively seeking problems and framing ageing and LTCs as wholly negative (Carter, 2006; Dewar and Macbride, 2017; Jack et al., 2019b). I argue that my research contributes to existing methodological knowledge by employing appreciative research amongst older community-dwelling adults. This enabled me to gain a rich understanding of how everyday occurrences make a difference in people's lives and highlight good practices across the region. I have argued that positive methodologies enable the identification of both what is working well and how we can support this, which was already a key driver of positive methodologies. However, it also gives space for what hasn't worked well and how realistic, but positive change could be drawn from this experience and why that matters. Despite giving the participants free rein to discuss what was important to them, they chose to talk about local-level change rather than large-scale systemic change. Appreciative methodology emphasised the impact of small interactions, and the participants were drawn to talking about their everyday reality. This included knowing where to seek information from, professionals taking concerns seriously and feeling listened to. Additionally, the positive interview prompts seem to draw older adults to think about the impact of ordinary connections with people, and they described feeling value in attending social settings and seeing family, describing the profound impact on their well-being (Bruggencate et al., 2018; Morgan et al., 2021).

The methodology choice has enabled a rich social examination of ageing with LTCs that is absent from clinical accounts. I have detailed the way the individuals' social experiences have contributed to how they view themselves, their conditions, and the services they access. The social construction of these ideas is familiar and well-documented (Green, 2009; Lloyd and Heller, 2012) but the positive aspects of it are largely hidden from knowledge and narrative. Successful research should emphasise good practice as much as it does areas for improvement.

My role as a researcher has influenced the findings as I introduced myself and my clinical background to the participants in advance of the interviews. If I had chosen not to do this, the participants may have been less inclined to open up to me as I maintained distance from them. Evidence suggests that building mutual trust is fundamental to creating supportive and friendly research environments, particularly when considering delicate topics such as health status (Kitamora, 2017; Guilemin and Heggen, 2009). I was unable to conduct this research in person, as had been the intention, due to the COVID-19 pandemic. However, in not doing so I have contributed to a growing body of knowledge surrounding how to engage and undergo research with older people using technology. The older people with the assistance of a guide posted out to them, were able to independently navigate accessing video calling platforms to participate in this research. However, this was dependent on the participants having access to appropriate technology, therefore it is also important to offer options. In this case, telephone calls were also offered. The need to explore the accessibility of engaging older people in research via technology transcends the necessity inflicted by the COVID-19 pandemic. As older people may not want to meet strangers in person due to confidence or physical accessibility reasons, technology could be used to reduce barriers and increase participation.

Reed (2010) concluded in their research that there is a need for further research exploring what works well for older people. There is still a paucity of research from the older person's perspective in this area and my research has contributed to this call for evidence. However, further research is needed across a larger sample and more diverse participants to explore the use of appreciative methods further.

6.3.2 Expert by Experience

In this section, I consider my contributions to knowledge surrounding the concept of expert by experience. (Tanner, 2010) highlighted the need for more research to overtly acknowledge how this can contribute to tailored policy and intervention, which has since been acknowledged in practice by The CQC (2022), The Kings Fund (2014) and others. I have supported this by recognising the unique experiences of the individuals and comparing how the things that matter to them overlap with existing local policies and drivers. Each participant brought unique personal experiences both past and present to the data. Drawing on their experience I was able to uncover some inconsistencies between political agendas and the participant priorities. The group were not a homogenous sample and the experiences they had differed. Despite the lack of cohesion amongst participants, they disclosed similar areas and priorities of importance. Like Burr (2015) this research understands that each person’s locality, social support group, condition and personal mindset will shape their experience and consequently their expertise. The participants knew which areas of change they wanted to see and there were clear commonalities between them, however, this did not align with current policy and stated future areas for improvement. This suggests that the changes that older adults feel would be most beneficial to them are not being explored by funders and policymakers. By engaging older adults to share these views there is the possibility of creating support that is tailored and more likely to improve wellbeing. However, the current findings demonstrate that older adults are not currently being adequately engaged in opportunities for feedback about current and future policymaking and that opportunities to enhance well-being could be overlooked as they may not have been considered by policymakers. For instance, the core finding from this study has been that people who staff services are as important as the service themselves and are key to engaging older adults with services.

There are many areas in which older people feel supported and recognise what is important to them as they age in place. The participants rely mainly on informal support networks from family, friends, and communities to meet their physical, social, and emotional needs. These findings contrast with the existing body of literature which places a greater emphasis on reliance on formalised health and social care services (Banerjee, 2015; Carrier, 2016; Dowling, 2022). The participants did recognise formalised services as important but identified general well-being as being tied more closely to informal connections with others. This challenged existing ideas of who is the expert in both providing and recommending care. For an outsider, it is easy to assume that older people will access health and social care professionals for referrals and recommendations for services. However, the participants in this study preferred to access informal or non-traditional forms of social care support and asked people with experience of services for recommendations rather than professionals. These views were considered more important as they had used the services rather than simply reading them from a list.

The participants identified several areas that could be strengthened to make a difference to them, including accessibility, communication and information, in both communities and across services. These are well-documented areas for improvement, not just for older adults but across wider health and social care services (Lewis and Buffel, 2020; Townsend et al., 2021; Vanleerberghe et al., 2017). However, the use of a positive-oriented framework allowed the participants to emphasise the things that matter most to them and support them, rather than continuing to produce lists of improvements that rarely filter into practice. This is important as it gives researchers a framework for how existing mechanisms are working across Greater Manchester and why it makes a difference in their lives.

6.3.3 Social Connection

The way that the participants framed their condition and its impact on their lives steered how they both felt about it, processed it and in turn lived their lives moving forward. Consequently, while I have raised several areas of note within this thesis, however, how the participants framed their outlook on life being older with a long-term condition could be a thesis in itself. What this research has contributed to knowledge is that older people know what is helpful and supportive for them but unless they are motivated to seek and use it then no amount of service development or improvement will make a significant impact on their lives. This shifts the narrative of how we see support for both older people and people with long-term health conditions. The focus should be personal and not structural, concentrating on supporting people with their diagnosis and its changes before we look to create and push services on them.

Although a significant body of research has been dedicated to how people adjust to illness and how it impacts them mentally (Friedson, 1970; Green 2009; Wurm and Benyamini, 2014), there is scope for future research to explore how personal mindset impacts both self-assessed quality of life and also health outcomes. Additionally, more research could be directed to how we encourage people to think positively about their life post-diagnosis and how we motivate them to continue to reach for and recognise positive outcomes and opportunities.

Lastly, having positive and beneficial social networks in place was indicative of having a more positive and proactive approach to life. This is consistent with existing research and emphasises the importance of maintaining and encouraging social contact as we age and in the face of health changes (Towsend et al., 2021). Notably a sizeable amount of literature establishes social connectivity as essential to successful ageing in place (Black et al., 2015; Brim et al., 2021; Buffel and Phillipson, 2023; Lebrusan and Gomez, 2023). This is consistent with the findings of this research and yet policy on promoting ageing in place generally overlooks this. There is a dominant focus on structural challenges to ageing in place, in the form of accessible housing and access to services (Ouden, 2021; Sixsmith and Sixsmith, 2008). However, existing policy fails to account for the social and community needs that shape decision-making around housing and care options. Increasing the number of available options to support people’s needs in the communities and social networks they know, and love, is important to maintaining well-being and increasing choice.

Building on social connectivity it was interesting that the majority of findings in this area related to covid. As established above, the desire for older people to remain connected to others has long been recognised. However, it is plausible that the social isolation imposed on the population during covid lockdowns has augmented or increased the desire to remain close to family and friends. Further research would be needed to explore whether COVID-19 has reframed the importance of social connectivity in the long term, however, certainly, this study evidences that in the short term, it had a significant bearing on the older adults in question. Research is already beginning to emerge dictating that the overall mental health impact of lockdown was less than feared upon various populations (Sun et al., 2023), however, again the positive aspects of lockdown including how it may have reframed people’s priorities is absent.

6.3.4 Conclusions for Future Direction

This research has implications for the future direction of supporting older people with long-term physical health conditions (LTCs) on both a local and national level. The key for the future direction of supporting older adults is that there is a mismatch between what policymakers and commissioners think older people need versus what the older people themselves believe they need.

Locally, one of the recommendations of this research is to make opportunities for older adults to provide local and service feedback available and accessible. Since the conception of this study, GMCA has announced a new older person panel to include the voices of older people on potential projects (GMCA, 2022). However, information on how to feedback to this panel appears to be by committing to membership and representation only. This illustrates that accessibility is still an issue within local settings and serves to disempower older people. Opportunities to engage older people's voices are essential, however, it should not be a one-level approach, instead having a variety of ways to engage with a feedback and opinion service would be more accessible. The assumption that older people have the time to run or stand for a panel erases the opportunity for those who may be managing an LTC or may already have a busy life and could be working or experiencing caring responsibilities. Equally, it appears that the panel takes only one person from each borough, this research has proven this to be problematic as it risks generalising all older people as a homogenous group. While the outcomes of this research did identify many commonalities in what was important between the participants, life experiences are varied and should be accounted for. Lastly, information on how the viewpoint of the panel is enacted is vague. Nominal opportunities to voice opinion but without intent to put this into practice are problematic and only serve to contribute to an ageist agenda. Local efforts to engage people need to be visible and genuine so that the change the older need has an increased likelihood of making it in practice.

These conclusions also have implications nationally. The devolution agenda is set to expand, meaning it is likely more local authorities will develop similar programmes as GMCA to tackle ageing in their area. As a pilot area, Greater Manchester has the responsibility to ensure they have developed a sound and replicable strategy. However, whilst some areas of accessibility have been successful the opportunity to engage with older adults and acknowledge their expertise by experience has fallen short. The outcome is that this research demonstrates that the future direction of engaging older people across the country in feedback schemes needs further research and development.

6.4 Limitations

A key limitation to be addressed is the sample size of the study, and particularly the impact of the COVID-19 pandemic on recruitment. Initial recruitment took place during the first lockdown of March-June 2020. This was complicated by several factors, not least the anxiety that was felt by older adults. In particular, about becoming unwell, as many had disengaged from friendship and social groups who could act as gatekeepers to this study. This was evidenced in the research by the accounts of some of the participants describing how their friends had disengaged socially. Additionally, many community organisations, as a traditional gatekeeper, had temporarily closed meaning I was unable to access participants this way. Furthermore, I was restricted to contacting organisations or individuals with a continuing online presence and who remained connected to organisations in this period, risking excluding those without internet access. However, whilst this set of unpredictable social circumstances led to what would be traditionally labelled a 'small' sample size (see section 3.7 Sampling), it produced a relatively homogenous group of participants which had a number of benefits to this research. Had the participants been more diverse it is likely that this research would have included different viewpoints and discussions and that the findings may not have been as congruous as they are. The findings represented in this study apply to a particular sub-section of older adults who are ageing in place in GM, most notably homeowners from white collar backgrounds in a position of relative financial and social stability. Homogeneity of the sample has meant that the findings from this study are more generalisable and credible in how to support ageing in place for individuals in this set of circumstances.

Whilst having a small and cohesive group of participants has yielded positives, it is important to acknowledge that the sample included in this study does not exemplify the diverse populations living and ageing in GM. Initially attempts to recruit individuals from a wide range of communities and backgrounds was compounded by the COVID-19 pandemic and consequently, there is a lack of representation among the participants. The difficulties in recruiting participants for academic research are well documented, and it is long established that minority communities are less likely to engage than white, middle-class individuals (Ekezie et al., 2021). I did not collect ethnicity data during this study as it was for the participants to divulge whether their ethnicity impacted what was important to them. Whilst some interviews were via video call, half the interviews took place on the phone and therefore I cannot say how ethnically diverse the sample is, only that it was not raised as a talking point. However, I acknowledge that this is problematic given I aimed to explore experiences in Greater Manchester, which I established as one of the most ethnically diverse areas of the UK (Wall, 2021). Another lack of representation comes from social background. The participants all, without being asked to, disclosed their careers prior to retirement, and this tended to reflect those who had experienced higher education and worked in a white-collar career. Again, this limits the scope of applicability of findings given Manchester's poverty levels in comparison with the remainder of the country. Current strategies for recruiting diverse communities, particularly during the COVID-19 assumed that there were existing connections with individuals or organisations applicable to the study (see: Claus and Jarvis, 2023; Kim et al., 2021). With the closure, partial closure, or reallocation of community resources during the pandemic, it was difficult to foster these connections. Whilst the findings of this study are credible and generalisable for a particular sub-section of those ageing in GM it is recognised that the findings may have looked different with wider representation and may not be applicable to all those ageing in place with long term conditions across the region.

Consideration of the context of COVID-19 on the responses of the participants could have been explored further and given a contemporary contextual analysis. However, placing focus on the pandemic could have overshadowed the importance of factors that existed before it. The impact of COVID-19 was interwoven into the narrative as applicable, however, by not choosing to focus on it, I was able to focus on the wider picture of support and wellbeing.

I have chosen to focus this study on physical long-term conditions rather than include mental health conditions as a primary LTC. Some participants did disclose mental health conditions however these were a secondary concern to a primary physical health condition. Widening the study to include mental health could have led to different research outcomes but not doing so could be seen as a strength. Exploring what people with mental health conditions think is positive in supporting them was not the aim of this research and it was therefore not included in the scope of the study. However, based on the findings of this research, mapping a similar study across mental health could be an area for future research as there will likely be similar opportunities to explore positive methodologies to understand how they can be best supported with their conditions.

6.5 Conclusions and Final Reflections

This study uncovered the positive aspects that support older people ageing in place and makes some key contributions to knowledge. I entered this research with more preconceptions than I realised, namely that what would be helpful to people would be external. However, the key finding of this study is that external support is needed but only if internally you want it and want to use it. You can put as many changes into effect as possible but as my grandma would say, you can lead a horse to water, but you can't make it drink. The voices of older adults often do not align with the policy makers emphasising the importance of including their agenda and voice for future work, which is a prominent theme in contemporary research (McNeil et al., 2016; Cheraghi-Sohi et al., 2013; Chapman 2019). Support looks different for everyone, having a range available, respecting personal constructions of what their ageing with an LTC looks like, and encouraging people to see the light in life after illness are key to ensuring successful ageing in place. But most importantly what this study has highlighted is that to support people to age well in place is having a positive mind frame and recognising that people are more important than structures.

This thesis also challenged perceptions of ageing in place as a fixed concept. I had subscribed to the traditional view that it would be to spend the rest of your life in your current home, however, the range of views expressed on the subject were refreshing.

Ageing in place is malleable and can change based on the needs and circumstances of the individuals. However, at the centre is people and community, with the draw being as much to those close to us as it is to the place.

When I set out to do this research, I thought I had an idea of what I would find. I'm pleased to say this has been challenged and I feel richer for not having been proved right in my preconceptions. A PhD is a journey and one I never thought I would take, and yet the findings from this study have the potential to transform not just how we think of older people in research but how I think and work and interact with them personally.

7.0 References

Abramsson, M., and Andersson, E. (2016). ‘Changing Preferences with Ageing – Housing Choices and Housing Plans of Older People’. *Housing, Theory and Society.* 33(2) pp. 217-241

Age UK. (2019a). *7 reasons we need the green paper.* [Online] [Accessed on: 27/5/19] https://www.ageuk.org.uk/discover/2019/february/7-reasons-we-need-the-green-paper/

Age UK. (2019b). *Policy Position Paper: Older Drivers (England)*. [Online] [Accessed on: 27/04/2023] https://www.ageuk.org.uk/globalassets/age-uk/documents/policy-positions/active-communities/ppp_older_drivers_policy_position.pdf

Age UK. (2022). ‘One in ten UK older people are reducing or stopping their social care or expect to do so in the coming months as they struggle with the cost of living’. [Online] 3rd November [Accessed on: 08/10/2023] https://www.ageuk.org.uk/latest-press/articles/2022/one-in-ten-uk-older-people-are-reducing-or-stopping-their-social-care-or-expect-to-do-so-in-the-coming-months-as-they-struggle-with-the-cost-of-living/

Aidukaite, J., Hort, S., and Ainsaar, M. (2022). ‘Current trends in social welfare policies toward the older people in the Baltic and Nordic countries: an explorative study’. *Journal of Baltic Studies*. 53(2) pp. 147–167.

Alderwick, H., and Dixon, J. (2019). ‘The NHS long term plan’. *BMJ*. 364 pp. 184.

Anderson, N. D., Damianakis, T., Kröger, E., Wagner, L. M., Dawson, D. R., Binns, M. A., Bernstein, S., Caspi, E., and Cook, S. L. (2014). ‘The benefits associated with volunteering among seniors: a critical review and recommendations for future research'. *Psychological bulletin.* 140(6) pp. 1505.

Andrews, G., and Phillips, D. (2005). *Ageing and Place: Perspectives, Policy, Practice*. Oxford: Routledge.

Angel, J., and Murdrazija, S. (2020). 'Local government efforts to mitigate the novel coronavirus pandemic among older adult'. *Journal of Aging and Social Policy.* 32(4-5) pp. 439-449.

Armentor, J. L. (2017). 'Living with a contested, stigmatized illness: experiences of managing relationships among women with fibromyalgia'. *Qualitative Health Research.* 27(4) pp. 462–473.

Aroogh, M. D., and Shahboulaghi, F. M. (2020). 'Social participation of older adults: A concept analysis'. *International journal of community based nursing and midwifery.* 8(1) pp. 55.

Aspinal, F., Glasby, J., Rostgaard, T., Tuntland, H. and Westendorp, R.G.J. (2016). 'New horizons: Reablement - supporting older people towards independence'. *Age and ageing*. 45(5) pp. 574-578.

Badshah, N., and Thomas, T. (2023). 'Junior doctors in England begin four-day strike over pay'. *The Guardian.* [Online] 11th April [Accessed on: 11/04/2023] https://www.theguardian.com/society/2023/apr/11/junior-doctors-in-england-begin-four-day-strike-over-pay

Baird, B., and Murray, R., (2022). 'NHS Satisfaction Survey Underlines Need to Support and Nurture General Practice'. *BMJ.* 377 pp. 942.

Baker, S., Warburton, J., Waycott, J., Batchelor, F., Hoang, T., Dow, B., Ozanne, E., and Vetere, F. (2018). “Combatting social isolation and increasing social participation of older adults through the use of technology: a systematic review of existing evidence”. *Australasian Journal on Ageing*. 37(3) pp. 184–193.

Bambra, C. (2019). *Health in hard times: austerity and health inequalities.* Policy Press.

Banerjee, S. (2015). ‘Multimorbidity—older adults need health care that can count past one’. *The Lancet (British edition).* 385(9968) pp. 587-589.

Barry, A. and Yuill, C. (2016). *Understanding the sociology of health*. Fourth ed., Los Angeles: SAGE.

Baxter, K., Heavy E., and Birks, Y. (2019). ‘Choice and control in social care: Experiences of older self-funders in England’*. Social Policy and Administration.* 54(3), pp. 460–474.

Baxter, L. F. (2020). ‘A Hitchhiker's Guide to Caring for an Older Person Before and during Coronavirus-19,’. *Gender, Work and Organization*. 27(5), pp. 763–773

BBC. (2023). *NHS strike dates for nurses, ambulance staff and junior doctors.* [Online] 13th March [Accessed on: 11/04/2023] https://www.bbc.co.uk/news/health-63561305

Beard, E., Brown, J., West, R., Angus, C., Kaner, E. and Michie, S. (2017). ‘Healthier central England or North–South divide? Analysis of national survey data on smoking and high-risk drinking’. *BMJ*. 7(3).

Berg-Weger, M., & Morley, J. E. (2020). ‘Loneliness in old age: an unaddressed health problem’. *The journal of nutrition, health & aging.* 24 pp. 243-245.

Berger, R. (2013). ‘Now I see it, now I don’t: researcher’s position and reflexivity in qualitative research’. *Qualitative Research.* 0(0) pp 1-6.

Bhaskar, R. (2013). *Philosophy and the idea of freedom*. Florence: Taylor and Francis.

Bimpong, K. A. A., Khan, A., Slight, R., Tolley, C. L., and Slight, S. P. (2020). ‘Relationship between labour force satisfaction, wages and retention within the UK national health service: a systematic review of the literature’. *Bmj Open*, 10(7).

Binstock, R., and George, L. (2006). *Handbook of Ageing and the Social Sciences*. London: Academic Press.

Black, K., Dobbs, D., and Young, T. L. (2015). ‘Aging in community: mobilizing a new paradigm of older adults as a core social resource’. *Journal of Applied Gerontology.* 34(2) pp. 219–43.

Blakeley, G. and Quilter-Pinner, H. (2019). ‘Who Cares? The financialisaton of adult social care’. *IPPR*. [Online] [Accessed on 01/10/2020] https://www.ippr.org/files/2019-09/who-cares-financialisation-in-social-care-2-.pdf

BMA. (2023a). *Health funding data analysis*. [Online] 10th August [Accessed on: 13/02/2024] https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/funding/health-funding-data-analysis

BMA. (2023b). *NHS backlog data analysis.* [online] [accessed on: 27/02/2023]. https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/nhs-backlog-data-analysis#:~:text=Waiting%20times%20have%20rocketedandtext=The%20number%20of%20patients%20waiting%20over%2012%20hours%20from%20decision,2022%20%E2%80%93%20a%2044%25%20increase

Board, M., and McCormack, B. (2018). ‘Exploring the meaning of home and its implications for the care of older people’. *Journal of Clinical Nursing.* 27(15-16) pp. 3070–3080.

Bossio, D., McCosker, A., Schleser, M., Davis, H., and Randjelovic, I. (2023). ‘Not that old person: older people’s responses to ageism revealed through digital storytelling’. *Journal of Sociology.* 59(1) pp. 232–250.

Bottery, S. (2019). ‘What’s your problem, social care? The eight key areas for reform’. *The Kings Fund*. [Online] 5th November [Accessed on: 28/09/2020] https://www.kingsfund.org.uk/publications/whats-your-problem-social-care

Bottery, S. (2020). ‘How Covid-19 has magnified some of social care’s key problems’. *The Kings Fund*. [Online] 25th August [Accessed on: 16/02/2021] https://www.kingsfund.org.uk/publications/covid-19-magnified-social-care-problems

Boyd, K. M. (2000). ‘Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts’. *Medical Humanities*. 26 pp. 9-17.

Bramley, D., and Moody., D. (2016). ‘Multimorbidity – the biggest clinical challenge facing the NHS?’. *NHS.* [Online] [Accessed on: 20/09/2020] https://www.england.nhs.uk/blog/dawn-moody-david-bramley/

Brim, B., Fromhold, S., and Blaney, S. (2021). ‘Older adults’ self-reported barriers to aging in place’. *Journal of applied gerontology.* Pp 1-9.

Brimblecombe, N., Pickard, L., King, D., and Knapp, M. (2017). 'Perceptions of unmet needs for community social care services in England. A comparison of working carers and the people they care for'. *Health and social care in the community*. 25(2) pp. 435-446.

Broese van Groenou, M. I., and De Boer, A. (2016). 'Providing informal care in a changing society'. *European journal of ageing.* 13 pp. 271-279.

Brosius, C., and Mandoki, R. (2020). 'Caring for old age. Perspectives from South Asia: An introduction'. Caring for Old Age. 1.

Brothers, A., Kornadt, A. E., Nehrkorn-Bailey, A., Wahl, H.-W., Diehl, M., and Palgi, Y. (2020). 'The effects of age stereotypes on physical and mental health are mediated by self-perceptions of aging'. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences.* 76(5) pp. 845–857.

Bruggencate., T.T., Luijkx, K., and Sturm, J. (2018). 'Social needs of older people: a systematic literature review'. *Ageing and Society*. 38(9) pp. 1745–1770

BSG. (2020). *Statement from the President and Members of the National Executive Committee of the British Society of Gerontology on COVID-19*. [Online] 20th March [Accessed on: 18/02/2021] https://www.britishgerontology.org/publications/bsg-statements-on-covid-19/statement-one

Buffel, T., and Phillipson, C. (2023). *Ageing in Place in Urban Environments: Critical Perspectives*. Abingdon: Routledge.

Bullen, E. (2016). 'Older People in Manchester'. *Manchester City Council*. [Online] [Accessed on: 10/12/18]

Burr, V. (1998). 'Realism, relativism, social constructionism and discourse.' *In* Parker, I. (ed.) *Social constructionism, discourse and realism*. London: SAGE,

Burr, V. (2015). *Social Constructionism*. 3rd ed. Hove: Routledge.

Bushe, G. R. (2010). 'Commentary on "Appreciative inquiry as a shadow process".' *Journal of Management Inquiry.* 19(3) pp. 234.

Bushe, G. R., and Kassam, A. F. (2005). 'When is appreciative inquiry transformational? A meta-case analysis'. *The journal of applied behavioral science.* 41(2) pp. 161-181.

Buzelli, L., Cameron, G., Duxbury, K., Gardener, T., Rutherford, S., Williamson, S., and Alderwick, H. (2022). 'Public perceptions of health and social care: what the new government should know'. *The Health Foundation.* [Online] [Accessed on: 10/04/2023] https://www.health.org.uk/publications/reports/public-perceptions-of-health-and-social-care-what-government-should-know

Cabinet Office. (2017). 'Government to set out proposals to reform care and support'. *UK Government.* [Online] [Accessed on: 03/09/2020] https://www.gov.uk/government/news/government-to-set-out-proposals-to-reform-care-and-support

Campbell, D. (2019). *Pledges to fix social care could cost Boris Johnson dearly*. *The Guardian*. [Online] 1st August [Accessed on: 04/04/2023] https://www.theguardian.com/uk-news/2019/aug/01/promising-to-fix-social-care-could-cost-boris-johnson-dearly

Carnemolla, P. (2018). 'Ageing in place and the internet of things - how smart home technologies, the built environment and caregiving intersect'. *Visualization in Engineering.* 6(1).

Carrier, J. (2016). *Managing Long-term conditions and chronic illness in primary care*. 2nd ed. Oxford: Routledge.

Carrier, J., and Newbury, G. (2016). ‘Managing long-term conditions in primary and community care’. *British Journal of Community Nursing*. 21(10), pp. 504–508.

Carter, B. (2006). ‘‘One expertise among many’—working appreciatively to make miracles instead of finding problems: using appreciative inquiry as a way of reframing research’. *Journal of Research in Nursing.* 11(1) pp. 48-63.

Carver, L. F., and Buchanan, D. (2016). ‘Successful aging: considering non-biomedical constructs’. *Clinical Interventions in Aging*, 11 pp. 1623–1630.

Centre for Ageing Better. (2017). *Inequalities in later life*. [Online] [Accessed on: 23/09/2020] https://www.ageing-better.org.uk/sites/default/files/2017-12/Inequalities%20insight%20report.pdf

Centre for Ageing Better. (2020). *Lockdown could leave next generation of retirees poorer and sicker than the last*. [Online] 18th June [Accessed on: 30/09/2020] https://www.ageing-better.org.uk/news/lockdown-could-leave-next-generation-retirees-poorer-and-sicker-last

Centre for Ageing Better. (2021a). *Too much experience: Older workers' perceptions of ageism in the recruitment process*. [Online] 23rd February [Accessed on 14/02/2022] https://ageing-better.org.uk/sites/default/files/2021-02/too-much-experience.pdf

Centre for Ageing Better. (2021b). *How has COVID-19 changed the landscape of digital* *inclusion?.* [Online] [Accessed on: 14th March 2023] https://www.ageingbetter.org.uk/publications/how-has-covid-19-changed-landscape-digital-inclusion

Centre for Ageing Better. (2022). *Creating age-friendly homes in Greater Manchester.* [Online] 12th April [Accessed on: 10/03/2023] https://ageing-better.org.uk/blogs/creating-age-friendly-homes-in-greater-manchester

Chapman, H., Farndon, L., Matthews, R. and Stephenson, J. (2018). 'Okay to Stay? A new plan to help people with long-term conditions remain in their own homes'. *Primary health care research and development*. 20 pp. 16.

Chapman, A. (2019). 'Thinking ahead? Exploring adult social care provision with older people in Northern Ireland'. *Health and Social Care in the Community*. 27(1) pp. 161-169.

Cheng, C., Inder, K., and Chan, S. (2020). 'Coping with multiple chronic conditions: An Integrative review'. *Nursing and Health Sciences.* 22(3) pp.486-497.

Cheraghi-Sohi, S., Bower, P., Kennedy, A., Morden, A., Rogers, A., Richardson, J., Sanders, T., Stevenson, F., and Ong, B. N. (2013). 'Patient Priorities in Osteoarthritis and Comorbid Conditions: A Secondary Analysis of Qualitative Data'. *Arthritis care and research*. 65(6), pp. 920–927

Chou, Y. and Kröger, T. (2020). 'Ageing in place together: older parents and ageing offspring with intellectual disability'. *Ageing and society*. pp. 1-15.

Clarke, L., and Bennett, E. (2012). 'Constructing the moral body: Self-care among older adults with multiple chronic conditions'. *Health.* 17(3) pp. 211-228

Claus, L. K., and Jarvis, S. S. (2023). ‘Building Trust: Strategies for Recruiting Underrepresented Populations in Research during the COVID-19 Pandemic’. *International journal of translational medical research and public health.* 7(1).

Clouder, L., and King, V. (2015). ‘What works? A critique of appreciative inquiry as a research method/ology’. *Theory and method in higher education research.* (pp. 169-190)

Coffey, A. (1999). *The ethnographic self: fieldwork and the representation of identity*. London; Thousand Oaks.

Colombier, C. (2018). ‘Population ageing in healthcare - a minor issue? Evidence from Switzerland’. *Applied Economics*. 50(15) pp. 1746-1760.

Compton, R. M., Owilli, A. O., Norlin, E. E., and Hubbard Murdoch, N. L. (2020). ‘Does problem-based learning in nursing education empower learning?’. *Nurse Education in Practice*, 44.

Cooperrider, D.L., and Srivatva, S. (1987). ‘Appreciative Inquiry in Organizational Life’. *Research in Organizational Change and Development*. 1(1).

Corneliusson, L., Sköldunger, A., Sjögren, K., Lövheim, H., Lindkvist, M., Wimo, A., Winblad, B., Sandman, P. and Edvardsson, D. (2019). ‘Well-being and thriving in sheltered housing versus ageing in place: Results from the U-age sheltered housing study’. *Journal of advanced nursing*. 76(3) pp. 856-866.

Corner, L., Brittain, K., and Bond, J. (2007). ‘Social aspects of ageing’. *Psychiatry*. 6(12) pp. 480–483.

Cookson, R., Propper, C., Asaria, M. and Raine, R. (2016). ‘Socio-Economic Inequalities in Health Care in England’. *Fiscal Studies*. 37(3-4) pp. 371-403.

Cooney, C. (2023). ‘Halving social care workforce funding in England an ‘insult’, ministers told’. *The Guardian.* [Online] 4th April [Accessed on: 05/04/2023] https://www.theguardian.com/society/2023/apr/04/halving-social-care-workforce-funding-in-england-an-insult-ministers-told

Crouch, M., and McKenzie, H. (2006). ‘The logic of small samples in interview-based qualitative research’. *Social science information.* 45(4) pp. 483-499.

Curtis, K., Gallagher, A., Ramage, C., Montgomery, J., Martin, C., Leng, J., Theodosius, C., Glynn, A., Anderson, J., and Wrigley, M. (2017). ‘Using appreciative inquiry to develop, implement and evaluate a multi-organisation ‘cultivating compassion’ programme for health professionals and support staff’. *Journal of Research in Nursing*. 22(1-2) pp. 150–165.

CQC. (2022). *Experts by Experience*. [Online] 28th July [Accessed on: 14/03/2023] https://www.cqc.org.uk/about-us/jobs/experts-experience

Daitch, V., Yelin, D., Awwad, M., Guaraldi, G., Milić, J., Mussini, C., Falcone, M., Tiseo, G., Carrozzi, L., Pistelli, F., Nehme, M., Guessous, I., Kaiser, L., Vetter, P., Bordas-Martínez, J., Durà-Miralles, X., Peleato-Catalan, D., Gudiol, C., Shapira-Lichter, I., and Margalit, I. (2022). “Characteristics of long-covid among older adults: a cross-sectional study”. *International Journal of Infectious Diseases*. 125 pp. 287–293.

Daly, M., and Westwood, S. (2018). ‘Asset-based approaches, older people and social care: an analysis and critique’. *Ageing and Society.* 38(6) pp. 1087–1099.

Davidson, R., Mitchell, R. and Hunt, K. (2008). ‘Location, location, location: The role of experience of disadvantage in lay perceptions of area inequalities in health’. *Health and place*. 14(2) pp. 167-181.

Davies, C. A. (2008). *Reflexive ethnography: a guide to researching selves and others*. 2nd ed., Oxford: Routledge.

Dean, E. (2018). "The government’s social care green paper and what it is expected to address", *Nursing Older People*. 30(4) pp. 10-11.

Dennis, B.K. (2014). ‘Understanding Participant Experiences: Reflections of a Novice Research Participant’. *International Journal of Qualitative Methods*. 13(1) pp. 395-410.

Department of Health (2001). *National Service Framework for Older People*. [online] DOH [accessed 01/09/2020]. https://www.gov.uk/government/publications/quality-standards-for-care-services-for-older-people

Department of Health (2012). *Caring for our future: reforming care and support*. Government White paper. [online] [accessed 01/09/2020]. https://www.gov.uk/government/publications/caring-for-our-future-reforming-care-and-support

Department of Health and Social Care. (2021a). ‘Department of Health and Social Care Outcome Delivery Plan: 2021 to 2022’. *UK Government.* [Online] 15th July [Accessed on: 14/04/2023] https://www.gov.uk/government/publications/department-of-health-and-social-care-outcome-delivery-plan/department-of-health-and-social-care-outcome-delivery-plan-2021-to-2022

Department of Health and Social Care. (2021b). *Integration and Innovation: working together to improve health and social care for all.* Government White paper. [online]

[accessed 01/10/2021]. https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all

Department of Health and Social Care. (2022). *The Health and Care Act.* C. 31. [Online] 15th July [Accessed on: 14/02/2024] https://assets.publishing.service.gov.uk/media/6363d911e90e0705a8c35457/health-and-care-act-2022-summary-and-additional-measures-impact-assessment.pdf

Department of Health and Social Care. (2023). 'Open consultation: Care workforce pathway for adult social care: call for evidence'. *UK Government*. [Online] 4th April [Accessed on: 05/04/2023] https://www.gov.uk/government/consultations/care-workforce-pathway-for-adult-social-care-call-for-evidence/care-workforce-pathway-for-adult-social-care-call-for-evidence

Dobner, S., Musterd, S. and Droogleever Fortuijn, J. (2014) "'Ageing in place': experiences of older adults in Amsterdam and Portland". *GeoJournal*. 81(2) pp. 197-209.

Doekhie, K. D., Strating, M. M., Buljac-Samardzic, M., and Paauwe, J. (2019). 'Trust in older persons: A quantitative analysis of alignment in triads of older persons, informal carers and home care nurses'. *Health & social care in the community.* 27(6).

Dorling, D. (2018). *Peak inequality: Britain's ticking time bomb*. Bristol; Policy Press.

Dowling, E. (2022). *The Care Crisis.* London: Verso.

Dunatchik, A., Icardi, R., and Blake, M. (2019). 'Predicting unmet need for social care'. *Journal of Long-Term Care.* Pp. 194-205.

Dury, R. (2014). ‘Older Carers in the UK: Who Cares?’. *British journal of community nursing*, 19(11), pp. 556–8.

Dwyer, S. C. and Buckle, J. L. (2009). ‘The Space between: On Being an Insider-Outsider in Qualitative Research’. *International Journal of Qualitative Methods*. 8(1), pp. 54–63.

Eastman, M. (2019). ‘Compassionate Ageism: Reinforcing ‘the terror of age; the weak, catastrophic victim of age’?’. *Independent Age.* [Online] 22nd March [Accessed on: 10/04/2023] https://www.independentage.org/ageism-plus/ageism-plus-blog/compassionate-ageism-reinforcing-terror-of-age-weak-catastrophic

Eaton, S., Roberts, S. and Turner, B. (2015). ‘Delivering person centred care in long term conditions’. *BMJ : British Medical Journal*. 350(14), pp. 181.

Ellis, A., and Fry, R. (2010). ‘Regional health inequalities in England’. *Regional Trends*. 42 pp. 60-79.

Equality Act. (2010). London: UK Government.

Eriksson, E., Wejåker Maria, Danhard, A., Nilsson, A., and Kristofferzon, M.-L. (2019). ‘Living with a spouse with chronic illness – the challenge of balancing demands and resources’. *Bmc Public Health*, 19(1) pp. 1–9.

Etherington, K. (2004). *Becoming a reflexive researcher: using our selves in research*. London: Jessica Kingsley.

Ekezie, W., Routen, A., Denegri, S., and Khunti, K. (2021). ‘Patient and public involvement for ethnic minority research: an urgent need for improvement’. *Journal of the Royal Society of Medicine*. 114(7) pp. 347-350.

Fenney, D. (2019). ‘A lav affair: do we care enough about public toilets?’. *The Kings Fund*. [Online] 26th April [Accessed on: 27/04/2023] https://www.kingsfund.org.uk/blog/2019/04/do-we-care-enough-public-toilets

Finlay, L. (2003). ‘The reflexive journey: Mapping multiple routes’. In Finlay, L. and Gough, B. *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences*. Oxford: Blackwell.

Flamion, A., Missotten, P., Marquet, M. and Adam, S. (2019). ‘Impact of Contact With Grandparents on Children's and Adolescents’ Views on the Elderly’. *Child development*. 90(4) pp. 1155-1169.

Foster, L. (2017). ‘Active Ageing, Pensions and Retirement in the UK’. *Journal of population ageing*. 11(2) pp. 117-132.

Francis, H., Carryer, J. and Wilkinson, J. (2020). ‘Self-Management Support? Listening to People with Complex Co-Morbidities’. *Chronic illness.* 16(3), pp. 161–172.

Freidson, E. (1970). *The Profession of Medicine*. New York: Harpers Row.

Friedan, B. (1993). *Fountain of Age.* New York: Simon and Schuster.

Garthwaite, K. and Bambra, C. (2017) ‘“How the other half live”: Lay perspectives on health inequalities in an age of austerity’. *Social science and medicine*. 187 pp. 268-275.

Gergen, K. J. (2001). Social construction in context. London: SAGE.

Glasby, J. (2017). *Understanding Health and Social Care*. Bristol: Policy Press.

Glasby, J., Zhang, Y., Bennet, M.R. and Hall, P. (2020). 'A lost decade? A renewed case for adult social care reform in England'. *Journal of social policy*. pp. 1-32.

Glasper, A. (2012). 'Caring for our healthcare future: the Government White Paper'. *British Journal of Nursing*. 21(16) pp. 992-993.

GMCA. (2018a). *Greater Manchester Ageing Strategy*. [Online] [Accessed on: 28/08/20] https://www.greatermanchester-ca.gov.uk/media/1166/gm_ageing_strategy.pdf

GMCA. (2018b). *Greater Manchester becomes UK's first age-friendly city-region*. [Online] [Accessed on: 01/09/2020] https://www.greatermanchester-ca.gov.uk/what-we-do/ageing/age-friendly-greater-manchester/

GMCA. (no date). *Greater Manchester Strategy Summary*. [Online] [Accessed on: 28/08/20] https://www.greatermanchester-ca.gov.uk/media/1083/greater_manchester_summary.pdf

GMCA. (2020). *£10m investment in housing to help disabled people and those in priority need*. [Online] [Accessed on: 27/04/2023] https://www.greatermanchester-ca.gov.uk/news/10m-investment-in-housing-to-help-disabled-people-and-those-in-priority-need/

GMCA. (2021). *Creating age-friendly homes in Greater Manchester*. [Online] [Accessed on: 10/03/2023] https://www.greatermanchester-ca.gov.uk/what-we-do/ageing/creating-age-friendly-homes-in-greater-manchester/

GMCA. (2022). *New panel launched to champion older people's voices in Greater Manchester*. [Online] 28th September [Accessed on: 14/03/2023] https://www.greatermanchester-ca.gov.uk/news/new-panel-launched-to-champion-older-people-s-voices-in-greater-manchester/

GMCA. (2023). *Greater Manchester putting place and older people's voices at the heart of age-friendly projects*. [Online] 2nd October [Accessed on: 12/11/2023] https://www.greatermanchester-ca.gov.uk/news/greater-manchester-putting-place-and-older-people-s-voices-at-the-heart-of-age-friendly-projects/

GMCA. (2024). *The State of Ageing in Greater Manchester*. [Online] 29th February [Accessed on 1/6/2024] https://www.greatermanchester-ca.gov.uk/media/9158/the-state-of-ageing-in-greater-manchester-january-2024.pdf

GMHSC. (2020). *Taking Charge is Working in Greater Manchester*. [Online] [Accessed on: 05/07/2022] https://www.gmhsc.org.uk/wp-content/uploads/2020/03/Taking-Charge-is-Working-in-Greater-Manchester.pdf

Gómez-Belda, A. B., Fernández-Garcés, M., Mateo-Sanchis, E., Madrazo, M., Carmona, M., Piles-Roger, L., and Artero, A. (2021). 'Covid-19 in older adults: what are the differences with younger patients?'. *Geriatrics and Gerontology International*. 21(1), 60–65.

Graybill, E.M., McMeekin, P. and Wildman, J. (2014). "Can Aging in Place Be Cost Effective? A Systematic Review". *PloS one*. 9(7) pp. 102705.

Green, G. (2009). *The end of stigma?: changes in the social experience of long-term illness.* London: Routledge.

Green, L. (2017). *Understanding the life course: sociological and psychological perspectives*. 2nd ed. Cambridge: Polity Press

Greenwood, N., Proud, C., Brearley, S., and Smith, R. (2019). ‘A qualitative study of older informal carers’ experiences and perceptions of their caring role’. *Maturitas*. 124 pp. 1-7.

The Guardian. (2023). *The doctor will call you now: are remote GP appointments safe?*. [Online] 2nd December [Accessed on: 28/01/2024] https://www.theguardian.com/society/2023/dec/02/the-doctor-will-call-you-now-are-remote-gp-appointments-safe

Guillemin, M., and Heggen, K. (2009). ‘Rapport and respect: Negotiating ethical relations between researcher and participant’. *Medicine, Health Care and Philosophy.* 12 pp. 291-299.

Hammond, S. A. (2013). *The thin book of appreciative inquiry*. 3rd ed., Bend, OR: Thin Book Publishing.

Harper, S. (2020). ‘The Covid-19 Pandemic and Older Adults: Institutionalised Ageism or Pragmatic Policy?’. *Journal of Population Ageing.* 13(4), pp. 419–425

Harper, S. (2021) ‘The Impact of the Covid-19 Pandemic on Global Population Ageing’. Journal of population ageing. 14, pp. 137–142.

Harris, K., Krygsman, S., Waschenko, J., and Laliberte Rudman, D. (2018). ‘Ageism and the older worker: A scoping review’. *The Gerontologist.* 58(2) pp. 1-14.

Hellawell, D. (2006). ‘Inside-Out: Analysis of the Insider-Outsider Concept As a Heuristic Device to Develop Reflexivity in Students Doing Qualitative Research’. *Teaching in Higher Education*. 11(4), pp. 483–494.

Heller, T. (2012) 'Naught for your comfort: quality of primary care for people with Long-term conditions' *In* Lloyd, C.E. and Heller, T. (2012). *Long-Term Conditions: Challenges in Health and Social Care.* London: Sage Publications Ltd.

Hennink, M., and Kaiser, B. N. (2022). 'Sample sizes for saturation in qualitative research: A systematic review of empirical tests'. *Social science & medicine*, 292.

Heron, J. (1996). *Co-operative Inquiry: research into the human condition*. London: Sage.

HESA. (2019). *Higher Education Student Statistics: UK, 2017/18 - Where students come from and go to study*. [Online] 17th January [Accessed on: 01/04/2020] https://www.hesa.ac.uk/news/17-01-2019/sb252-higher-education-student-statistics/location

Hillcoat-Nalletamby, S., and Ogg, J. I. M. (2014). 'Moving beyond 'ageing in place': older people's dislikes about their home and neighbourhood environments as a motive for wishing to move'. *Ageing and Society.* 34(10) pp. 1771–1796.

Hoddinott, S., Fright, M. and Pope., T. (2022). 'Austerity in public services: lessons from the 2010's'. *Institute for Government*. [online] [accessed on: 27/02/2023] https://www.instituteforgovernment.org.uk/sites/default/files/publications/austerity-public-services.pdf

House of Commons. (2013). *Public engagement in policy-making*. [Online] [Accessed on: 27/02/2023] https://publications.parliament.uk/pa/cm201314/cmselect/cmpubadm/75/75.pdf

Hughes, R. (2012b). 'Caring For Our Future: a White Paper to reform adult social care'. *British Journal of Healthcare Assistants*. 6(8) pp. 410-411.

Hung, L., Phinney, A., Chaudhury, H., Rodney, P., Tabamo, J., and Bohl, D. (2018). ‘Appreciative inquiry: bridging research and practice in a hospital setting’. *International Journal of Qualitative Methods.* 17(1).

Hunter, D. J., Kieslich, K., Littlejohns, P., Staniszewska, S., Tumilty, E., Weale, A., and Williams, I. (2016). ‘Public involvement in health priority setting: future challenges for policy, research and society’. *Journal of Health Organization and Management*. 30(5) pp. 796-808.

Institute for Government. (2023). *The local government finance settlement is unlikely to end council ‘bankruptcies’*. [Online] 21st December [Accessed on: 28/01/2024] https://www.instituteforgovernment.org.uk/comment/local-government-finance-settlement-council-bankruptcies

Jack, K., Ridley, C., & Turner, S. (2019a). ‘Effective communication with older people’. *Nursing older people.* 35(3).

Jack, K., Tetley, J., and Chambers, A. (2019b). ‘The education of nurses working in care homes for older people: an appreciative inquiry’. *International Journal of Older People Nursing.* 14(2).

James, B. D., Wilson, R. S., Barnes, L. L., and Bennett, D. A. (2011). ‘Late-life social activity and cognitive decline in old age’. *Journal of the International Neuropsychological Society.* 17(6) pp. 998-1005.

Jarret, T. (2019). ‘Adult social care: the Government’s ongoing policy review and anticipated Green Paper (England)’. *House of Commons Library*. [Online] 30th September [Accessed on: 8/9/20] https://commonslibrary.parliament.uk/research-briefings/cbp-8002/

Jefferies, D. (2022). The steady crisis across the NHS. *Bmj*, 377.

Johnson, P. (2011) 'Transcending the polarity of light and shadow in appreciative inquiry: an appreciative exploration of practice.' *In* Zandee, D., Cooperrider, D. and Avital, M. (eds.) *Generative organization: advances in appreciative Inquiry*. Vol. 4. Bingley: Emerald Publishing. pp. 189-207.

Jowsey, T., Pearce-Brown, C., Douglas, K. A., and Yen, L. (2014). ‘What motivates Australian health service users with chronic illness to engage in self-management behaviour?’. *Health Expectations.* 17(2) pp. 267–277.

Karakus, M., and Patton, L. (2011). ‘Depression and the Onset of Chronic Illness in Older Adults: A 12-Year Prospective Study’. *The Journal of Behavioral Health Services and Research.* 38 pp. 373-382.

Katzmarzyk, P. T., Salbaum, J. M. and Heymsfield, S. B. (2020). ‘Obesity, Noncommunicable Diseases, and Covid-19: A Perfect Storm’. *American journal of human biology: the official journal of the Human Biology Council*. 32(5), p. 23484.

Kalánková, D., Stolt, M., Scott, P. A., Papastavrou, E., and Suhonen, R. (2021). ‘Unmet care needs of older people: a scoping review’. *Nursing Ethics*. 28(2) pp. 149–178.

Khunti, K., Sathanapally, H., Mountain, P. (2023). ‘Multiple long term conditions, multimorbidity, and co-morbidities: we should reconsider the terminology we use’. *The BMJ.* 383 pp. 2327.

Kim, K., Gollamudi, S.S. and Steinhubl, S. (2017). ‘Digital technology to enable aging in place’. *Experimental gerontology*. 88, pp. 25-31.

Kim, N. H., Wilson, N., Mashburn, T., Reist, L., Westrick, S. C., Look, K., Korey, K., and Carpenter, D. (2021). 'Lessons learned recruiting a diverse sample of rural study participants during the COVID-19 pandemic'. *International Journal of Drug Policy.* 97.

Kingston, A., Robinson, L., Booth, H., Knapp, M., and Jagger, C. (2018). 'Projections of multi-morbidity in the older population in England to 2035: estimates from the Population Ageing and Care Simulation (PACSim) model'. *Age and ageing*. 47(3) pp. 374-380.

Kirpitchenko, L. and Voloder, L. (2014). *Insider research method: the significance of identities in the field*. California: SAGE.

Klee, D., Mordey, M., Phuare, S., and Russell, C. (2014). 'Asset based community development–enriching the lives of older citizens'. *Working with Older People*.

Klusmann, V., Notthoff, N., Beyer, A. K., Blawert, A., and Gabrian, M. (2020). 'The assessment of views on ageing: a review of self-report measures and innovative extensions'. *European journal of ageing.* 17(4) pp. 403–433.

Kolade, O., Porat-Dahlerbruch, J., van Achterberg, T., and Ellen, M. (2022). 'Strategies for engaging senior citizens and their informal caregivers in health policy development: a scoping review protocol'. *BMJ open.* 12(10).

Kornhaber, R., Walsh, K., Duff, J., and Walker, K. (2016). 'Enhancing adult therapeutic interpersonal relationships in the acute health care setting: an integrative review'. *Journal of multidisciplinary healthcare*. 9 pp. 537-546.

Kuh, D., Cooper, R., Hardy, R., Richards, M. and Ben-Shlomo, Y. (2014). *A life course approach to healthy ageing.* Oxford: Oxford university Press.

Lacobucci, G. (2021). ‘Covid-19: England sees biggest fall in life expectancy since records began in wake of pandemic’. *The BMJ.* 374.

Langford, D., Edwards, N., Gray, S. M., Fleig, L., and Ashe, M. C. (2018). ‘“Life goes on.” Everyday tasks, coping self-efficacy, and independence: Exploring older adults’ recovery from hip fracture’. *Qualitative health research.* 28(8) pp. 1255-1266.

Lebrusán, I., and Gómez, M.V. (2022). ‘The Importance of Place Attachment in the Understanding of Ageing in Place: ‘the Stones Know Me”’. *The International Journal of Environmental Research and Public Health.* 19, pp. 17052–17052.

Levin, A., Hanage, W., Owusu-Boaitey, N., Cochran, K.B., Walsh, S.P., and Meyerowitz-Katz, G. (2020). ‘Assessing the age specificity of infection fatality rates for COVID-19: systematic review, meta-analysis, and public policy implications’. *European journal of epidemiology*. 35, pp. 1123-1138.

Levitas, R. (2012). ‘The Just’s Umbrella: Austerity and the Big Society in Coalition policy and beyond’. *Critical social policy.* 32(3) pp. 320-342.

Lewis, C. and Buffel, T. (2020). ‘Aging in place and the places of aging: A longitudinal study’. *Journal of aging studies*. 54 pp. 100870.

LGBT Foundation. (2019). *Greater Manchester LGBT Action Plan*. [Online] [Accessed on: 27/04/2023] https://dxfy8lrzbpywr.cloudfront.net/Files/1b8b9d2e-8783-4a29-92e8-91e4065fa232/Greater_Manchester_LGBT_Action.pdf

Lippert-Rasmussen, K. (2019). ‘Is it unjust that elderly people suffer from poorer health than young people? Distributive and relational egalitarianism on age-based health inequalities’. *Politics, Philosophy and Economics*. 18(2) pp. 145-164.

Lloyd, C.E. and Heller, T. (2012). *Long-Term Conditions: Challenges in Health and Social Care.* London: Sage Publications Ltd.

Local Government Association. (2022). Housing our ageing population. [Online] 27/09/2022 [Accessed on: 01/09/2023] https://www.local.gov.uk/publications/housing-ageing-population

Löfgren, M., Larsson, E., Isaksson, G., and Nyman, A. (2022). 'Older adults' experiences of maintaining social participation: creating opportunities and striving to adapt to changing situations'. *Scandinavian journal of occupational therapy.* 29(7) pp. 587-597.

Lum, T. Y., and Lightfoot, E. (2005). 'The effects of volunteering on the physical and mental health of older people'. *Research on aging* 27(1) pp. 31-55.

Lunenfeld, B. and Stratton, P. (2013). 'The Clinical Consequences of an Ageing World and Preventive Strategies'. *Best Practice and Research Clinical Obstetrics and Gynaecology*. 27(5) pp. 643–659.

Macdonald, B., Luo, M., and Hülür, G. (2021). 'Daily social interactions and well-being in older adults: The role of interaction modality'. *Journal of Social and Personal Relationships.* 38(12) pp. 3566-3589.

Madden, R. (2017). *Being ethnographic: a guide to the theory and practice of ethnography*. 2nd ed., London: SAGE.

Manchester City Council. (2019). *Indices of Deprivation 2019*. [Online] [Accessed on 15/10/20] https://secure.manchester.gov.uk/downloads/download/414/research_and_intelligence_population_publications_deprivation

Mangset, M., Tor, E. D., Førde, R., and Wyller, T. B. (2008). 'we're just sick people, nothing else': ... factors contributing to elderly stroke patients' satisfaction with rehabilitation’. *Clinical Rehabilitation.* 22(9) pp. 825–835.

Martz, E., and Livneh, H. (2016). ‘Psychosocial adaptation to disability within the context of positive psychology: findings from the literature’. *Journal of occupational rehabilitation*. 26 pp. 4-12.

Matricardi, P.M., Dal Negro, R.W. and Nisini, R., (2020). ‘The first, holistic immunological model of COVID-19: implications for prevention, diagnosis, and public health measures’. *Pediatric Allergy and Immunology.* 31(5), pp.454-470.

Means, R. (2007). ‘Safe as Houses? Ageing in Place and Vulnerable Older People in the UK’. *Social policy and administration*. 41(1) pp. 65-85.

Menezes, D., Woolrych, R., Sixsmith, J., Makita, M., Smith, H., Fisher, J., Garcia-Ferrari, S., Lawthom, R., Henderson, J., and Murray, M. (2023). ‘‘You really do become invisible’: examining older adults’ right to the city in the United Kingdom’. *Ageing & Society.* 43(11) pp. 2477-2496.

Merton, R. (1972). “Insiders and outsiders: A chapter in the sociology of knowledge”. *American Journal of Sociology.* 78, pp. 9–47.

Meyer, J., Heath, H., Holman, C., & Owen, T. (2006). ‘Moving from victim blaming to an appreciative inquiry: exploring quality of life in care homes’. *Quality in Ageing and Older Adults.* 7(4) pp. 27-36.

Meyer, C., Hickson, L., Lovelock, K., Lampert, M., and Khan, A. (2014). ‘An investigation of factors that influence help-seeking for hearing impairment in older adults’. *International journal of audiology.* 53(1) pp. 3-17.

Meyer, K., and Willis, R. (2018). ‘Looking Back to Move Forward: The Value of Reflexive Journaling for Novice Researchers’. *Journal of Gerontological Social Work*. 62(5) pp. 578-585.

Michael, Y.L. and Yen, I.H. (2014). ‘Aging and Place—Neighborhoods and Health in a World Growing Older’*. Journal of aging and health*. 26(8) pp. 1251-1260.

Miller, E., and Brockie, L. (2015). ‘The disaster flood experience: older people's poetic voices of resilience’. *Journal of Aging Studies.* 34 pp. 103–112.

Milne, M. ‘Disbaility and illmess: the perspectives of people living with a long-term health condition. *In* Lloyd, C.E. and Heller, T. (2012). *Long-Term Conditions: Challenges in Health and Social Care.* London: Sage Publications Ltd.

Ministry of Housing, Communities and Local Government. (2019). *The English Indices of Deprivation 2019 (IoD2019)*. [Online] [Accessed on: 28/08/20] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/835115/IoD2019_Statistical_Release.pdf

Miserandino, C. (2010). *The Spoon Theory*. [Online] [Accessed on: 25/04/2023] https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/

Mitchell-Williams, Z., Wilkins, P., McLean, M., Nevin, W., Wastell, K., and Wheat, R. (2004). ‘The importance of the personal element in collaborative research’. *Educational Action Research.* 12 pp. 329–346.

Mitsi, A., Kourakos, M., Poulimenakou, G., Latsou, D., and Sarris., M. (2018). ‘Therapeutic Relationship and Quality of Life in Chronic Diseases’. *American Journal of Nursing Science*. 7(3-1) pp. 103-108.

McNally, D., Sharples, S., Craig, G., and Goraya, A. (2015). ‘Patient leadership: Taking patient experience to the next level?’. *Patient Experience Journal.* 2(2) pp. 7-15.

McNeil, H., Elliott, J., Huson, K., Ashbourne, J., Heckman, G., Walker, J., and Stolee, P. (2016). ‘Engaging older adults in healthcare research and planning: a realist synthesis’. *Research Involvement and Engagement.* 2 pp. 1-18.

Modig, K., Rau, R. and Ahlbom, A. (2020). ‘Life expectancy: what does it measure?’. *BMJ open*. 10(7) pp. e035932.

Monahan, C., Macdonald, J., Lytle, A., Apriceno, M. B., and Levy, S. R. (2020). ‘Covid-19 and ageism: how positive and negative responses impact older adults and society’. *The American Psychologist.* 75(7), pp. 887–896

Monson, A., Harvey, C., & Baldwin, A. (2021). ‘Lost voices: Using a case study to illustrate narrative inquiry: Research brief’. *Applied Nursing Research*. 62

Moore, R. C. and Hancock, J. T. (2020). ‘Older Adults, Social Technologies, and the Coronavirus Pandemic: Challenges, Strengths, and Strategies for Support’. *Social Media Society*, 6(3), pp. 1-5

Morgan, T., Wiles, J., Park, H. J., Moeke-Maxwell, T., Dewes, O., Black, S., Williams, L., and Gott, M. (2021). ‘Social connectedness: what matters to older people?’. *Ageing & Society.* 41(5) pp. 1126-1144.

Morris, J., Schlepper, L., Dayan, M., Jefferies, D., Maguire, D., Merry, L., and Wellings, D. (2023). ‘Public satisfaction with the NHS and social care in 2022: Results from the British Social Attitudes survey’. *The Kings Fund.* [Online] 29th March [Accessed on:

10/04/2023] https://www.kingsfund.org.uk/publications/public-satisfaction-nhs-and-social-care-2022

Moss-Morris, R. (2013). ‘Adjusting to chronic illness: time for a unified theory’. *British Journal of Health Psychology.* 18(4) pp. 681–686.

Moudatsou, M., Stavropoulou, A., Philalithis, A., & Koukouli, S. (2020). ‘The role of empathy in health and social care professionals’. *Healthcare (Basel, Switzerland).* 8(1).

Murray, R. (2021). ‘Raising the levy: will the new health and social care tax work?’. *The Kings Fund.* [Online] 9th September [Accessed on: 06/04/2023] https://www.kingsfund.org.uk/blog/2021/09/raising-levy-health-and-social-care-tax

Naegele, G., and Walker, A. (2007). ‘Social Protection: Incomes, Poverty and the Reform of Pension Systems’. *In* Bond, J. (2007). *Ageing in society: European perspectives on gerontology*. 3rd ed. London: Sage.

Naseem, Z. and Khalid, R., (2010). ‘Positive thinking in coping with stress and health outcomes: Literature review’. *Journal of Research & Reflections in Education*. 4(1).

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., and Galea, A. (2012). ‘Long-term conditions and mental health: the cost of co-morbidities’. *The Kings Fund.* [Online] 9th February [Accessed on: 25/04/2023] https://www.kingsfund.org.uk/publications/long-term-conditions-and-mental-health

Needham, C. (2011). *Personalising public services: understanding the personalisation narrative*. Bristol; Policy Press.

Nettleton, S. (2013). *The sociology of health and illness* (3rd ed.). Cambridge: Polity.

NHS. (2020). *Floaters and flashes in the eyes*. [Online] [Accessed on 08/05/2023] https://www.nhs.uk/conditions/floaters-and-flashes-in-the-eyes/

NHS Digital. (2019). *Adult Social Care Activity and Finance Report, England - 2018-19.* [Online] 22nd October [Accessed on: 10/12/20] https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2018-19

NHS Digital. (2021). *Adult Social Care Activity and Finance Report, England - 2020-21.* [Online] 21st October [Accessed on: 13/12/21] https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2020-21/2.-requests-for-support

NHS Digital. (2022). *Latest key statistics on adult social care include council spending in 2021-22: statistical press release.* [Online] 20th October [Last accessed: 28/02/2024] https://digital.nhs.uk/news/2022/adult-social-care-stats-2021-22

NHS England. (no date). *Improving care for older people.* [Online] [Accessed on: 04/04/2023] https://www.england.nhs.uk/ourwork/clinical-policy/older-people/improving-care-for-older-people/#:~:text=Generally%2C%20someone%20over%20the%20age,healthier%20than%20someone%20aged%2060.

NHS England. (2015). 'Practical Guide to Healthy Ageing'. [Online] 11th April [Accessed on: 12/11/2023] https://www.england.nhs.uk/publication/practical-guide-to-healthy-ageing/

NHS England. (2019). *NHS long term plan*. [Online] [Accessed on 29th March 2022] https://www.england.nhs.uk/long-term-plan/

Noble K., and McIlveen P. (2012). ‘Being, Knowing, and Doing: a Model for Reflexivity in Social Constructionist Practices’. In McIlveen P., Schultheiss D.E. (eds). *Social Constructionism in Vocational Psychology and Career Development. Career Development Series*. Rotterdam: SensePublishers.

Novak, M., Costantini, L., Schneider, S. and Beanlands, H. (2013). ‘Approaches to self-management in chronic illness’. *Seminars in dialysis*. 26(2) pp. 188-194.

Nuffield Trust. (2022). *The costs of Brexit make severe challenges even harder for the NHS and social care*. [Online] 19th December [Accessed on: 10/04/2023] https://www.nuffieldtrust.org.uk/news-item/the-costs-of-brexit-make-severe-challenges-even-harder-for-the-nhs-and-social-care

O'Reilly, K. (2009). *Key concepts in ethnography*. London: SAGE. [Online] [Accessed on: 18/04/2023] https://methods.sagepub.com/book/key-concepts-inethnography/n31.xml

ONS. (2018). *Health state life expectancies, UK: 2015 to 2017*. [Online] [Accessed on: 24/8/20] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/2015to2017#:~:text=In%20the%20UK%20in%202015,for%20females%20was%2063.6%20years

ONS. (2019a). *Living longer: caring in later working life.* [Online] [Accessed on: 09/03/2023] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2019-03-15#older-workers-will-increasingly-have-caring-responsibilities

ONS. (2019b). *National population projections: 2018-based*. [Online] [Accessed on: 24/8/20] https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2018based#:~:text=The%20UK%20population%20is%20projected,over%20the%20next%2025%20years

ONS. (2021). *National life tables – life expectancy in the UK: 2018 to 2020.* [Online] [Accessed on: 28/06/2022] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2018to2020

ONS. (2022a). *Health state life expectancies, UK: 2018 to 2020*. [Online] [Accessed on: 12/07/22] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/2018to2020

ONS. (2022b). *Household total wealth in Great Britain: April 2018 to March 2020*. [Online] [Accessed on: 20/11/2023] https://www.ons.gov.uk/peoplepopulationandcommunity/personalandhouseholdfinances/incomeandwealth/bulletins/totalwealthingreatbritain/april2018tomarch2020

Ortlipp, M. (2008). 'Keeping and Using Reflective Journals in the Qualitative Research Process'. *The Qualitative Report.* 13(4) pp. 695-705.

Ouden, W. V.-den, van Boekel, L., Janssen, M., Leenders, R., and Luijkx, K. (2021). 'The impact of social network change and health decline: a qualitative study on experiences of older adults who are ageing in place'. *Bmc Geriatrics.* 21(1)

Owen, N., Dew, L., Logan, S., Denegri, S., and Chappell, L. (2022). 'Research policy for people with multiple long-term conditions and their carers'. *Journal of Multimorbidity and Comorbidity.* 12 pp. 1-8.

Pakenham, K.I. (2008). ‘Making Sense of Illness or Disability: The Nature of Sense Making in Multiple Sclerosis (ms)’. *Journal of health psychology*. 13(1), pp. 93–105.

Palmer, K., Monaco, A., Kivipelto, M., Onder, G., Maggi, S., Michel, J.-P., Prieto, R., Sykara, G., and Donde, S. (2020). ‘The potential long-term impact of the covid-19 outbreak on patients with non-communicable diseases in Europe: consequences for healthy ageing’. *Aging Clinical and Experimental Research.* 32(7), pp. 1189–1194.

Pani-Harreman, K., Bours, G.J.J.W., Zander, I., Kempen, G.I.J.M. and van Duren, J.M.A. (2021). ‘Definitions, key themes and aspects of ‘ageing in place’: a scoping review’. *Ageing and Society*. 41 pp 2026-2059.

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). California: Sage Publications.

Peacock, M., Bissell, P., and Owen, J. (2014). ‘Dependency denied: health inequalities in the neo-liberal era’. *Social Science and Medicine.* 118, pp. 173–180.

Pemberton, S., Peel, D. and Lloyd, G. (2015). ‘The ‘filling in’ of community-based planning in the devolved UK?’. *The Geographical journal*. 181(1) pp. 6-15.

Philip, K. E. J., Lonergan, B., Cumella, A., Farrington-Douglas, J., Laffan, M., and Hopkinson, N. S. (2020). ‘Covid-19 related concerns of people with long-term respiratory conditions: a qualitative study’. *BMC Pulmonary Medicine*, 20(1), pp. 319–329.

Pierson, J. (2008). *Going Local*. Abingdon: Routledge.

Pillow, W. (2003). ‘Confession, catharsis, or cure? rethinking the uses of reflexivity as methodological power in qualitative research’. *International Journal of Qualitative Studies in Education.* 16(2) pp. 175–196.

Ploeg, J., Denton, M., Tindale, J., Hutchison, B., Brazil, K., Akhtar-Danesh, N., Lillie, J. and Plenderleith, J.M. (2009). ‘Older adults’ awareness of community health and support services for dementia care’. *Canadian Journal on Aging*. 28(4) pp. 359-370.

Polacsek, M., Boardman, G. H., and McCann, T. V. (2019). ‘Help-seeking experiences of older adults with a diagnosis of moderate depression’. *International journal of mental health nursing.* 28(1) pp. 278-287.

Porter, T., Ong, B., and Sanders, T. (2020). ‘Living with multimorbidity? The lived experience of multiple chronic conditions in later life’. *Health*. 24(6) pp. 701-718.

Power, K. (2020). ‘The COVID-19 pandemic has increased the care burden of women and families’. *Sustainability: Science, Practice and Policy.* 16(1) pp. 67-73.

Public Health England (PHE). (2017*). Health profile for England: 2017*. [Online] [Accessed on: 28/01/20] https://www.gov.uk/government/publications/health-profile-for-england/chapter-1-life-expectancy-and-healthy-life-expectancy

Public Health England (PHE). (2018). *Local action on health inequalities: Understanding and reducing ethnic inequalities in health*. [Online] [Accessed on: 24/09/2020] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/730917/local_action_on_health_inequalities.pdf

Public Health England (PHE). (2019). *A consensus on health ageing*. [Online] [Accessed on: 04/09/2020] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/882847/Healthy_Ageing_Consensus_Statement-GW-1165.pdf

Radley, A. (1994). *Making Sense of Illness*. London: SAGE.

Rao, J., Chandra, J. and Jennings, P. (2010). 'Ethnicity, health and health inequalities'. *Ethnicity and Inequalities in Health and Social Care.* 3(2) pp. 3-5.

Read, R., and Fenge, L.-A. (2019). 'What does Brexit mean for the UK social care workforce? perspectives from the recruitment and retention frontline'. *Health and Social Care in the Community*. 27(3) pp. 676–682.

Reed, J. (2007). *Appreciative inquiry: research for change*. London: SAGE.

Reed, J. (2010). 'Appreciative inquiry and older people - finding the literature'. *International Journal of Older People Nursing.* 5(4) pp. 292–298.

Reed, S., Oung, C., Davies, J., Dayan, M., and Scobie, S. (2021). 'Integrating health and social care'. *Nuffield Trust*. [Online] December [Accessed on: 12/11/2023] https://www.nuffieldtrust.org.uk/sites/default/files/2021-12/integrated-care-web.pdf

Reeves, D., Pye, S., Ashcroft, D.M., Clegg, A., Kontopantelis, E., Blakeman, T. and van Marwijk, H. (2018). 'The challenge of ageing populations and patient frailty: can primary care adapt?'. *BMJ.* 362, pp. 3349.

Reuman, L. R., Mitamura, C., and Tugade, M. M. (2013). 'Coping and disability'. *In* Wehmeyer, M. L. The Oxford handbook of positive psychology and disability. Oxford: Oxford University Press.

Reynolds, L. (2020). ‘The Covid-19 Pandemic Exposes Limited Understanding of Ageism’. *Journal of aging and social policy*. 32(4-5), pp. 499–505.

Robine, J. and Cubaynes, S. (2017). ‘Worldwide demography of centenarians’. *Mechanisms of ageing and development*. 165 pp. 59-67.

Robinson, D., Green, S., and Wilson, I. (2020). ‘Housing options for older people in a reimagined housing system: a case study from England’. *International Journal of Housing Policy.* 20(3) 344-366.

Robinson, P. (2020). ‘Long-term conditions and severe acute respiratory syndrome sars-cov-2 (covid-19)’. *British Journal of Community Nursing*. 25(5) pp. 247–251.

Rose, K., Kozlowski, D. and Horstmanshof, L. (2023). ‘Experiences of Ageing in Place in Australia and New Zealand: A Scoping Review’. *Journal of Community & Applied Social Psychology.* 33(3) pp. 623–645.

Russell, C. (2011). ‘Pulling back from the edge: an asset-based approach to ageing well’. *Working with Older People.* 15(3) pp. 96-105.

Saeed, A., Fisher, J., Mitchell-Smith, Z., Brown, L.J. (2020). ‘’You’ve got to be old to go there’: psychosocial barriers and facilitators to social eating in older adults.' *Gerontologist.* 60(4) pp. 628-637.

Sanderson, M., Allen, P., Osipovic, D., Petsoulas, C., Boiko, O., and Lorne, C. (2023). ‘Developing architecture of system management in the English NHS: evidence from a qualitative study of three Integrated Care Systems’. *BMJ open*. 13(2).

Schone, H. Q. (2019). *Contested illness in context: An interdisciplinary study in disease definition*. Oxon: Routledge.

Schroyen, s., Adam, S., Jerusalem, G., and Missotten, P. (2015). 'Ageism and its clinical impact in oncogeriatry: state of knowledge and therapeutic leads'*. Clinical Interventions in Aging*. 10 pp. 117-125

Seedsman, T. (2020). 'Health literacy as a tool to erase pressure on long-term care systems: perspective and issues on healthy aging across the life course'. *Journal of aging and long-term care.* 3(1) pp. 11-25.

Sheard, D.J., Clydesdale, G., and Maclean, G. (2019). 'Governance Structure and Public Health Provision'*. Journal of Health Organization and Management.* 33(4) pp.426-442

Singh, S., Gray, A., Shepperd, S., Stott, D.J., Ellis, G., Hemsley, A., Khanna, P., Ramsay, S., Schiff, R., Tsiachristas, A., Wilkinson, A., and Young, J. (2022). 'Is comprehensive geriatric assessment hospital at home a cost-effective alternative to hospital admission for older people?'. *Age and Ageing.* 51(1)

Sixsmith., A, Horst, B.R., Simeonov, D., and Mihailidis, A. (2022). 'Older People's Use of Digital Technology During the COVID-19 Pandemic'. *Bulletin of Science and Technology Society*. 42(1-2) pp. 19–24.

Sixsmith, J., Lan Fang, M., Woolrych, R., Canham. S.L., Battersby, L., and Sixsmith, A. (2017). 'Ageing well in the right place: partnership working with older people'. *Working with Older People*, 21(8).

Sixsmith, A. and Sixsmith, J. (2008). 'Ageing in Place in the United Kingdom'. *Ageing international*. 32(3) pp. 219-235.

Skills for Care. (2021). The state of the adult social care sector and workforce in England. [Online] [Accessed on: 1/12/21] https://www.skillsforcare.org.uk/adult-social-care-workforce-data-old/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-State-of-the-Adult-Social-Care-Sector-and-Workforce-2021.pdf

Sky News. (2023). GP phone and online appointments 'could put patients at risk'. [Online] 29th November [Accessed on: 28/01/2024] https://news.sky.com/story/gp-phone-and-online-appointments-could-put-patients-at-risk-13018662

Smith, S. (2021). What's in a word? Rephrasing and reframing disability. *In* Brown, N. Lived Experiences of Ableism in Academia. Bristol: Policy Press.

Snowden, M. (2015). 'Use of diaries in research'. *Nursing Standard.* 29 (44) pp. 36.

Spiliopoulos, G., and Timmons, S. (2023). 'Migrant NHS nurses as 'tolerated' citizens in post-brexit britain'. *The Sociological Review.* 71(1) pp. 183–200.

Steel, N., Ford, J.A., Newton, J.N., Davis, A.C.J., Vos, T., Naghavi, M., Glenn, S., Hughes, A., Dalton, A.M., Stockton, D., Humphreys, C., Dallat, M., Schmidt, J., Flowers, J., Fox, S., Abubakar, I., Aldridge, R.W., Baker, A., Brayne, C., Brugha, T., Capewell, S., Car, J., Cooper, C., Ezzati, M., Fitzpatrick, J., Greaves, F., Hay, R., Hay, S., Kee, F., Larson, H.J., Lyons, R.A., Majeed, A., McKee, M., Rawaf, S., Rutter, H., Saxena, S., Sheikh, A., Smeeth, L., Viner, R.M., Vollset, S.E., Williams, H.C., Wolfe, C., Woolf, A. and Murray, C.J.L. (2018). 'Changes in health in the countries of the UK and 150 English Local Authority areas 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016'. *The Lancet (British edition).* 392(10158) pp. 1647-1661.

Stewart, J., Crockett, R., Gritton, J., Stubbs, B. and Pascoe, A. (2014). 'Ageing at home? Meeting housing, health and social needs'. *Journal of integrated care*. 22(5/6) pp. 242-252.

Stones, D. and Gullifer, J. (2016). ‘’At home it's just so much easier to be yourself’: older adults' perceptions of ageing in place’. *Ageing and society*. 36(3) pp. 449-481.

Storeng, S.H., Krokstad, S., Westin, S. and Sund, E.R. (2017). ‘Decennial trends and inequalities in healthy life expectancy: The HUNT Study, Norway’. *Scandinavian journal of public health*. 46(1) pp. 124-131.

Strassmann, A., Çolak, Y., Serra-Burriel, M., Nordestgaard, B. G., Turk, A., Afzal, S., and Puhan, M. A. (2023). ‘Nationwide indoor smoking ban and impact on smoking behaviour and lung function: a two-population natural experiment’. *Thorax*. 78(2) pp. 144–150.

Sun, Y., Wu, Y., Fan, S., Dal Santo, T., Li, L., Jiang, X., Li, K., Wang, Y., Tasleem, A., Krishnan, A., He, C., Bonardi, O., Boruff, J.T., Rice, D.B., Markham, S., Levis, B., Azar, M., Thombs-Vite, I., Neupane, D., Agic, B., Fahim, C., Martin, M.S., Sockalingham, S., Turecki, G., Benedetti, A., and Thombs, B.D. (2023). ‘Comparison of mental health symptoms before and during the covid-19 pandemic: evidence from a systematic review and meta-analysis of 134 cohorts’. *BMJ.* 380.

Swift, J. K., Mullins, R. H., Penix, E. A., Roth, K. L., and Trusty, W. T. (2021). ‘The importance of listening to patient preferences when making mental health care decisions’. *World psychiatry*. 20(3) pp. 316–317.

Swinkels, J. C., van Tilburg, T. G., and Broese van Groenou, M. (2022). ‘Why do spouses provide personal care? A study among care-receiving Dutch community-dwelling older adults’. *Health & Social Care in the Community*. 30(4).

Tan, M., Li, H., and Wang, X. (2023). ‘Analysis of the current status of rehabilitation motivation and its influencing factors in older adults with stroke: a cross-sectional study’. *Frontiers in Aging Neuroscience.* 15.

Tanner, D. (2010). *Managing the ageing experience: learning from older people*. Bristol: Policy Press.

Taskforce for Lung Health. (2023). *Occupational Lung Disease*. [Online] [Accessed on: 25/04/2023] https://www.taskforceforlunghealth.org.uk/taskforce/data-tracker/occupational-lung-disease/occupational-lung-disease#:~:text=The%20current%20estimate%20for%20the,disease%20just%20from%20COPD%20alone.

Tetley, J., Coxtask, N., Jack, K. and Witham, G. (2018*). Nursing older people at a glance*. Chichester: Wiley Blackwell.

Thayer C, Skufca L. (2020). 'Media Image Landscape: Age Representation in Online Images'. *Innovation in Aging*. 16(4)

The Kings Fund. (2014). *Commission on the Future of Health and social Care in England: Final summary of the work and recommendations of the experts by experience group*. [Online] [Accessed on: 14/03/2023] https://www.kingsfund.org.uk/sites/default/files/media/Experts%20by%20experience%20appendix%20final.pdf

The Kings Fund. (2020*). What are health inequalities?.* [Online] 18th February [Accessed on: 24/09/20] https://www.kingsfund.org.uk/publications/what-are-health-inequalities

The Kings Fund. (2022). *Social Care 360*. [Online] 1st March [Accessed on: 21/02/2023] https://www.kingsfund.org.uk/publications/social-care-360

The Kings Fund. (2023). *Briefing: Debate in the House of Lords: The future of adult social care, Thursday 30 March 2023.* [Online] 30th March [Accessed on: 05/04/2023] https://www.kingsfund.org.uk/sites/default/files/2023-03/House%20of%20Lords%20Social%20Care%20Debate%20-%20briefing.pdf

Thorlby, R., Gardener, T., Everest, G., Allen, L., Shembavnekar, N., Fisher, R., Dunn, P., Turner-Berry, F., Fraser, C., Briggs, A., and Alderwick, H. (2021). 'The NHS Long Term Plan and COVID-19: Assessing progress and the pandemic's impact'. *The Health Foundation.* [Online] [Accessed on: 11/04/2023] https://www.health.org.uk/publications/reports/the-nhs-long-term-plan-and-covid-19#:~:text=Our%20analysis%20finds%20that%20the,and%20increased%20demands%20on%20services.

Thurairajah, K. (2019). *Practicing reflexivity: balancing multiple positionalities during fieldwork*. London: SAGE.

Timonen, V. (2008). *Ageing Societies*. Berkshire: Open University Press.

Townsend, B. G., Chen, J. T.-H., and Wuthrich, V. M. (2021). 'Barriers and facilitators to social participation in older adults: a systematic literature review'. *Clinical Gerontologist*. 44(4), pp. 359–380.

Townsend, P., Phillimore, P., and Beattie, A. (2023). *Health and deprivation: inequality and the North.* (Vol. 8). Abingdon: Taylor & Francis.

Troutman-Jordan, M. and Kazemi, D. M. (2020). 'Covid-19's Impact on the Mental Health of Older Adults: Increase in Isolation, Depression, and Suicide Risk. an Urgent Call for Action.(report)'. *Public Health Nursing*, 37(5), p. 637.

Tsertsidis, A., Kolkowska, E. and Hedström, K. (2019). ‘Factors influencing seniors’ acceptance of technology for ageing in place in the post-implementation stage: A literature review’. *International journal of medical informatics*. 129, pp. 324-333.

Unison. (2023). *Nurses, paramedics, blood collection workers and other NHS staff in new strike over pay*. [Online] 22nd February [Accessed on: 11/04/2023] https://www.unison.org.uk/news/press-release/2023/02/nurses-paramedics-blood-collection-workers-and-other-nhs-staff-in-new-strike-over-pay-says-unison/

United Nations. (2018). *Health inequalities in old age*. [Online] [Accessed on: 24/09/2020] https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2018/04/Health-Inequalities-in-Old-Age.pdf

United Nations. (2019). World Population Ageing 2019. [Online] [Accessed on: 27/08/2020] https://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2019-Highlights.pdf

UK Government. (2022). *Build Back Better: Our Plan for Health and Social Care*. [Online] 8th March. [Accessed on 06/04/2023] https://www.gov.uk/government/publications/build-back-better-our-plan-for-health-and-social-care/build-back-better-our-plan-for-health-and-social-care

UK Government. (2022). *Reversal of the Health and Social Care Levy Factsheet*. [Online] 23rd September [Accessed on: 06/04/2023] https://www.gov.uk/government/publications/the-growth-plan-factsheet-on-cancellation-of-national-insurance-rise-and-health-and-social-care-levy/reversal-of-the-health-and-social-care-levy-factsheet

UK Government. (2023a). *Policy paper: A consensus on healthy ageing*. [Online] 10th February [Accessed on: 12/11/2023] https://www.gov.uk/government/publications/healthy-ageing-consensus-statement/a-consensus-on-healthy-ageing

UK Government. (2023b). *Policy paper: Next steps to put People at the Heart of Care*. [Online] 4th April [Accessed on: 28/01/2024] https://www.gov.uk/government/publications/adult-social-care-system-reform-next-steps-to-put-people-at-the-heart-of-care/next-steps-to-put-people-at-the-heart-of-care#recognising-skills-for-careers-in-care

Vanleene, D., and Verschuere, B. (2018). 'Co-production in community development'. *In* Brandsen, Steen and Verschuere. *Co-Production and Co-Creation*. London: Routledge.

Vanleerberghe, P., De Witte, N., Claes, C., Schalock, R.L. and Verté, D. (2017). 'The quality of life of older people aging in place: a literature review'. *Quality of life research*. 26(1) pp. 2899-2907.

Vasileiou, K., Barnett, J., Thorpe, S., and Young, T. (2018). 'Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period'. *BMC medical research methodology.* 18 pp. 1-18.

Verity, R., Okell, L.C., Dorigatti, I., Winskill, P., Whittaker, C., Imai, N., Cuomo-Dannenburg, G., Thompson, H., Walker, P.G.T., Fu, H., Dighe, A., Griffin, J.T., Baguelin, M., Bhatia, S., Boonyasiri, A., Cori, A., Cucunubá, Z., FitzJohn, R., Gaythorpe, K., Green, W., Hamlet, A., Hinsley, W., Laydon, D., Nedjati-Gilani, G., Riley, S., van Elsland, S., Volz, E., Wang, H., Wang, Y., Xi, X., Donnelly, C.A., Ghani, A.C. and Ferguson, N.M. (2020). 'Estimates of the severity of coronavirus disease 2019: a model-based analysis'*. The Lancet infectious diseases*. 20(6) pp. 669-677.

Villena-Sanchez, J., and Boschmann, E. E. (2022). 'A scoping review of the daily mobilities of older adults in the Global South'. The Canadian Geographer. 66(1) pp. 119-131.

Vlachantoni, A. (2019). 'Unmet need for social care among older people'. *Ageing and Society*. 39(4) pp. 657-684.

Vreugdenhil, A. (2014). ''Ageing-in-place': Frontline experiences of intergenerational family carers of people with dementia'. *Health Sociology Review: Longevity: Sociological Perspectives on Health, Illness and Service Provision.* 23(1) pp. 43-52.

Wang, S., Bolling, K., Mao, W., Reichstadt, J., Jeste, D., Kim, H. and Nebeker, C. (2019). "Technology to Support Aging in Place: Older Adults' Perspectives". *Healthcare (Basel)*. 7(2) pp. 60.

Wall, J. (2021). 'Older People in Manchester: Profile of Manchester residents aged 66+'. *Manchester City Council*. [Online] [Accessed: 21/02/2023] https://www.manchester.gov.uk/download/downloads/id/21993/a12_profile_of_older_people_in_manchester_2021.pdf

Walshe, K., Coleman, A., McDonald, R., Lorne, C. and Munford, L. (2016). 'Health and social care devolution: The Greater Manchester experiment'. *BMJ*. 352 pp. i1495.

Warnes, T., and Philips, J. (2007). 'Progress in Gerontology: Where are we now?' In Bernard, M., and Scharf, T. (ed.). *Critical Perspective on Ageing Societies*. Bristol: Policy Press.

Warren, S. (2022). 'The cap on care costs: what does the government proposal mean?'. *The Kings Fund.* [Online] 4th March [Accessed on: 04/04/2023] https://www.kingsfund.org.uk/blog/2022/03/cap-care-costs-what-does-government-proposal-mean

Watkins, S., Murphy, F., Kennedy, C., Dewar, B., and Graham, M. (2019). ‘Caring for an older person with dementia in the emergency department (ed): an appreciative inquiry exploring family member and ed nurse experiences’. *Journal of Clinical Nursing.* 28(15-16) pp. 2801–2812.

Webber, R., May, V. and Lewis, C. (2023). ‘Ageing in Place Over Time: The Making and Unmaking of Home.’ *Sociological Research Online*. 28(3), pp. 759–774.

Weil, J., Kamber, T., Glazebrook, A., Giorgi, M., and Ziegler, K. (2021). ‘Digital inclusion of older adults during covid-19: lessons from a case study of older adults technology services (oats)’. *Journal of Gerontological Social Work*. 64(6) pp. 643–655.

Whatley, M. C., Siegel, A. L. M., Schwartz, S. T., Silaj, K. M., and Castel, A. D. (2020). ‘Younger and older adults' mood and expectations regarding aging during covid-19’. *Gerontology and Geriatric Medicine*, 6 pp. 1-9.

White, C. and Edgar, G. (2010). ‘Inequalities in healthy life expectancy by social class and area type: England, 2001-03’. *Health statistics quarterly*. 45 pp. 28.

White, C., Lentin, P. and Farnworth, L. (2016). ‘Multimorbidity and the Process of Living with Ongoing Illness’. *Chronic illness.* 12(2) pp. 83–97.

Whitehead, M., Taylor-Robinson, D., and Barr, B. (2021). ‘Poverty, health, and covid-19’. *The BMJ*. 372.

Whitney, D. K., and Trosten-Bloom, A. (2010). *The power of appreciative inquiry: a practical guide to positive change*. San Francisco: Berrett-Koehler.

Wiles, L.K., Kay, D., Luker, J.A., Worley, A., Austin, J., Ball, A., Bevan, A., Cousins, M., Dalton, S., Hodges, E. and Horvat, L. (2022). ‘Consumer engagement in health care policy, research and services: A systematic review and meta-analysis of methods and effects’. *PloS one*, 17(1).

Williams, J., Roberts, G. and Griffiths, A. (2014). *Adult social care law in England*. Basingstoke: Palgrave Macmillan.

Woolrych, R., Sixsmith, J., Duvvuru, J., Portella, A., Fang, M.L., Menezes, D., Henderson, J., Fisher, J., and Lawthom, R. (2021). 'Cross-National Perspectives on Ageing and Place: Implications for Age-Friendly Cities and Communities.' *The Gerontologist.* 62(1) pp. 119-129.

World Health Organization (WHO). (2002). *Active Ageing*. A Policy Framework. Geneva: WHO.

World Health Organization (WHO). (2020). *Decade of healthy ageing*. [Online] [Accessed on: 04/09/2020] https://www.who.int/docs/default-source/decade-of-healthy-ageing/final-decade-proposal/decade-proposal-final-apr2020-en.pdf?sfvrsn=b4b75ebc_5

World Health Organization (WHO). (2022). *Ageing and Health*. [Online] 1st October [Accessed on: 21/03/2023] https://www.who.int/news-room/fact-sheets/detail/ageing-and-health

Wohland, P., Rees, P., Nazroo, J. and Jagger, C. (2015). ‘Inequalities in healthy life expectancy between ethnic groups in England and Wales in 2001’. *Ethnicity and Health*. 20(4) pp. 341-353.

Wolfenden, L., Wiggers, J., Paul, C., Freund, M., Lecathelinais, C., Wye, P., and Gillham, K. (2012). ‘Increasing the use of preventative health services to promote healthy eating, physical activity and weight management: the acceptability and potential effectiveness of a proactive telemarketing approach’. *Bmc Public Health*. 12, pp. 953–953.

Wood, R., Sutton, M., Clark, D., McKeon, A. and Bain, M. (2006). "Measuring inequalities in health: the case for healthy life expectancy". *Journal of epidemiology and community health*. 60(12) pp. 1089-1092.

Woolham, J., Daly, G., Sparks, T., Ritters, K. and Steils, N. (2017). ‘Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment’. *Ageing and society*. 37(5) pp. 961-984.

Wright, S., & Simpson, M. (2020). ‘Devolution and social policy’. *In* Bochel, H., and Daly, G. *Social Policy*. London: Routledge.

Wurm, S., and Benyamini, Y. (2014). ‘Optimism buffers the detrimental effect of negative self-perceptions of ageing on physical and mental health’. *Psychology and Health*. 29(7) pp. 832–848.

Yarnall, A., Sayer, A., Clegg, A., Rockwood, K., Parker, S., and Hindle, J. (2017). ‘New horizons in multimorbidity in older adults’. *Age and Ageing*. 46(6) pp. 882–888.

Zhaoyang, R., Scott, S. B., Martire, L. M., and Sliwinski, M. J. (2021). ‘Daily social interactions related to daily performance on mobile cognitive tests among older adults’. *PLoS One.* 16(8).

Zhou, W., Oyegoke, A.S. and Sun, M. (2019). ‘Causes of Delays during Housing Adaptation for Healthy Aging in the UK’. *International journal of environmental research and public health*. 16(2) pp. 192.

8.0 Appendices

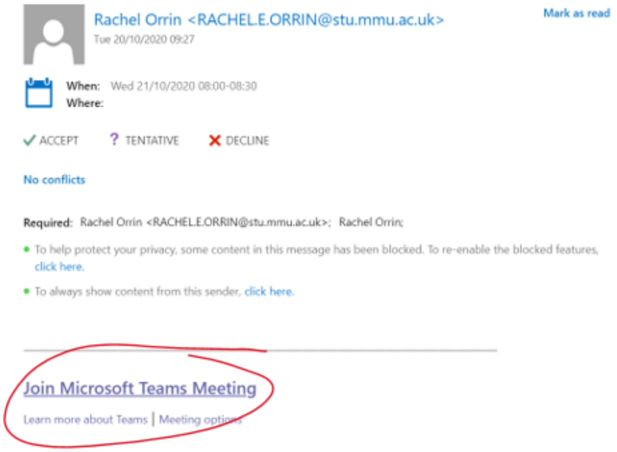
Appendix 1: Interview Prompts

1. How does it affect everyday living/which services do you access/use
2. Can you tell me the best thing about that/them?
3. Since you've had this condition tell me about a time you'll never forget?
4. What was it about that?
5. Can you tell me about a particular time you felt supported or enabled with your condition?
6. What did you most value about that interaction?
7. If you could change one thing, what would it be and why?
8. What has been your most unexpected experience?
9. What is one thing that if done well would make the most difference to you?
10. Are there any examples of success you would like to share?

Appendix 2: A Guide To Using Microsoft Teams

Using Microsoft Teams

1. You will receive a meeting request from me that will look like this. On the day, you will need to click 'Join Microsoft Teams meeting' as indicated below.



Rachel Orrin <RACHEL.E.ORRIN@stu.mmu.ac.uk>
Tue 20/10/2020 09:27

Mark as read

When: Wed 21/10/2020 08:00-08:30
Where:

✓ ACCEPT ? TENTATIVE ✗ DECLINE

No conflicts

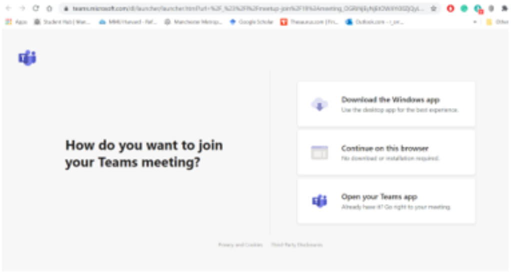
Required: Rachel Orrin <RACHEL.E.ORRIN@stu.mmu.ac.uk>; Rachel Orrin;

- To help protect your privacy, some content in this message has been blocked. To re-enable the blocked features, click here.
- To always show content from this sender, click here.

Join Microsoft Teams Meeting

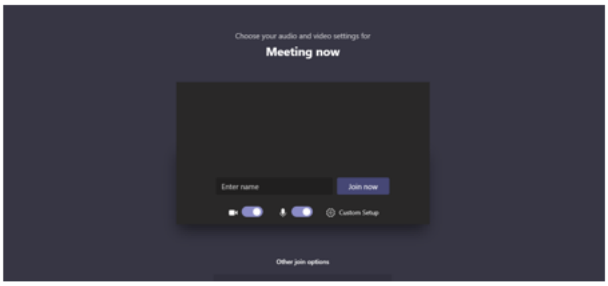
Learn more about Teams | Meeting options

2. It will open as so. If you have a Microsoft teams account press open teams app. If not select open in browser.



How do you want to join your Teams meeting?

3. If you have an account it should open and allow you to join as normal. If not it will look as below. Enter your name and press 'join meeting', and that's it!



Choose your audio and video settings for
Meeting now

This process was completed on a laptop, however, it should work the same on a mobile or tablet. If you have any problems however, I will be available to help.

Appendix 3 – Participant Information Letter

Participant Information Sheet

Ageing well at home: using appreciative inquiry with Manchester's older adults with long term health conditions

1. Invitation to research

I would like to invite you to take part in my study looking at supporting older adults with long-term physical health conditions to age well at home. My name is Rachel and I am a PhD researcher at Manchester Metropolitan University. My research project is using a method called 'appreciative inquiry' which looks at what systems and organisations are doing well rather than their weaknesses. This research is organised through Manchester Metropolitan University and funded by the White Rose Doctoral Training Partnership.

2. Why have I been invited?

You have been chosen to participate in this research because you are over the age of 65 and living in your own home. Additionally, you will need to have a long-term physical health condition, as defined by the NHS as being: *a health problem that requires ongoing management over a period of years or decades… that cannot currently be cured but can be controlled with the use of medication and/or other therapies*

I am studying this group of people as statistically older adults with long-term health conditions are more likely to spend additional time in hospital and enter into assisted living arrangements. This research seeks to understand how ageing and illness can be effectively managed in your own home.

3. Do I have to take part?

It is up to you to decide. I will describe the study and go through the information sheet, which we will give to you. We will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason.

4. What will I be asked to do?

Before participating in this research, you will be asked to sign a consent form, consenting to your participation and data collection. This project will take place over 1 year and take place in two phases. Phase one will consist of a short 1-1 interview concerning your experiences of accessing and using local health and social care services and ageing in place. It will begin in Early 2021. Due to the ongoing Corona Virus pandemic, interviews will take place over the phone or suitable web chat facility (such as Skype or Zoom). The interview will be audio recorded for later transcription should you agree to this.

Phase two of the study will commence later in 2021 (COVID dependant) and may be a group workshop with approximately 10-15 other participants. You are not required to participate in phase two should you not want to. The workshop will be held in a convenient local location and last for approximately 2 or 3 hours. In the workshops we will be processing some anonymised comments from phase one (the interviews) into 'provocative propositions'. Provocative propositions are statements of aspirations that challenge the way that things currently happen in the system. The provocative propositions are to be co-created amongst yourselves (as the participants) to represent your ideals for how local services can best support you. Data from phase two (the workshop) will be collected in through notetaking and audio recordings. Any recordings will be transcribed and anonymised for later analysis. Please note that phase two of the study is dependent on the relaxing of COVID-19 guidelines and may be subject to change. As participants you will be notified as early as possible to any changes and may leave the study at any time.

5. Are there any risks if I participate?

There are no foreseen risks to participating in this study. All venues used for participation will be prior approved to ensure suitability. If at any time during the study, you feel distressed please voice concerns with the principal investigator and access support through your GP or contact Age UK Manchester's Counselling Service on: 0800 027 57 87.

6. Are there any advantages if I participate?

There are no obvious advantages to taking part in this research, however, your participation will contribute to a wider knowledge on ageing, long-term conditions, and on appreciative inquiry as a method. Additionally, your participation could help shape future services in your area.

7. What will happen with the data I provide?

When you agree to participate in this research, we will collect from you personally identifiable information. The Manchester Metropolitan University ('the University') is the Data Controller in respect of this research and any personal data that you provide as a research participant.

The University is registered with the Information Commissioner's Office (ICO), and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University's Data Protection Policy.

We collect personal data as part of this research (such as name, telephone numbers or age). As a public authority acting in the public interest we rely upon the 'public task' lawful basis. When we collect special category data (such as medical information or ethnicity) we rely upon the research and archiving purposes in the public interest lawful basis.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained.

We will not share your personal data collected in this form with any third parties.

If your data is shared this will be under the terms of a Research Collaboration Agreement which defines use, and agrees confidentiality and information security provisions. It is the University's policy to only publish anonymised data unless you have given your explicit written consent to be identified in the research. **The University never sells personal data to third parties.**

We will only retain your personal data for as long as is necessary to achieve the research purpose. For further information about use of your personal data and your data protection rights please see the University's Data Protection Pages (https://www2.mmu.ac.uk/data-protection/).

8. What will happen to the results of the research study?

The results of this study will be used in my PhD thesis, additionally, the data could be used for future publications in academic journals and for presentations at conferences. However, any data used will be anonymised and pseudonyms allocated.

9. Who has reviewed this research project?

This research project has been reviewed by Manchester Metropolitan faculty research ethics committee.

10. Who do I contact if I have concerns about this study or I wish to complain?

For any concerns or questions in the first instance please contact myself, Rachel Orrin on:

13116894@stu.mmu.ac.uk .

Alternatively, you could contact the following;

Supervisor: Dr Jenny Fisher on J.Fisher@mmu.ac.uk

Or:

Head of Faculty Ethics: Professor Juliet Goldbart on j.goldbart@mmu.ac.uk or 0161 247 2578. 1.03 Brooks Building, Manchester Metropolitan University, 53 Bonsall St, Hulme, Manchester M15 6GX.

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT